

The background is a solid orange color. Scattered across it are stylized, flat icons of eating utensils. At the top left is a white cup. To its right is a grey spoon. On the left side, a grey fork points downwards. On the right side, another grey spoon points downwards. In the center, there is a white circle representing a plate. A grey knife is positioned horizontally across the top of the plate. A grey fork is positioned vertically on the right side of the plate. A grey spoon is positioned vertically on the left side of the plate. At the bottom, a white knife is positioned horizontally. The text is centered over the orange background.

Eating well:

children and adults
with learning
disabilities

Nutritional and practical guidelines

THE CAROLINE WALKER TRUST

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By Dr Helen Crawley

THE CAROLINE WALKER TRUST

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Foreword

The Caroline Walker Trust (CWT) is dedicated to the improvement of public health by means of good food. It was established in 1988 to continue the work of the campaigning nutritionist Caroline Walker, who passionately believed that everyone deserved access to good-quality food. The CWT has produced a series of publications which provide practical guidance on eating well for those who care for vulnerable people in our society. The CWT's first expert report – *Nutritional Guidelines for School Meals*, published in 1992 – set the standard for the provision of nutrient-based standards which the Trust continued in its *Eating Well* reports for: older people; under-5s in child care; looked after children and young people; and children at school.

The aim of all the CWT reports is to provide a summary of current knowledge about the eating and drinking issues for specific population groups and to provide nutrient-based standards, practical guidelines and recommendations which people can use as the basis for developing policy both nationally and locally. In the last 20 years there has been much greater public and political awareness of the need for good food and good nutrition. However, shocking reports of negligence in ensuring that some of the most vulnerable people in the UK are enabled to eat well still make the news each year. From the evidence compiled in this report it would appear that there is still much work to be done to ensure good nutritional health for people with learning disabilities and their families and to raise awareness of the need for good nutritional health to be given higher priority in national and local initiatives. We hope that this report will stimulate discussion, training and policy development among all those who support children, young people or adults with learning disabilities throughout the UK, and that others will now take up the challenge to put the nutritional and practical guidelines in this report into action.

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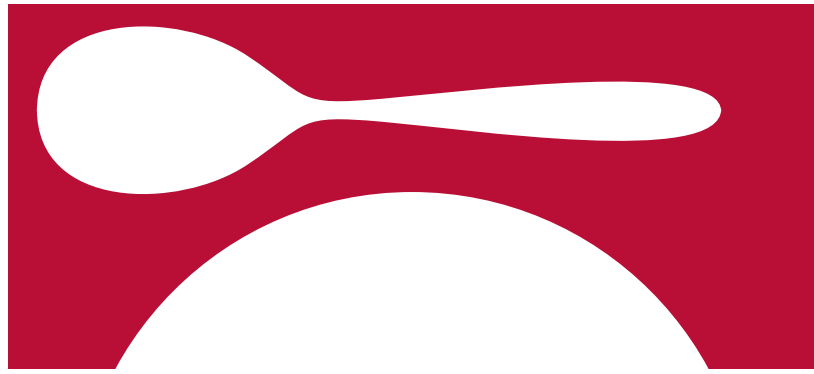
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Chapter 1

Summary and recommendations

Summary

Food and drink bring enormous pleasure to our lives. Eating and drinking well have an important part to play in the health and wellbeing of people of all ages in the UK. Simple changes to what we eat and how much we eat can contribute to a better quality of life, and enabling eating well should always be seen as one of the most positive things we can do as part of providing support and good care.

Since the turn of this century, a number of policy documents across the UK have provided a new platform for the promotion of better health among people with learning disabilities. In 2000 *The Same as You?*,¹ published in Scotland, provided the first new national document on learning disability policy. This was followed: in 2001 by *Valuing People*² in England; in 2002 by *Fulfilling the Promises*³ in Wales; and in 2005 by *Equal Lives* in Northern Ireland.⁴ The rights of people with learning disabilities to be valued and supported as equal citizens and to receive equitable health care and support are now fully enshrined in policy. However, there is no doubt that people with learning disabilities have greater health needs when compared with the general population and that their health needs are frequently unrecognised and unmet.⁵

Why nutritional guidelines are needed for people with learning disabilities

There is considerable evidence that people with learning disabilities are more likely than those in the general population to have nutritionally-related ill health, and that this is less recognised by support staff and professionals than it is when it occurs in the general population.⁶ Issues relating to body weight (both overweight and underweight), swallowing difficulties, gastro-oesophageal reflux disorder, diabetes, bowel disorders and oral health are frequently reported among people with learning disabilities.⁵ The prevalence of other common age-related disorders which might be linked to poor diet – such as hypertension (high blood pressure), stroke and coronary heart disease – among people with learning disabilities may be similar to the prevalence in the general population. However, many of these conditions and the related ill health are avoidable. People with learning disabilities are also frequently poorer, live in more challenging circumstances, and may be socially excluded, all factors which may contribute to poorer eating patterns.

The evidence presented in this report suggests that there is an urgent need for training in how to enable people with learning disabilities to eat well and to provide healthy eating choices for their families if they become parents. Despite evidence of excellent practice in some areas of the UK and considerable innovative work promoting better health, the nutritional health status of many people with learning disabilities remains poor.

Some evidence suggests that people with learning disabilities have a 58% increased risk of dying before they are 50 years old compared to the general population.⁷ The main cause of the increased risk is respiratory diseases such as pneumonia,⁸ exacerbated by swallowing difficulties, aspiration of food, posture, feeding difficulties and gastro-oesophageal reflux disease,⁹ but early death has also typically been associated with congenital heart disease, cerebral palsy, more limited mobility, and residence in hospital.⁷ It is highly likely that poor nutritional status throughout life contributes to this reduced lifespan, as well as contributing to morbidity (ill health) and poorer quality of life. It is also acknowledged that there is insufficient attention paid to the health needs of people with learning disabilities, a lack of basic health promotion, insufficient support to achieve a healthy lifestyle, and under-identification of particular health conditions, all of which require specific action.⁵

In this report we outline the reasons why people with learning disabilities might be more vulnerable to poor nutrition, and how positive changes to eating and drinking can improve their health and wellbeing. We also provide

practical guidelines to explain what good nutrition means and the steps that can be taken to make positive changes. From the evidence reviewed a series of recommendations and a summary of some important practical guidelines have also been compiled with the purpose of improving good nutrition for this population group and these are given on pages 10-18.

What is the scope of this report?

This is an evidence-based report which summarises available information on the nutritional needs of children, young people and adults with learning disabilities. It also looks at issues around food choice and eating well, and provides practical information to support these groups and those caring for or supporting them.

This report is the latest in a series of expert reports from the Caroline Walker Trust, which has produced nutritional and practical guidelines for: under-5s in child care; school-aged children; looked after children and young people; older people in residential care and for community meals. Details of all these reports, and a report from VOICES on eating well for older people with dementia, can be found on the Caroline Walker Trust website www.cwt.org.uk.

The aims of this report

The aims of this report are:

- To improve the health and wellbeing of children, young people and adults with learning disabilities by providing practical guidelines and information to improve their nutritional health
- To provide clear, evidence-based background information about the importance of good nutrition and physical activity to the health of children, young people and adults with learning disabilities
- To offer practical and nutritional guidelines to enable all those with a responsibility for providing food for children, young people and adults with learning disabilities to develop suitable menus and make good food choices
- To offer practical and nutritional guidelines to enable children, young people and adults with learning disabilities to make good food and drink choices for themselves and their families
- To highlight some of the important practical issues which need to be considered when helping children, young people and adults with learning disabilities to eat and drink well
- To provide examples of good practice in encouraging eating well for children, young people and adults with learning disabilities
- To make recommendations about the training and support needed to ensure that children, young people and adults with learning disabilities are enabled to eat and drink well and can provide good food choices for their families if they become parents
- To act as a resource document for all those working for better standards of care for children, young people and adults with learning disabilities
- To raise public and political awareness of the importance of eating well for children, young people and adults with learning disabilities.

Who the report is for

- Policy makers, primary care trusts, inspectors and regulators, health and safety authorities, GPs and other health professionals, health and social services staff, teachers, community workers, CAFCASS officers, judges, legal representatives, Independent Mental Capacity Advocates, and others who are responsible for ensuring that children, young people and adults with learning disabilities receive the best possible care and support throughout their lifetime
- Commissioners and contractors of services for children, young people and adults with learning disabilities
- Managers, catering staff, support staff and others in care settings (including residential and day care settings) who support children and adults with learning disabilities
- MPs, MSPs, MEPs, civil servants, journalists, researchers, writers and others who may wish to know more about the importance of eating well for people with learning disabilities.

We hope that the information in this report will be used to support children, young people and adults with learning disabilities to improve their own nutritional health and that of their families. To that end we recommend that the relevant Health Departments in England, Scotland, Wales and Northern Ireland should make easy-to-read versions of the main messages in this report, in appropriate languages and formats, available for people with learning disabilities, to act as guidance on issues around food and healthy eating.

Relatives and friends of people with learning disabilities who may want to know more about eating well and who may wish to promote better nutrition in environments where food is provided for the people they care for and support may also find this report useful.

Recommendations

These recommendations are addressed to:

- all those who make, implement and enforce policy and legislation – specifically national and European government, health and social care commissioners, local authorities, and the Judiciary
- those who regulate, inspect or manage services for children, young people and adults with learning disabilities, and
- those professional bodies and sector skills councils responsible for training and development.

Policy development

- 1 The nutrient-based standards for food and drink for children, young people and adults shown on page 117 should become minimum standards for all residential, day care and other settings where children, young people or adults with learning disabilities are provided with food and drink.
- 2 Government departments should make reference to the nutrient-based standards and practical guidelines in this report in all guidance and legislation affecting residential, day care and domiciliary support for children, young people and adults with learning disabilities.
- 3 All those responsible for legislative change to national minimum care standards for residential, day care and domiciliary care should include standards which will ensure children, young people and adults are supported in all settings by staff and managers who are competent in enabling service users to eat well.
- 4 Local authorities and relevant NHS bodies and primary care trusts should work in partnership to ensure continuity of nutritional care for individual children, young people or adults with learning disabilities throughout their lifespan. General practice should be proactive in identifying and working with patients with learning disabilities to coordinate, monitor and manage their nutritional health.
- 5 The relevant Health Departments in England, Scotland, Wales and Northern Ireland should make easy-to-read versions of the main messages in this report, in appropriate languages and formats, available for children, young people and adults with learning disabilities.
- 6 Appropriate health promotion agencies should ensure that the practical guidelines in this report, or an easy-to-read version of them, are made available to family, friends and support staff of children, young people and adults with learning disabilities.
- 7 All agencies that provide practical information and advice on healthy eating to the UK population – for example, the Food Standards Agency, the Department of Health, Health Scotland, the Health Promotion Agency Northern Ireland, the Welsh Assembly and relevant voluntary organisations – should ensure that all their existing and new advice is provided in formats that are appropriate for people with learning disabilities and their family, friends and supporters.
- 8 Agencies which provide information for health professionals – such as the National Institute for Health and Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) – and relevant voluntary organisations should ensure that all professionals involved in the support of children, young people and adults with learning disabilities receive appropriate information about promoting good nutrition.
- 9 Nutrition should be identified nationally as a priority in the support and care of children, young people and adults with learning disabilities and the government department with responsibility for Valuing People should make sure that the promotion of eating well is included when determining new priorities.
- 10 All those who regulate services for people with learning disabilities should ensure that inspection reports include specific and detailed comments on food service and the management of nutritional issues in that setting, based on the information in this report.

Commissioning services

- 11 Local authorities should ensure that detailed nutritional and practical guidelines are included in their specifications when commissioning catering and other services for the support of children, young people or adults with learning disabilities in residential, day care or domiciliary settings. Local authorities who provide such services 'in house' should similarly adopt, implement and monitor nutritional and practical guidelines in these settings.

- 12 Nutrition should feature in the commissioning guidelines when primary care trusts seek services which will be directed to people with learning disabilities. Local authorities and primary care trusts should make nutrition a priority in any relevant services they commission.
- 19 Those who validate and assess undergraduate professional courses for doctors, dentists, nurses and other health and social care workers should ensure that the courses provide students with adequate information about good nutrition for children, young people and adults with learning disabilities and about how to monitor nutritional status.

Coordinated healthcare planning

- 13 GPs should be involved in promoting the nutritional health of children, young people and adults with learning disabilities throughout their lives.
- 14 GPs should proactively offer people with learning disabilities an annual health check. This should look at a range of indicators related to nutritional health such as body weight, weight change, bowel health, oral health, specific medical conditions, difficulties around eating and drinking, and medication reviews.
- 15 Everyone with a learning disability should be encouraged to be involved in developing their own health action plan, with support from a health facilitator, and to include in it information about their nutritional health.
- 20 Training in the provision of dental care for people with learning disabilities and the importance of advising people with learning disabilities and their families, friends and support staff on food and drink choices which impact on oral health should be included in the undergraduate curriculum for dentists and in training for dental nurses and oral health promoters.
- 21 Learning and skills councils should accredit courses in nutrition and health and basic cookery for all people with learning disabilities, and make courses or training accessible for family, friends and other supporters where appropriate. Special courses should be made available for those people with learning disabilities who are parents or who wish to or are likely to become parents. Courses should also be made available for people with learning disabilities from ethnic minorities who are likely to be under-represented in post-school education.

Education and training

- 16 Managers of residential, day care and domiciliary services, and all those who contract and supply staff to support people with learning disabilities, should ensure that those they employ or contract, including agency staff, have had and continue to have suitable on-going training about eating well, and information and training on how to use the nutritional and practical guidelines in this report.
- 17 The nutrient-based standards and practical guidelines in this report should be used as part of training and guidance for all those who regulate residential, day care or domiciliary services for children, young people and adults with learning disabilities.
- 18 NVQs, SVQs and other appropriate social care qualifications are important training opportunities for support workers and other staff. Qualifications at all levels should contain an appropriate section on nutrition and eating well which allows students to understand the information in this report.
- 22 All those who support people with learning disabilities should have training in recognising and managing swallowing difficulties (dysphagia).
- 23 All those who support people with learning disabilities should receive first aid training to ensure that they know how to deal with choking among ambulatory, chairbound or bedbound people as appropriate.

Legal representation and advocacy

- 24 Judges, magistrates and magistrates' clerks, legal representatives (barristers, solicitors and legal executives), guardians ad litem, Independent Mental Capacity Advocates, and other advocates should use the information in this report when dealing with issues around good nutrition for children, young people or adults with learning disabilities.
- 25 The Judicial Studies Board, the Court of Protection, the Office of the Public Guardian, the Official Solicitor and the Ministry of Justice should be aware that there are nutritional and practical guidelines which can help those who are responsible for supporting children,

young people and adults with learning disabilities and their families to eat well in all settings.

26 Social workers, court-appointed guardians and Children and Family Court Advisory and Support Service (CAFCASS) officers who work with families of children with learning disabilities or with learning-disabled parents should be aware that practical guidelines on eating well are available to help them support their clients to eat well. They should also ensure that learning-disabled parents have access to information and support to give them the best possible opportunity to learn how to care for the nutritional health of their children.

27 Any staff who undertake child or adult protection investigations should be aware of the recommendations, and the nutritional and practical guidelines in this report. It is essential that staff are well informed about the signs and consequences of poor nutrition.

Practical guidelines

A summary of practical guidelines to help children, young people and adults with learning disabilities to eat well is given below. For further explanation and more detail about these guidelines, see the relevant chapters of this report, which put the guidelines into context.

Eating well

- Children, young people and adults with learning disabilities should wherever possible be encouraged by family, friends and support staff to eat a varied diet. They should eat foods from each of the four main food groups every day to ensure they get all the nutrients they need. The four main food groups are:
 - bread, pasta, other cereals (such as rice), and potatoes and other starchy roots (such as yam)
 - fruit and vegetables
 - milk and dairy foods such as yoghurt and cheese
 - meat, fish and meat alternatives such as eggs, peas, beans and lentils, soya and nuts.
- Fruit and vegetables are particularly important for good health. Everyone should be encouraged to eat at least 5 portions of a variety of different fruits and vegetables every day.
- Most people in the UK eat too much fat, saturated fat and sugar. Foods which are high in fat and sugar (particularly snacks) can contribute to overweight and obesity if they are eaten frequently or in large amounts. Many people with learning disabilities, and in particular those who are overweight or obese, should be encouraged to replace fatty and sugary foods, drinks and snacks with more fruit and vegetables and other lower-fat and lower-sugar alternatives.
- Most people in the UK eat too much salt and this can contribute to high blood pressure, which is a risk factor for coronary heart disease and stroke. Most people are encouraged to reduce the amount of high-salt foods and snacks they eat and to reduce the amount of salt they use in cooking and at the table.
- Adults are encouraged to eat a portion of oily fish each week – for example, salmon, trout, mackerel, herring or sardines – since the long-chain fats in oil-rich fish have been shown to help with heart health. There is no equivalent food suitable for vegetarians, but a diet which is rich in wholegrain cereals, peas, beans and lentils, vegetables and fruit will contribute to a diet low

in fat and saturated fat and high in complex carbohydrates and fibre which is recommended to prevent heart disease.

For more information on eating well, see chapter 3.

Nutrition and pregnancy

- All pregnant women should ensure that they attend all the appointments made available to them with health professionals throughout their pregnancy, so that they can be supported appropriately. Pregnant women with learning disabilities should be enabled to obtain and attend such appointments and sufficient support should be provided at those appointments to ensure that they can access the information or recommendations made on how to eat well and on the foods they need to avoid while pregnant.
- Women with learning disabilities who are planning a pregnancy, and those who may become pregnant (that is, if they are sexually active and not using contraception) should take a daily supplement of 400 micrograms of folic acid before pregnancy and during the first 12 weeks of pregnancy. Women who have a history of neural tube defect or diabetes mellitus, or who take anti-convulsant drugs, should talk to a health professional about the amount of folic acid they need, as they have greater needs than other women.
- Women should take a supplement of vitamin D during pregnancy. For pregnant women, Healthy Start vitamins, which contain vitamin D (as well as folic acid and vitamin C), are available free to beneficiaries through the Healthy Start scheme. Women who are not entitled to free vitamins are advised to consult a health professional about the appropriate vitamin D supplement to take during pregnancy.
- For women with learning disabilities who are planning a pregnancy, or who are pregnant or breastfeeding, drugs should be prescribed cautiously and regular drug reviews carried out, in order to minimise the risk of harm to the fetus or child.
- Pregnant women with learning disabilities should be counselled about the importance of avoiding alcohol during pregnancy since this has been associated with increased risk of a baby being born with a learning disability.
- Women with learning disabilities who are overweight at the start of pregnancy should be given accessible advice, tailored to their needs and circumstances, on how to eat sensibly during pregnancy and after they have given birth.

For more information on nutrition and pregnancy, see Pregnancy on page 54.

Infant nutrition

- Supporting women with learning disabilities to breastfeed, and finding innovative ways to ensure that all infants receive breast milk – regardless of their mother's disability or any disability in the child – should be seen as a priority. Breast milk is hygienic, easily digested and nutritionally unique, and contains important antibodies to help babies fight infections. Breastfeeding can also protect women from some diseases of later life. Women with learning disabilities should be offered specific and tailored support to help them breastfeed their infants if they wish to do this.
- All parents and carers of infants with learning disabilities should be given advice and on-going support on infant feeding and weaning so that they can establish appropriate eating patterns in their children which will promote good nutritional health in later life.
- All parents who have learning disabilities themselves should be given clear, accessible advice and on-going support on how to feed and wean their infants appropriately.
- Breastfed babies over 6 months of age and all children between 1 and 4 years should receive daily vitamin drops (containing vitamins A, C and D). Vitamin drops containing vitamins A, C and D for children from the age of 6 months until their 4th birthday are available free to beneficiaries under the Healthy Start scheme (www.healthystart.nhs.uk).

For more information on infant nutrition, see Infants on page 52.

Nutritional needs of children and young people

- All parents and other carers of children with learning disabilities, and all parents with learning disabilities who have children themselves, should be given appropriate information on eating well for their children, to ensure that they can prevent underweight and overweight and establish appropriate eating habits for their children to prevent nutritionally-related ill health in later life.
- Children with learning disabilities who eat a poor variety of foods – for example, because they are very selective or because they have eating difficulties – may be at greater risk of nutritional insufficiency, and care should be taken that sources of important nutrients such as vitamin A,

vitamin C, iron, zinc and calcium are included in their diet regularly.

- The teenage years can be a critical time for weight gain or dietary change among young people with learning disabilities as they gain greater independence in food choice. Young people with learning disabilities should wherever possible be encouraged to be active and eat a varied diet.

See also Drinks on page 16.

For more information on children see page 52, and for more information on young people see Teenagers on page 54.

Bone health

- To minimise the possibility of low bone density, people with learning disabilities should be as mobile as possible, spend time outside in the summer sunshine safely, and have adequate vitamin D and calcium intakes.
- Anyone with a learning disability who has little regular exposure to summer sunshine, young children, pregnant and breastfeeding women, those who live in residential care and all older adults (aged 65 years or more) should be considered for vitamin D supplementation. Where this is the case, advice should be sought from a medical practitioner.
- People with learning disabilities who are at increased risk of falling and fracturing their bones should be assessed by a multi-disciplinary team to ensure that sufficient preventative strategies are put in place to prevent falls and that adequate calcium and vitamin D intakes are ensured.

For more information on bone health, see Bone disorders on page 47.

Undernutrition

- It is important that children, young people and adults with learning disabilities are offered a good variety of foods that they will accept and which ensure their nutritional needs are met. Where people with learning disabilities have small appetites or eating difficulties, it may be difficult for them to eat enough food to obtain all the nutrients they need. Support staff therefore need to be aware of the importance of adopting strategies to encourage sufficient food intake.
- It is essential that all those who support people with learning difficulties are alert to undernutrition and are

trained to spot the signs that food intake is inadequate as soon as possible and to take appropriate action by informing the person's medical practitioner.

For more information on undernutrition, see chapter 5.

Healthy body weight

- Support staff should be able to monitor weight change easily and to act on changes appropriately. All residential settings should have weighing scales, preferably sitting scales, for monthly weight checks. The scales should be checked appropriately. Support staff should be shown how to act on the weight data recorded, and there should be an appropriate chart in each person's care plan which highlights when action is needed because of significant weight change.
- Challenging the perception of what are normal body weights for children, young people and adults with learning disabilities is essential. It is important that health professionals are given clear information on the growth and development that should be expected among people with learning disabilities and the importance of intervention if an individual is below or above a healthy body weight for their height.
- Where weight gain is rapid and avoidable, or where someone is very heavy for their height and where a careful assessment has been made by a dietitian or medical practitioner that weight maintenance or weight loss would be beneficial, individuals with learning disabilities should be supported to reduce the amount of calories they eat and to be more active.

For more information on healthy body weight, see chapter 5.

Physical activity

- Everyone should be as active as possible as physical activity builds muscle strength and overall fitness, encourages better mobility and balance, increases appetite and burns up calories. Activity also helps prevent constipation, coronary heart disease and osteoporosis, and has been associated with better mental health.
- Where practical, children and young people with learning disabilities should be encouraged to do moderate-intensity activity – for example, playing with their friends in a playground, swimming or playing football – for at least an hour a day. Adults should aim to do, or build up to, at least 30 minutes' moderate-intensity activity a day on at least five days of the week.

- Where people with learning disabilities also have physical disabilities which make movement difficult, it is important that they are given as much help as possible to be as active as they can be, even if this involves only very limited chair-based movement.
- People with learning disabilities may find activity more enjoyable if they do this with others, and support staff should consider taking part in activities with service users wherever possible.

For more information, see Physical activity on page 66.

Nutrition support

- People who receive some or all of their nutrients through a naso-gastric or gastrostomy tube will often rely on support staff to help manage their artificial nutrition support, ideally with back-up from a dietitian or nutrition support nurse. Training should always be given so that support staff know how to manage tube feeding and solve any practical problems people may have.

For more information on nutrition support, see page 62.

Constipation

- All those who support people with learning disabilities should be alert to signs which may indicate constipation, such as a reluctance to go to the toilet, obvious discomfort, long periods spent in the toilet, a change in eating habits, unexplained diarrhoea, food refusal, or unexplained challenging behaviour.
- To avoid constipation it is important that adults are as mobile as possible, and have sufficient fluid and sufficient fibre in their diet. Children and young people who are constipated should seek advice from a dietitian or medical practitioner on the amount of fluid and fibre appropriate to their needs.

For more information on constipation, see page 72.

Dysphagia (swallowing difficulties)

- Dysphagia should always be considered when there are unexplained eating or breathing difficulties, changes in eating patterns, distress associated with eating, or recurrent chest infections.
- Those who are at high risk of dysphagia should be assessed for vulnerability and their care plans updated accordingly. The involvement of a speech and language therapist with specialist knowledge of swallowing

disorders is critical in creating a management strategy and in training the person himself or herself, as well as his or her family, friends or support staff.

- Medication reviews of a person with dysphagia should take into account swallowing difficulties, as the person may be unable to swallow tablets or other medication or supplements.

For more information on dysphagia, see page 28.

Oral health

- All children, young people and adults with learning disabilities should visit the dentist twice a year.
- Cutting down on the amount of sugar eaten, and on how frequently sugary foods and drinks are consumed throughout the day, will help to prevent dental decay.
- Good daily oral hygiene is essential, including brushing the teeth twice a day with fluoride toothpaste. Children under the age of 8 years and anyone who may have difficulty in brushing their teeth independently should be helped when brushing their teeth.
- Support staff should be offered training on the importance of oral health and how to help someone clean their teeth.
- All those who support people with learning disabilities should be alert to changes in behaviour such as loss of appetite, unwillingness to participate in activities, sleeplessness, irritability or self-harm, and should find out if mouth or tooth pain is a possible cause of the behaviour change.

For more information on oral health, see page 75.

The eating environment and timing of meals and snacks

- All children, young people or adults with learning disabilities should be respected as individuals and their food preferences and religious and cultural requirements around food should be accommodated.
- Food should be appetising and attractively served, to ensure that people enjoy their food. This is particularly important if the food has its form or texture changed for people with swallowing difficulties.
- The timing of meals and snacks throughout the day should be organised to fit around the needs of the individual being supported. Some people may need frequent small meals and snacks throughout the day.

- It is important to ensure that everyone has enough time to eat and drink and that, where necessary, food is kept warm safely during the meal for those who eat and drink slowly.
- It is important to ensure that people arrive at mealtimes ready for the eating occasion, for example, having had the opportunity to go to the toilet and wash their hands or collect their hearing aid, glasses or dentures. Where possible, children, young people and adults with learning disabilities should have the opportunity to serve themselves at mealtimes and independence in eating should be encouraged. The appropriate cutlery, crockery, tables and chairs should be available to ensure that everyone is as comfortable and independent as possible.
- To make mealtimes a time of pleasant social sharing, and as good practice, staff should sit with the people they support during meals and snacks, and where appropriate share the same foods and drinks.
- Mealtimes offer an opportunity for support staff to model eating skills and to encourage social interaction and conversation. To encourage this, distractions such as television are best avoided during mealtimes.

For more information on the eating environment and timing of meals and snacks, see pages 82 and 83.

Breakfast

- Breakfast is an important meal, firstly because many breakfast foods are a very good source of fibre and other important nutrients, and secondly because, if breakfast is missed, it is more likely that individuals will be tempted by other snack foods later in the day.
- For those who have a good appetite in the morning that recedes as the day continues, breakfast should be seen as an opportunity to eat a significant amount of energy (calories) and other nutrients, and a range of foods should be offered, rather than just traditional breakfast foods.

For more information on breakfasts, see page 83.

Snacks

- A variety of snacks should be offered and these should be included in menu plans. Snacks provide an opportunity to supplement nutritional intakes between meals and can be particularly important for those with small appetites or who are fussy or selective eaters, or who are growing rapidly. However, for those people with learning disabilities who are gaining weight or who have

been advised to lose weight, snacks that are high in fat and sugar (such as confectionery, savoury snacks, soft drinks, cakes, biscuits and ice cream) should be kept to a minimum as these frequently contribute significant extra calories to the diet.

For more information on snacks, see page 83.

Drinks

- It is important that everyone is encouraged to drink a sufficient, but not excessive amount, of fluid each day and it should not be assumed that people will necessarily drink enough fluid without encouragement. Most adults need at least 1.2 litres of fluid a day (about 6 glasses) but older people or people who are prone to constipation should be encouraged to have at least 1.5 litres a day (about 7 to 8 glasses). However, excessive fluid (more than 5 litres a day) can be very dangerous and advice should be sought from a medical practitioner if there is concern that someone is drinking excessively.
- Free, fresh, chilled tap water should always be offered with meals and regularly throughout the day and should be widely available in any places where people with learning disabilities may live, work or visit.
- The amount of soft drinks given to children with learning disabilities should be limited since these offer little nutritional benefit and may suppress appetite and prevent children eating more nutritious foods. If soft drinks (such as squashes) containing saccharin are given to the under-5s, they should be diluted much more than they would be for an adult – for example, a dilution of 1 part squash to 10 parts water.
- If sugary, fruit-based or fizzy drinks are given to children and young people with learning disabilities, they should be kept to mealtimes since frequent consumption of soft drinks is related to tooth decay and tooth erosion. Drinks other than milk or water are highly likely to contribute to tooth decay, so they should not be given at bedtime or during the night.

For more information on drinks, see page 84.

Vitamin, mineral and herbal supplements

See also: page 13 for information on supplements for pregnant women and on vitamin drops for children; and page 14 for information on vitamin D supplements.

- Advice should always be sought from a medical practitioner or pharmacist before any dietary

supplements are taken, as high doses of certain vitamins and minerals and some herbal supplements can cause adverse reactions and may interfere with the absorption of other nutrients or with the action of medicines.

For more detailed information on vitamin, mineral and herbal supplements, see page 89.

Food allergy and food intolerance

- If a child, young person or adult with a learning disability has a medically diagnosed food allergy, this needs to be taken extremely seriously. It is important that everyone understands the importance of avoiding contact with those foods that may trigger a serious reaction. Full information on the food allergy should be carefully recorded in care plans and be communicated to schools, day centres and any other places that the person may visit regularly.
- It is important that food allergies should be medically diagnosed. People with learning disabilities, their family, friends and support staff should be discouraged from attempting to restrict a person's diet due to a perceived allergy or intolerance, as this may make it difficult for the person to get all the nutrients they need. This is particularly true if foods such as milk and milk products or bread and other cereals are avoided.

For more information on food allergy and food intolerance, see page 91.

Food hygiene and safety

- It is important to remind children, young people and adults with learning disabilities, and their family, friends and support staff, about the importance of washing their hands with soap and water before eating meals or snacks and after going to the toilet.
- Support staff should always wash their hands with soap and water before preparing food or before helping people to eat, and after they have blown their nose.
- Support staff should seek information about food hygiene and safety, and requirements for training, from their local authority's environmental health department.
- Support staff need to ensure they know how to store food safely, handle leftover food, and cook and heat food appropriately.
- Children under 5 and anyone who has any form of eating difficulty should never be left unattended when eating or drinking, as they may choke.

For more information on food hygiene and safety, see page 92.

Philosophy of care – rights and responsibilities

- Managers and support staff should be aware of the code of practice of the Mental Capacity Act 2005 which presumes that anyone over the age of 16 has the right to make his or her own decisions and must be assumed to have the capacity to do so unless proved otherwise, and that people should be supported to make their own decisions and choices.

For more on the Mental Capacity Act, see page 98.

Helping people make good choices

- A variety of foods and drinks should be made available to everyone and support staff should be trained and supported to help people with learning disabilities make informed choices. Where there are communication difficulties around food and drink choices and eating, support staff should be encouraged to develop skills in interpreting people's wishes.
- Courses on nutrition and health and on basic cookery for people with learning disabilities, and for their friends and family, should be made available. Special courses for those people with learning disabilities who are parents should also be made available.

For more information on making choices see page 98.

Organisational culture

- In all settings it is essential that there is a commitment to good nutrition and an awareness of the wider role of food and drink in contributing to wellbeing and quality of life. Managers and staff at all levels need to demonstrate their commitment to good nutrition by ensuring everyone receives adequate training and support.
- Efforts should be made to find out about the food preferences and eating patterns of people with learning disabilities – including those who move into new or residential settings, regardless of how long they will stay there. This information should be recorded, shared with all support staff, and regularly updated.
- People with learning disabilities should be encouraged to include information about food and nutritional health in their health action plan which is compiled to explain their health needs, and in all care plans.

For more information on organisational culture, see page 100.

Staff training and support

- The importance of staff training cannot be over-emphasised. In order that children, young people and adults with learning disabilities are supported to eat and drink well, it is essential that everyone involved in supporting them has a clear idea about what eating well means in practice and that appropriate training is on-going for all staff, regardless of whether they are permanent, temporary, employed through an agency or involved in a voluntary capacity.
- It is important that anyone who supports those who need assistance with eating is trained to help in a sensitive and efficient way. Helping someone with eating difficulties to eat can be complex and stressful and it is essential that staff are given sufficient support from colleagues when this is challenging.

For more information on staff training and support, see page 100.

Involving and listening to family and friends

- A real partnership between families, friends and support staff is essential so that everyone works together to ensure that each individual eats and drinks in a way that they prefer and which is appropriate, safe and health-promoting. In residential and day care settings it is important that adequate notice of, and the reasons for, changes to meals and snacks are given to everyone so that people can comment on and discuss the changes before they are introduced.

For more information on involving and listening to family and friends, see page 100.

Monitoring nutritional status

- All support staff should be able to make simple nutritional assessments that might alert them to changes in the nutritional status of those they care for.

For more information on monitoring nutritional status, see page 105.

Maintaining independence in eating, and helping people to eat

- Those who are able to eat independently, even if this is by hand only, should be encouraged to do so to maximise independence and dignity. If independent

eating skills are not encouraged, there may be a rapid decline to dependence.

- Where people need help with eating, it is essential for staff to be trained in helping them to eat and to do this in a sensitive and efficient way.
- The use of finger foods – foods which are presented in a form that can be eaten easily by hand without the need for cutlery – should be used as a way of preserving eating skills and promoting independence for those who have difficulty using utensils or who do not recognise the purpose of cutlery.
- Some people with swallowing difficulties may need to have their food or fluid modified. Specialist advice should always be sought when texture modification is required, to ensure that the person's nutrient needs are met and the food is of the correct texture.

For more information, see pages 132-135.

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Chapter 2

About learning disabilities

What is learning disability?

Learning disability is a term used to describe the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), along with a reduced ability to cope independently (impaired social functioning), which started before adulthood, and has a lasting effect on development.¹ The classification of a learning disability as mild, moderate or severe is often related to the amount of support that a person might require and is frequently based on IQ (intelligence quotient). An IQ of 50-69 is sometimes termed as 'mild learning disabilities', an IQ of 35-49 as 'moderate learning disabilities', an IQ of 20-34 as 'severe learning disabilities', and an IQ of less than 20 as 'profound learning disabilities'.² The requirement for the additional support someone may need is not solely based on IQ but includes an assessment of the person's communication and social skills and their ability to manage their everyday lives. Some people with mild to moderate learning disabilities make their way through life without using special services or being categorised as having learning disabilities at all, while others can live independently with support. Severe learning disability is also defined as needing significant help with daily living,¹ and profound learning disability has been defined as having severely limited understanding, immobility or restricted mobility and requiring constant supervision.² Many people with learning disabilities also have sensory and/or physical impairments which make them more in need of assistance, and some people have very complex health needs which require significant intervention. In this report, the term severe learning disabilities

is used to describe all those individuals who have significant support needs that might be considered either severe or profound.

It has been estimated that well over a million people in England (about 2% of the population) have some form of learning disability, although estimates vary widely and no definitive figures are available.³ Valuing People estimated that about 25 people in 1,000 have mild or moderate learning disabilities (about 1.25 million people), and estimates in Scotland suggest that about 20 people in every 1,000 have mild or moderate learning disabilities (about 100,000 people).⁴ Estimates from Northern Ireland suggest there are about 12,000 people with a moderate learning disability.⁵ In Wales there are around 13,500 people on local authority learning disability registers.⁶

The number of people with severe learning disability in England was estimated as about 210,000 people (0.4% of the population)¹ by Valuing People in 2001. Of these, around 65,000 were children and young people, 120,000 were adults of working age and 25,000 were older people. More recent estimates from the Department of Health suggest that there are about 160,000 adults and between 55,000 and 75,000 children with a moderate to severe learning disability in England.⁷ In Scotland it has been estimated that 3 to 4 people in every 1,000 have severe learning disabilities (equivalent to about 15,000-20,000 people, of whom 4,000-5,000 are under 16 years of age).⁴ In Northern Ireland in 2003 it was estimated that there were about 4,500 people with severe learning disabilities, about 1,700 of whom are under 16 years of age.⁵

It is anticipated that the total number of people with learning disabilities will increase by 1% (about 15,000 people) by 2008, partly due to increased life expectancy of people with learning disabilities and partly because of an increased incidence.⁸ Rising maternal age associated with increased risk of Down's syndrome and increasing numbers of children with complex and multiple disabilities, who now survive into adulthood, will contribute to the rise. Also adding to the increase is a sharp rise in the number of school-aged children with autistic spectrum disorders, some of whom have learning disabilities, and a greater prevalence of learning disabilities among people of South Asian origin.¹

In 2004, it was estimated that there were between 4.5 and 11.3 million people with learning disabilities across the 25 member states of the European Union at that time, about 1.3 million of whom have moderate or severe learning disabilities.⁹ Differences in the definitions of learning disability make it a challenge to estimate prevalence figures, and also standard terminology across countries is not used. 'Intellectual disability' is the term used in the US

and the Republic of Ireland, and both 'learning disabilities' and 'learning difficulties' are used in the UK. After consultation with our stakeholders, it was agreed that the term 'learning disabilities' would be used in this report.

Who has learning disabilities in the UK?

People with learning disabilities are born into families from all walks of life and from all ethnic groups. Some of the primary causes of learning disabilities are genetic and include Down's syndrome, Fragile X syndrome, phenylketonuria, Prader-Willi syndrome, and congenital abnormalities such as congenital hypothyroidism.

Secondary disorders, which can occur during or after birth, may result from external factors such as oxygen deprivation, or alcohol or drug abuse. They may also occur as a result of a traumatic birth, meningitis or head injury,¹⁰ or as a result of a child being undernourished, abused or neglected.¹¹ Low birthweight and prematurity are strongly correlated to the later development of learning disabilities.¹² There are, however, incidences where no reason for the learning disabilities can be identified.¹⁰

Severe learning disabilities are more common in males, young people, and people of South Asian origin, but are uniformly spread among all socioeconomic groups. Mild learning disabilities are more common among males, young people and those from families living in poverty or with other mental health and social difficulties.¹³ More boys are born with learning disabilities than girls because some causes are genetically determined and associated with males, so that approximately 60% of cohorts of children and young adults with learning disabilities are likely to be male. This ratio decreases with age as women typically live longer than men.¹⁴

Learning disability and different ethnic groups

The number of people with learning disabilities from ethnic groups is not known, but it is estimated that the prevalence of learning disabilities among South Asians aged between 5 and 32 years is up to three times higher than in other communities.¹⁵ It is suggested that this greater prevalence is due in part to high levels of social deprivation among South Asian people with learning disabilities and their families, and poorer access to health services, as well as greater genetic risk.¹⁶ Prevalence within other minority ethnic groups is not as well documented, but it has been suggested that there is also a relatively high prevalence in the African Caribbean community.¹⁷ There is an expectation

that the number of people with learning disabilities from ethnic minority groups will increase in the UK.¹⁸

Parents with learning disabilities

There are no precise figures on the number of parents with learning disabilities in the population. The most recent evidence comes from the first national survey of adults with learning disabilities in England¹⁹ where 1 in 15 of the adults interviewed had children. It is generally acknowledged that the number of parents with learning disabilities is rising and that their needs are not adequately addressed.²⁰ Parents with learning disabilities are far more likely than other parents to have their children removed from them and permanently placed outside the family home, and the national survey mentioned above found that 48% of the parents interviewed were not looking after their own children.

Care and support for people with learning disabilities

Almost all children with learning disabilities live with their families, while most adults live either with their families or in some form of communal housing or other supported accommodation.²¹ Of those who live at home, many are supported by older parents: Mencap estimates that almost 30,000 people with severe learning disability live at home with family carers aged over 70 years.²²

People with learning disabilities may live in a variety of settings including family homes, group residential accommodation, their own homes, sheltered housing, hostels, with landlords or landlords, in private shared arrangements supported by home carers or others, or in other forms of supported lodgings. It is difficult to get a clear picture of where people live since some people are funded through direct payments or via individual budgets, some receive specific 'Supporting People' funding and some receive home care services. It is estimated that in 2006 there were about 35,260 supported residents with learning disabilities in England aged between 16-64 years, 80% of whom lived in independent residential accommodation.²³

In Scotland in 2005, there were 5,691 supported residents in 861 care homes, of which 50% were privately owned, 44% voluntary and 6% provided by the NHS.²⁴ In Northern Ireland in 2003, around 450 people with learning disabilities were still resident in long-stay hospitals, and around 1,900 people lived in residential and nursing homes or in supported living accommodation.⁵ In 2005-2006

there were 92 residential homes in Northern Ireland solely for people with learning disabilities, providing 1,105 places. In Wales, about half of adults with learning disabilities live with their families, approximately 20% live in their own homes, 20% in residential care and about 10% in supported living arrangements.⁶

It is estimated that about £4.6 billion is spent each year in the UK to provide formal services for people with learning disabilities.²⁵

Respite care

Some people with learning disabilities will spend some time away from their own home in respite care, either overnight or for short breaks. In 2005-2006 in England, 12,000 people with learning disabilities were supported for overnight respite services and 5,800 for short-term residential breaks.²⁶

Costs of residential care

The average cost of a place in residential care in the private and voluntary sector in Scotland in 2005 was £696 a week²⁴ and in England in 2005-2006 the average cost of a residential care place for an adult aged 18 years or above was £895 per person per week.²⁷ The cost of caring for people with learning disabilities is, however, likely to be very variable and for those with severe learning disabilities and challenging behaviour or forensic needs (ie. learning-disabled offenders) the cost may be considerably higher.

Children with learning disabilities in foster care

It is not known how many children with learning disabilities are looked after in foster care in the UK as a whole, but estimates from Wales suggest that, in 2005-2006, of the total of 3,353 children fostered in Wales,²⁸ 125 were children with learning disabilities under the age of 16,²⁹ suggesting that about 4% of fostered children may have a learning disability. Approximately 60,000 children in England are looked after by local authorities³⁰ and it is likely that around 2,500 children with a learning disability are looked after in foster care.

Home care for people with learning disabilities

A number of people with learning disabilities may receive home care (called domiciliary care) in their own homes. In England in 2005-2006²⁷ £1,240 million was spent on day care and domiciliary services for people with learning disabilities, with an average of £346 per person per week

spent on home care services for adults with learning disabilities receiving home care. Home care is provided by local authorities and by private agencies. The main purchasers of home care are local authorities who buy 80% of the hours of care provided by the independent sector.²⁹ In 2005-2006 there were 27,000 people with learning disabilities in England receiving home care services.²⁶ In 2004 there were estimated to be 163,000 home care workers in England, 65% of whom worked in the independent sector. In Scotland, 3,066 people with learning disabilities received home care in 2006, ³² 85% of whom were under 65 years of age. In Scotland the majority of home care is provided by in-house local authority teams (76% in 2006) but the use of the independent sector is growing. There are estimated to be 27,200 home care workers in Scotland, with about 6,700 in the independent sector.³² The number of people with learning disabilities receiving home care services in Wales is not currently available but, in 2006, 45% of publicly funded home care was provided by the independent sector and increasing use of the independent sector is also being seen in Wales.³³ In Northern Ireland, 880 people with a learning disability received home help and meals services in 2005-2006. ³⁴ In 2002 it was estimated that there were about 4,250 homecare workers and managers in the independent sector working for 92 independent sector homecare providers.³⁵

Domiciliary care is regulated by the National Minimum Care Standards for Domiciliary Care and equivalent legislation in Scotland, Wales and, in the near future, Northern Ireland. (See Appendix 1 for a summary of these standards.) The standards in England provide little support for eating well but more extensive support is provided by the Scottish standards. The current Scottish standards explicitly expect service users to be supported around eating well and acknowledge the key role of home care workers in identifying people who may be at risk of poor nutrition.

Community meals are also part of homecare services and some people with learning disabilities may also receive these. In 2005-2006, 1,100 people with learning disabilities in England received community meals.²⁶

Day services

Day services have undergone significant change in recent years and rather than congregating large numbers of people with learning disabilities in 'adult training' or 'social education' centres for activities, day centres are more frequently administrative bases from which more integrated activities – such as work experience and college courses – are coordinated. It is estimated that about 58,000 people with learning disabilities in England used

local authority day care services in 2005-2006. ²⁶ The average cost of day care services for adults with learning disabilities in England in 2005-2006 was £277 per person per week.²⁷

Employment and benefits

It has been estimated that about 17% of people with learning disabilities are in paid employment¹⁹ but most people with learning disabilities are reliant on state welfare benefits. The main welfare benefit is Income Support which includes a premium for people with disabilities. Many may also receive the Disability Living Allowance and the Independent Living Fund and some people may get housing benefit. There can be financial disincentives for those moving to employment. Although a number of schemes attempt to allow transition to work without the loss of income, the loss of benefits such as housing benefit can still be a disincentive to moving to full-time employment. There has been a growth in 'supported employment' agencies (mostly funded by local authority social services departments) which aim to find paid employment for people with learning disabilities. Bringing up a child with severe disabilities is likely to have serious cost implications and have an impact on a family's entry into and escape from poverty.³⁶ It has recently been estimated that nearly half (44%) of all children with learning disabilities in Great Britain were experiencing poverty, compared with just under one-third (30%) of children who do not have learning disabilities, and it is established that poverty is likely to be associated with poorer health and wellbeing.³⁷

How does having a learning disability impact on everyday life?

Learning disabilities can affect many different aspects of a person's life, and individuals will be affected differently. Some of the aspects of daily life frequently affected include:

- **Reasoning** (sometimes called cognition) – the person may not be able to organise and put thoughts together, use thinking and learning strategies or learn from mistakes
- **Memory** – difficulties remembering facts and instructions
- **Social behaviour** – difficulties with social judgement,

tolerating frustration and making friends

- **Physical coordination** – the person may have difficulty with handwriting, manipulating small objects, running and jumping
- **Physical and mental health** – people with learning disabilities may be more likely to have other health difficulties
- **Organisation** – managing time and belongings, or carrying out a plan
- **Communication** – difficulties with expressive and receptive communication
- **Reading** – difficulties decoding, recognising and understanding words
- **Written language** – may not find it easy to write, spell and organise ideas
- **Mathematical skills** – may not find it easy to understand arithmetic.

People with severe learning disabilities may find most tasks associated with daily living impossible to carry out without assistance, and may well have a number of physical and health difficulties which impact on their quality of life.

People with severe learning disabilities may have additional difficulties with:

- **Communication** – Communicating thoughts and feelings can be difficult and frustrating for people with severe learning disabilities. The person may not be able to talk clearly and communication may be by signing (eg. Makaton) or through other forms of non-verbal communication such as gestures, body language, facial expressions or by using resources such as Talking Mats (see page 153). In addition the person may not be able to understand speech unless very simple language and short sentences are used.
- **Challenging behaviour** – People with severe learning disabilities may show aggressive, disruptive or socially unacceptable behaviours and may have little or no sense of danger. Such behaviour may well be an expression of an underlying problem such as pain or distress.
- **Physical difficulties** – restricted mobility, motor skills, posture, swallowing, chewing and eating difficulties may make simple tasks of daily living difficult.
- **Ill health** – People with severe learning disabilities are more likely also to have other physical and mental health difficulties which impact on daily life such as epilepsy, autistic spectrum disorders, sensory impairments, gastrointestinal disorders (problems with the digestive system) and respiratory problems.

Causes of learning disabilities and their impact on health

Some of the causes of learning disabilities and their impacts on health are outlined below. While support staff may feel uncomfortable about labelling people, it is important to people's health to understand the implications of certain conditions. This list is not exhaustive since there are many conditions that can lead to some level of learning disability – for example, a stroke or an accident, including road traffic accidents. A review of many of the major specific disorders and their impact can be found in *Physical Health of Adults with Intellectual Disabilities*, by Prasher and Janicki.³⁸ For information on how to find out more about the conditions detailed here, see Appendix 4.

Cerebral palsy

Currently about 1 in 400 children born develop cerebral palsy.³⁹ Learning disabilities are not inevitable but can occur as a result of the brain damage that has caused the cerebral palsy.⁴⁰ In about 1 in 50 cases of cerebral palsy, learning disabilities are a result of poor brain development, and in about 1 in 10 cases they are due to damage to the brain during birth. Other causes of cerebral palsy include brain cells damaged by lack of oxygen resulting from infections such as meningitis or encephalitis while the child is young and the brain is still developing.

Cerebral palsy can cause difficulties with speech, hearing, balance, coordination and sight. It can also cause limbs to stick rigidly in abnormal positions, and epilepsy. People with cerebral palsy often have specific difficulties with swallowing, gastrointestinal difficulties, low body weight, and a greater risk of heart disease, and women with cerebral palsy have been reported to be at greater risk of iron deficiency.³⁸

Congenital hypothyroidism

This affects about 0.1 to 2 births per 1,000. It is a general term for a collection of genetic disorders of the thyroid or pituitary glands resulting in too little, or very rarely the total absence of, thyroid hormone production. The most frequent form (1 in 3,000 births) is an incomplete development of the thyroid. Girls are twice as likely to suffer congenital hypothyroidism as boys.

Those with the disease have a thick, protruding tongue, poor feeding and muscle tone, prolonged jaundice, constipation and delayed development. Early diagnosis and treatment with thyroxine can prevent irreversible damage to the nervous system seen in the first few months of life, which can otherwise result in poor mental and physical development of the child.⁴¹

Down's syndrome

One in every 1,000 children born in the UK has Down's syndrome,⁴² which is the most common congenital cause of learning disability, caused by an extra chromosome at position 21. About 600 babies are born with Down's syndrome each year and it is estimated that there are about 60,000 people with Down's syndrome living in the UK,⁴² 80% of whom are over 50 years of age,⁴³ reflecting a significantly higher previous incidence of Down's syndrome. The chance of having a child with Down's syndrome increases rapidly with maternal age, from approximately 1 in every 1,500 births for those giving birth at 20 years of age, to 1 in every 350 births at age 35, and 1 in every 30 births at age 45 years.⁴⁴

The life expectancy and life chances for people with Down's syndrome have dramatically improved in recent years and people with Down's syndrome are increasingly able to live rich and varied lives, which may include becoming parents. However, there are a number of health difficulties which may be more common among people with Down's syndrome, including an increased incidence of obstructed gastrointestinal tract, respiratory difficulties, thyroid disorders and congenital heart problems.⁴⁵ Compared with the general population, people with Down's syndrome are more likely to have insulin-dependent diabetes, obesity, depression, difficulties with hearing and vision, and early onset dementia similar to Alzheimer's disease.⁴² People with Down's syndrome also have a different bone arrangement of the skull and may have a smaller oral cavity, both of which could affect chewing.⁴⁵ In addition, in Down's syndrome the ligaments which normally hold the joints stable are more slack and this can particularly impact on the joint at the base of the skull which might make neck dislocation more likely if someone is given vigorous treatment during a choking incident.⁴⁶

Fetal alcohol syndrome

Fetal alcohol syndrome is the most common non-genetic cause of intellectual disability in the western world. For every 10,000 births in the UK, 19.5 babies have fetal alcohol syndrome and 1 in 100 have alcohol-related neuro-developmental disorder.⁴⁷ Alcohol drunk by the mother while pregnant can pass into the developing fetus and in large amounts can cause both physical disabilities such as a distinctive poor formation of the mid face, structural abnormalities of the brain, congenital heart defects and growth retardation, as well as learning disability.⁴⁸ The Department of Health suggests that pregnant women or those trying to conceive should avoid drinking alcohol.⁴⁹ For more information about eating well in pregnancy see page 54.

Fragile X syndrome

This occurs in approximately 1 in 4,000 males and 1 in 8,000 females. It is caused by abnormal expansion of the DNA at the top of one arm of the X chromosome and results in learning disabilities which can range from mild to severe. People with Fragile X syndrome can also have some behavioural difficulties, have difficulties establishing relationships with family, friends and support staff, and distorted or delayed language or speech skills.⁵⁰

Neurofibromatosis

Neurofibromatosis is a genetic disorder of the nerve tissue. There are two types, depending on the gene affected. (Neurofibromatosis type 1 is caused when chromosome 17 is affected, and type 2 is caused by chromosome 22.) The disorder can be inherited or occur spontaneously. It can cause tumours, and affect the nerves, bones or organs. Neurofibromatosis type 1 (nf1) occurs in 1 in 2,500 people worldwide and there are about 25,000 people with nf1 in the UK. Between 30% and 60% of those with nf1 will also have learning disabilities. Features include a lack of fine motor skills, failure to understand non-verbal communication, poor spatial awareness, poor short-term memory, and impulsive or unpredictable behaviour. The symptoms vary and are often overlooked or mistaken for idleness or naughtiness.⁵¹

Phenylketonuria (PKU)

PKU is a genetic disorder which results in the inability to use the essential amino acid phenylalanine, resulting in changes in the metabolism of myelin and amines, and interference of the nervous system. Approximately 1 in every 10,000 babies in the UK are born with PKU.⁵² Some forms of PKU are treatable with a lifelong diet low in phenylalanine (using protein substitutes which contain tyrosine and no or very little phenylalanine). PKU can result in cognitive deficits including severe brain damage, increased hyperactivity and learning disabilities. A national screening programme detecting affected infants (the 'heel prick' test given to babies shortly after birth) provides early treatment and reduction of symptoms.⁵³

Prader-Willi syndrome (PWS)

This is caused by a defect in chromosome 15. The incidence of those with PWS is estimated to be about 1 in 10,000 births.³⁸ PWS causes weak muscle tone, varying degrees of learning disability, and poor emotional and social development, and it is associated with increased risk of affective psychosis (mood-altered state).¹⁴ Hyperphagia (abnormally increased or excessive appetite) and food foraging, possible binge eating and pica (eating non-food

items) are common, resulting in an impaired ability to recognise that enough has been eaten.⁵⁴ In the past, life expectancy for those with PWS was short, mainly due to health problems associated with extreme obesity, but better dietary management and understanding of the syndrome is improving life expectancy.⁵⁵

Prematurity

About 4 in every 10 babies born before 26 weeks have moderate to severe learning disabilities, and these very premature babies are also more likely than other babies to have cerebral palsy, blindness and profound deafness.¹²

Rett syndrome

Rett syndrome is a complex neurological disorder. It affects mainly girls. Although present at birth, it becomes more evident during the second year of life. People with Rett syndrome have severe learning disabilities and are highly dependent on others for their needs, including eating and drinking, throughout their lives. At least 1 in every 10,000 females born has Rett syndrome and it is believed to be the second most common cause of severe learning disability in girls.³⁸

Tuberous sclerosis

Tuberous sclerosis is a genetic disorder where approximately 33% of cases are inherited. It is estimated to affect 1 in 7,000 people in the UK, with a total of 8,000 people affected. Tuber-like growths on the brain become hard and calcify with age. They can also affect the skin and any other organ in the body. Symptoms include white skin patches and the appearance of nodules on the skin. Seventy per cent of people with tuberous sclerosis have epilepsy and approximately 50%-60% have learning disabilities, with 25% classed as having severe learning disabilities. Twenty-five per cent of people with tuberous sclerosis are autistic, and another 25% show aspects of autistic spectrum disorder.⁵⁶

Turner syndrome

Turner syndrome affects females and is caused by absence of all or part of the second X chromosome. It occurs in 1 in 2,000 live female births and up to 10% of all miscarriages. The primary characteristics are short stature and early ovarian failure, resulting in failure to produce eggs and hormones necessary for the development into puberty. People with Turner syndrome also experience heart, kidney, thyroid and hearing problems, are more likely to have coeliac disease and have varying degrees of severity of non-verbal memory and attention span.⁵⁷ This syndrome has been linked to anorexia nervosa and possible body image disturbance.⁵⁴

Other health difficulties associated with learning disabilities

People with learning disabilities may also have a physical disability or another health problem such as epilepsy, thyroid disorder, osteoporosis, sight or hearing problems, mental ill health including dementia, or congenital heart disease. Epilepsy, thyroid disorders, mental ill health, eating disorders, dementia, and attention deficit hyperactivity disorder and autism spectrum are discussed in more detail below. Other conditions are included in the sections on health and practical difficulties associated with eating (see pages 47 and 28).

Epilepsy

About 30% of people with learning disabilities also have epilepsy,⁵⁸ increasing in incidence with increasing severity of learning disability.⁵⁹ It has also been estimated that about 20%-25% of children and young people with learning disabilities have epilepsy but that this increases to over 50% for children with severe learning disability.⁶⁰ Some of the many different types of epileptic seizure can be hard to recognise and include strange, repetitive or unusual behaviour and confusion. In some people with a learning disability it may be difficult to distinguish a seizure from usual behaviour and the person may be unable to communicate how they are feeling. Drugs are normally used to control seizures, but this may prove more difficult in people with learning disabilities because of the underlying cause. The side effects of drugs – such as nausea, drowsiness, inflamed gums, disturbed vision, poor attention and behaviour change – may result in a person becoming withdrawn or developing challenging behaviour as they are unable to express themselves.⁵⁹ Drugs frequently given to control epilepsy may impact on nutritional status since they may cause constipation or diarrhoea, nausea, weight loss or weight gain, and may interfere with vitamin K absorption and folate metabolism.³⁸

Thyroid disorders

Thyroid disease can occur at any age but is more common among older people and is particularly common in people with Down's syndrome.⁶¹ Thyroid disease can be difficult to diagnose and should be suspected if changes in behaviour are reported or there is an unexplained increase in appetite and/or weight loss (hyperthyroidism), or decreased appetite and/or weight gain (hypothyroidism). Other symptoms of thyroid disorder include dry skin, constipation, tiredness, irregular menstruation and depression.

Learning disabilities and mental health

Between 25% and 40% of people with learning disabilities also have mental ill health.²² Over a third (36%) of children and adolescents with learning disabilities in Britain have a diagnosable psychiatric disorder and are six times more likely to have a diagnosable psychiatric disorder than children and adolescents without learning disability.⁶² It has been suggested that some mental health disorders among people with learning disabilities are related to poverty and social exclusion, and may not necessarily all be directly related to the learning disability itself.⁶²

Many learning disability syndromes of genetic origin are associated with psychiatric disorders⁶³ and people with learning disabilities are more likely to experience traumatic life events that make them vulnerable to mental ill health.⁶⁴ One study reported that having a learning disability increased the risk of schizophrenia by three times that of the general population.⁶⁵

Learning disabilities and mental health are two separate diagnoses but, as those with learning disabilities are often unable to express themselves, mental illness can fail to receive proper attention or diagnosis. It has been reported that between 10% and 39% of adults with learning disabilities have mental health needs arising from diagnosed psychiatric and behavioural difficulties.¹⁰

Communication needs and lack of awareness by support staff and other professionals can lead to mental ill health being under-diagnosed and unmanaged⁶⁶ and many symptoms of mental health are written off as challenging behaviour, or assumed to be less important because of the context of a person's learning disability.⁶⁷

Mental ill health can in itself also be a risk factor for becoming obese or for under-eating⁶⁸ and people with mental ill health are often treated with drugs such as tranquillisers and anti-depressants which can have unpleasant side effects. A report published by Sustain⁶⁹ has suggested potential links between diet and mental health and it would appear prudent to encourage a balanced diet for anyone with mental health disorders.

Eating disorders

Eating disorders, anorexia nervosa, bulimia nervosa and atypical eating disorders have been reported to be more prevalent among people with learning disabilities compared with the rest of the population.^{70, 71} In a recent sample of service users of a project for people with learning disabilities in South London, 13% were found to have binge eating disorder and about 1% anorexia nervosa.⁷² The causes of eating disorders are complex and poorly understood,⁷³ but among people with learning

disabilities they have been associated with being younger, having reported abuse, having poorer social networks, having difficulties with eating and drinking, and having other behavioural disorders.⁷¹ Eating disorders are likely to co-exist with other associated eating difficulties and abnormal eating behaviours such as pica, selective eating, vomiting, regurgitation and rumination, chewing and spitting out food and food refusal. (For more on eating behaviour and dealing with eating difficulties, see page 108.)

Dementia

Dementia is defined as the “Deterioration of intellectual faculties, such as memory, concentration, and judgement, resulting from an organic disease or a disorder of the brain. It is sometimes accompanied by emotional disturbance and personality changes.”⁴⁰ The term dementia encompasses a number of physical disorders of the brain arising from a variety of causes. It has no cure and is ultimately fatal. Those affected are progressively unable to care for themselves; they lose the ability to communicate and eventually need help with all aspects of everyday life, including eating where they may fail to recognise food or know what to do with it.⁷⁴ In addition, there is now evidence that swallowing difficulties in Alzheimer's disease (the most commonly occurring form of dementia) occurs mid-way through the illness rather than as a terminal symptom.⁷⁵ The physical and psychological changes associated with dementia place an added burden on family, friends and support staff and reduce the life expectancy and quality of life of those with the condition.

It has been reported that 21% of older people with learning disabilities have dementia, compared with 5.7% of the general population.⁴² Research commissioned by the Down's Syndrome Association found that, in over 50% of those people with both Down's syndrome and dementia, the onset of dementia occurred before the age of 60 – several decades earlier than would be expected for the general population.⁴²

This is of particular relevance, as life expectancy of those with Down's syndrome is increasing due to improving health care, and ageing brings changes in health status and needs. Many age-associated diseases go unnoticed in those with learning disabilities because of a lack of awareness of support staff or clinicians, deficient or non-existent screening practices, or a lack of focus on health surveillance.⁷⁶ Polypharmacy (taking several different medicines) and inadequate medication reviews are also common in those with learning disabilities and their importance grows as a person's medical condition becomes more complicated.⁷⁷

The need for eating well among older people with dementia has been discussed in the report *Eating Well for Older People with Dementia*.⁷⁸ For details of this and other resources to support those with dementia, see page 154.

Attention deficit hyperactivity disorder (ADHD) and autism spectrum

These conditions are not just specific to learning disabilities. However, someone who has one of these conditions is more likely than other people to have a learning disability.

ADHD

Attention deficit hyperactivity disorder (ADHD) refers to a range of difficulties associated with poor attention span and in people with learning disabilities it is largely overlooked and under-managed. In the general population, 1.7% of children have ADHD and boys are more likely to be affected than girls. Of those affected, between 25% and 30% have learning disabilities, and children and adolescents with learning disabilities are eight times more likely to have ADHD than their peers.⁶² ADHD can be caused by stress such as family problems, or by biological factors including brain injuries as a result of traumatic birth, or pre-birth problems such as hypoxia (shortage of oxygen).

Failure to recognise ADHD could prevent someone from reaching their true potential and receiving correct specialist help, and this may be more common among those with learning disabilities where there might already be challenging behaviour or poor attention span.⁷⁹

For information on the effect of artificial food colours on behaviour and concentration, see page 32.

Autistic spectrum disorder

Autistic spectrum disorder (ASD) is a relatively new term which reflects that there are a number of conditions encompassed by the term 'autism'. ASD is estimated to occur in approximately 1 in 200 people but is 33 times more common among children and adolescents with learning disabilities than in the general population.⁶² People with ASD have difficulties with verbal or non-verbal communication, and in understanding social behaviour. These difficulties affect their ability to form relationships, and those with ASD often exhibit restrictive, obsessional or repetitive behaviour, often reflected in food and drink choices and around mealtimes. Apart from learning disabilities, autistic spectrum disorders are also associated with obsessive compulsive disorder, ADHD and mental health issues such as depression and anxiety.⁸⁰ Asperger's syndrome is a form of autism, but people with Asperger's syndrome do not usually have a learning disability.

The impact of learning disabilities on eating and drinking

Learning disabilities are likely to impact on a person's ability to eat and drink well and to enjoy eating and drinking in a number of ways:

- **Lack of understanding about the need for a balanced diet** may lead to poor food choices among both disabled individuals and family, friends and support staff.
- **Physical and dental health problems and difficulties with eating, chewing or swallowing** may directly impact on food choice and the ability to eat well unaided.
- **Lack of experienced skilled staff, specialist eating and drinking equipment or insufficient support at mealtimes** to help with slow eaters or those who require modified texture foods and drinks may cause difficulties and frustrations.
- **Digestive problems** such as gastro-oesophageal reflux disorder may deter people from eating.
- **Bowel function** problems such as constipation and diarrhoea may deter people from eating because of the unpleasant consequences.
- **Poor communication skills** may mean that food choices are overlooked, the temperature of food is wrong, and portion sizes are misjudged.
- **Sensory impairments, the need for assistance with eating, and loss of eating independence** may reduce enjoyment at mealtimes.
- Some **medicines** may have side effects which play a part in abnormal eating behaviour, appetite changes or eating disorders.⁵⁴ There may also be interactions between particular drugs and nutrients.
- **Structural brain damage or dysfunction** such as epilepsy, seen in some people with learning disabilities, have been linked to appetite, metabolic and weight changes, hyperphagia (abnormally increased or excessive appetite), and episodes of binge eating.
- Some people with learning disabilities have **abnormal eating behaviours or disorders** and a greater number of eating disorders are commonly observed among people with learning disabilities.⁵⁴
- **Poverty**, poor housing and social isolation may mean that food choice is restricted, and that affordable, good-quality food cannot be accessed easily.

There is little information available on the nutritional intakes or nutritional status of adults with learning

disabilities. Limited data from two small studies carried out in residential care suggests that adults with learning disabilities typically eat diets low in fruit and vegetables and high in fat and protein,^{81,82} although this is also true of a majority of adults in the UK population. Information on the nutritional intake of children with learning disabilities is discussed on page 52.

Factors which may contribute to problematic eating and drinking

Dysphagia

Dysphagia is the term used to describe eating and drinking disorders which may include difficulties in dealing with food or drink in the mouth, difficulties with movements of the mouth such as sucking and chewing that prepare food for swallowing, as well as the process of swallowing itself.⁸³ The prevalence of dysphagia among people with learning disabilities is unknown but it is likely that estimates of dysphagia in the community of 5%-8%, based on dysphagia referrals, are likely to be under-estimates.⁸⁴ Dysphagia is more common among adults with learning disabilities who have a physical disability such as cerebral palsy, those who have physical disability of the palate, teeth or tongue, and those with the greatest health needs.⁸⁴

Dysphagia can lead to aspiration of food or fluid into the lungs, which causes coughing and gagging and which can also cause choking and death through asphyxiation.⁸⁵ Aspiration is also related to respiratory tract infections and pneumonia, which are a leading cause of death among people with learning disabilities.¹⁴ It is frequently acknowledged that dysphagia – despite its potential life-threatening implications for people with learning disabilities in terms of undernutrition and dehydration as well as choking and aspiration – is frequently under-diagnosed and poorly managed.⁸⁶ For information on how to recognise and support swallowing difficulties, see page 74. Information on how to modify the consistency of solids and liquids and manage the physical environment to support those with swallowing difficulties can be found on pages 133 and 112.

Dyspepsia (indigestion)

This is very common in children with complex neurological difficulties and common in adults with similar difficulties.⁸⁷ There are three types of dyspepsia: gastro-oesophageal reflux disease (GORD); functional (dysmotility) dyspepsia; and structural (organic) dyspepsia.

Gastro-oesophageal reflux disease (GORD)

GORD is a major clinical problem in people with learning

disabilities and is frequently overlooked and under-estimated.⁸⁸ It has been estimated to occur in 48% of people with learning disabilities,¹⁴ but to occur more frequently among those with cerebral palsy, severe learning disabilities, those taking anti-epileptic drugs and those with a history of rumination (see the next page).⁸⁸ It has also been reported to occur in up to 75% of neurologically impaired children.⁸⁹ Factors which increase the risk of GORD include cerebral palsy, use of anti-convulsant drugs, drugs which slow gastric emptying, benzodiazepines, and having an IQ less than 35.³⁸ GORD is caused by acid from the stomach entering the oesophagus, causing pain and symptoms including heartburn, painful swallowing, vomiting, vomiting blood and regurgitation and re-chewing of food. The very severe pain that can be caused by GORD can lead to challenging behaviour, particularly among individuals with learning disabilities who are unable to express themselves. If the symptoms go unnoticed or unreported and the condition untreated, the oesophagus can be permanently damaged and oesophageal cancer can develop.³⁸ GORD is a highly treatable condition, so it is essential that it is recognised and treated, as it would be for the rest of the population.

Functional (dysmotility) dyspepsia

This is due to abnormal movement of the stomach or oesophagus. Symptoms may include a poorly emptying stomach (which can be seen in the person as fullness, refusal to eat, abdominal pain, or effortless large-volume vomiting). Treatment is either to change or stop any drugs causing the abnormal movements, or to use drugs that encourage normal movements.

Structural (organic) dyspepsia

This is dyspepsia caused by damage to the lining of the stomach or duodenum, such as a gastric ulcer. The commonest cause is infection by the *helicobacter pylori* bacteria. People living in close proximity to each other are particularly prone to this – such as people living in a community home. An equally common cause is the use of non-steroidal anti-inflammatory drugs (NSAIDs) such as aspirin, ibuprofen and diclofenac. This type of dyspepsia is treated by treating the cause of the damage. The symptoms of ulceration may be mild, or masked by communication difficulties. An untreated ulcer can perforate and result in death, so early diagnosis is crucial.

Pica

Pica is the term used for eating non-food items such as plaster, coal, faeces, soil or cigarette ash. Pica, which is not normally seen in the general population (except occasionally among pregnant women and children aged 1-6 years⁹⁰), has been associated with severe learning

disabilities, schizophrenia, depression, large group living, younger age and male gender, autism, dehydration, and swallowing difficulties.^{71,72} It has been reported among between 9% and 25% of people in residential care and between 0.3% and 14% of people with learning disabilities living in the community.⁹¹ Eating non-food items can prevent the absorption of vital nutrients, cause lead or nicotine toxicity, block the colon, or produce medical problems if the ingested item is toxic or harmful.⁹¹ There has been debate as to whether pica may be associated with mineral deficiencies and there is some evidence that pica is more common among those with low iron and zinc status,⁹² but whether this is the cause of pica or a consequence of the pica itself has not been established. Strategies for dealing with problem eating behaviours among people with pica are considered on page 111.

Polydipsia

Polydipsia is the excessive drinking of non-alcoholic drinks in the absence of the physiological stimulus to drink or a physiological condition such as diabetes. Acute excessive fluid consumption (which has been defined as more than 5 litres of fluid a day) can result in restlessness, confusion, lethargy, nausea, diarrhoea, vomiting, convulsions, seizures, coma and even death.⁹³ Chronic polydipsia may result in long-term physical complications such as incontinence, renal failure, cardiac failure and dementia. This disorder has been noted in particular among schizophrenics and those with autism and pica, and a prevalence rate of 14.5% has been suggested among those with learning disabilities.⁹³ There are likely to be behavioural aspects to polydipsia: it has been suggested that excessive drinking of fluid might be associated with agitation, stress or pre-menstrual stress, or might be a reaction to conditions such as toothache or constipation. Polydipsia may also be linked to lifestyle factors such as smoking or experience of limited availability of fluids, or to the side effects of some medication, but more research is needed to explore the factors which may contribute to this condition.

Hyperphagia

Hyperphagia, also known as polyphagia, is an abnormally increased or excessive appetite which is insatiable. The person is continually seeking food, often to the point of gastric pain or vomiting. It is often linked to damage to the hypothalamus. This condition is frequently seen in people with Prader-Willi syndrome⁵⁵ and can lead to excessive weight gain.

Rumination

Rumination involves the continuous regurgitation, re-chewing and sometimes re-swallowing of food. It has been

associated with hiatus hernia, infections of the gastrointestinal system or congenital abnormalities.⁹⁴

Drooling

The escape of saliva from the mouth as drooling can result from problems with the facial and palate muscles. It is possible that the main causes are inadequate swallowing and lip closure and head-forward posture. Drooling can cause chronic irritation of the facial skin, infections around the mouth area, halitosis (bad breath), and dehydration due to fluid loss, and can be undignified and unpleasant. Many management techniques – surgical, non-surgical and pharmacological – have been used, but none appear to be universally successful, and many of the drugs have problematic side effects. Management is mainly aimed at alleviating the symptoms and maintaining the head in an upright position.⁹⁵ Some strategies to support those who have difficulties with drooling are outlined on page 110.

Bruxism

Bruxism, or the grinding of teeth, can lead to tooth wear and in severe cases can lead to tooth pain, infections and oral wounds when it is also associated with cheek chewing. Bruxism has been reported among people with learning disabilities, particularly among people with cerebral palsy where it is suggested it may be linked to anxiety and communication problems.⁹⁶ Bruxism is also associated with Rett syndrome and Down's syndrome as well as gastro-oesophageal reflux and to the long-term use of some drugs including some given for treating depression or behavioural problems.⁹⁷ Teeth-grinding requires careful individual assessment to prevent damage to the teeth and oral tissues and to treat any pain which might interfere with eating and drinking.

Other difficulties associated with eating among people with learning disabilities

Regurgitation, vomiting, binge eating, selective eating and spitting out of food are all difficulties that have been associated with those with learning disabilities, and without treatment may cause dehydration, electrolyte imbalance, malnutrition and possibly increased mortality.⁷¹ Strategies to support those who have difficulties with eating and drinking can be found on page 108.

Asphyxiation and choking

In long-stay hospital wards it used to be common for people to eat their food very quickly in an attempt to ensure no-one else ate it, especially if they were often hungry and had no access to snacks. Some people with learning disabilities in residential care still have this behaviour and it has been linked to increased risk of

asphyxiation and choking.⁸⁵ Risk of choking can also be associated with bolting food – for example, in people who take food from someone else’s plate and bolt it to avoid detection.⁹⁸ For information on how to handle choking incidents see page 75, and for strategies to deal with problem eating behaviours see page 108.

Posture and mobility

There are high rates of mobility difficulties among people with learning disabilities that increase with age and which contribute to nutritionally-related ill-health such as chronic constipation, gastro-oesophageal reflux disease and osteoporosis.¹⁴ People may also have postural difficulties and be unable to sit up straight or hold their head up, making eating and drinking more difficult. For advice on positioning for eating and drinking, see page 107.

Sensory disabilities

An individual with learning disabilities is very likely to have difficulties with communication. It is estimated that about 40% of people with learning disabilities have a hearing impairment⁹⁹ and an association between people with Down’s syndrome and hearing impairment has been well established.¹⁰⁰ However, it can be difficult to diagnose and recognise hearing problems among people with learning disabilities and this is particularly true for age-related hearing loss. Older people with learning disabilities and hearing loss may appear difficult and uncooperative and exhibit challenging behaviour, or they may be misdiagnosed with dementia, so careful, regular and patient assessment of hearing ability is essential.¹⁰¹

Among adults with learning disabilities, almost 50% have some degree of visual impairment either at near or long distance, and 1%-5% have severe impairment or blindness.¹⁰² There will also be age-related deterioration of vision. People with Down’s syndrome have a higher prevalence of sight problems than other people with learning disabilities. People who cannot see well are likely to find tasks of daily living more challenging. They may find it harder to prepare food, may not see if food is unfit to eat, or may be unable to read food labels, or cooking and preparation instructions. It is important to ensure that people with learning disabilities have their sight tested regularly, that corrective glasses are available and that these are worn.

The effects of drugs on nutritional status

Many people with learning disabilities take a number of different drugs, both those prescribed by medical practitioners as well as over-the-counter medicines. Many drugs influence appetite, food intake and ultimately nutritional status. Some drugs can cause loss of appetite and some cause adverse responses to food such as nausea, dry mouth or loss of taste. Some drugs may also alter bowel function, causing constipation or diarrhoea. If drugs cause drowsiness, people may miss meals and snacks. It is also important to recognise that poor nutritional status can impair drug metabolism and people who are dehydrated or who have had recent weight loss may experience greater side effects.¹⁰³

Psychotropic medicines

Between 20% and 50% of people with learning disabilities are found to be prescribed psychotropic medication¹⁰⁴ which is given for treating mental illness (anti-psychotic medication), helping with challenging behaviour (anxiolytic medication) and reducing anxiety and depression (anti-depressants). The side effects of some anti-psychotics and anti-depressants may include weight gain, a craving for sugary foods, raised blood cholesterol levels, dry mouth and an increased incidence of diabetes. All anti-psychotics and some anti-depressants cause constipation. Newer SSRI drugs (selective serotonin re-uptake inhibitors) which may be given for depression or other psychological difficulties may cause nausea, vomiting, diarrhoea and constipation and the mood stabiliser lithium can cause nausea, vomiting, diarrhoea, polydipsia and weight gain.¹⁰⁵

Drugs for epilepsy

Drugs which may be given to control epilepsy (particularly phenytoin) can lead to vitamin D deficiency and may put people with limited exposure to sunlight at risk of osteoporosis¹⁰⁶ (see page 47). Some drugs given to control epilepsy may also interfere with the absorption of folic acid¹⁰⁷ and vitamin K¹⁰⁸ and may cause constipation, diarrhoea, nausea, weight loss or weight gain.³⁸

Drugs for other conditions

Certain diuretics, beta-blockers, drugs to manage urinary incontinence and anti-histamines can cause a dry mouth.¹⁰⁹ Many anti-dementia drugs have side effects such as nausea, diarrhoea, vomiting, loss of appetite, weight loss and abdominal pain.¹¹⁰

Drugs which affect swallowing function

Medication which alters levels of alertness (eg. some anti-psychotics and drugs given for controlling epilepsy),¹¹¹ those which alter muscle tone or coordination (such as some anti-depressants), and medicines which delay the swallowing process or increase salivation (such as some anti-psychotics)¹¹² can all impact on swallowing function.

Managing medication among people with swallowing difficulties

There are also particular problems in managing medication among those with swallowing difficulties and some side effects of the drugs themselves – such as having a dry mouth – can make taking medication more difficult. Guidance on managing medication among adults with swallowing difficulties has been produced.¹¹³

Medication reviews

It is important that there are regular reviews of medication among people with learning disabilities and that side effects which may impact on eating, drinking and nutritional status are considered carefully when medication is prescribed. A very detailed handbook for support staff about medication and people with learning disabilities has been written by Miriam Wilcher for South Birmingham Primary Care Trust (see page 155).

Can diet be used to prevent or treat learning disabilities?

The brain is the largest organ in the body and it is affected by what we eat and drink, but the links between the diet and the brain are complex. We know that diet can impact on development in the womb: the role of folic acid, for example, in preventing neural tube defect births is well established. However, to what extent diet and dietary manipulation can impact on the brain and its function after it has developed remain speculative, as much of the research has been done on small groups or groups of people in special circumstances. We know that learning disability associated with specific inborn errors of metabolism (for example phenylketonuria) can be prevented when a person consumes, from birth, a diet that manages the levels of amino acids in the blood which may damage the nervous system, but these are very specific metabolic diseases. The evidence so far accumulated for other conditions or for the population as a whole does not show that diet can prevent or cure brain-related disorders. There is, however, increasing interest in the role of

polyunsaturated fats and some minerals and vitamins in potentially relieving the symptoms of some mental illnesses, improving the effectiveness of medication for some conditions, and reducing the side effects of some medications.⁶⁹

A review of research studies of food supplements among people with Down's syndrome has failed to find any evidence that any form of nutritional supplementation improves the outcome in Down's syndrome.¹¹⁴ A large trial of vitamin and mineral supplementation of children with Down's syndrome recently completed by the Institute of Child Health in London may, however, provide some new evidence in this area.

Eating and drinking well during pregnancy, breastfeeding for at least six months, and weaning infants onto a varied and nutrient-dense diet are all recommended to ensure that children have an optimum start in life. Encouraging all those with learning disabilities to eat well would seem intuitively to be a sensible approach and of particular relevance to those who have both learning disabilities and mental ill health and those who may have had poor nutritional experiences in early life.

Can diet impact on behaviour and learning in children?

There has been a longstanding interest in whether dietary components can influence the behaviour and learning of children, but it is a difficult area to research and there remains insufficient evidence to reach clear conclusions in many areas. Overall, research shows that a good, varied diet is the best way to ensure optimal mental and behavioural performance in children, and that only those children who have very poor nutritional status (for example those with severe iron deficiency) may benefit from significant dietary manipulation.¹¹⁵

There also remains insubstantial evidence that giving children fish-oil supplements impacts on their performance. It is better to concentrate on giving children good-quality food rather than relying on expensive supplements.

For information on the effect of artificial food colours on behaviour and concentration in children, see page 32.

Can diet be used to treat specific conditions found among people with learning disabilities?

Autistic spectrum disorders

There is some belief that dietary restriction or dietary supplementation will benefit people with autistic spectrum disorders (ASD), although there is only weak evidence that these strategies are beneficial. The most common dietary treatments suggested are the exclusion of gluten and casein from the diet and/or nutritional supplementation, for example with high doses of vitamin B₆ and magnesium.

A recent guideline from SIGN (Scottish Intercollegiate Guidelines Network) reviewed all the current literature looking at potential dietary interventions, dietary supplementation and ASD and concluded that there is insufficient evidence that exclusion diets, including those that exclude casein (found in milk and milk products) and gluten (found in wheat, rye, barley and oats), or supplementation with vitamins and minerals, have significant benefits for children and young people with ASD.¹¹⁶

Advice on diet and food intake should be sought for children and young people with ASD who display significant food selectivity and dysfunctional feeding behaviour or who are on restricted diets that may be adversely impacting on their growth or producing physical symptoms of recognised nutritional deficiencies. Advice should be sought from a registered dietitian (see *Where to get advice about eating well* on page 151).

For more information on diet and ASD, see the websites of the British Dietetic Association at www.bda.uk.com and of SIGN at www.sign.ac.uk.

Attention deficit hyperactivity disorder (ADHD)

The role of diet in ADHD is controversial. A review of studies that have attempted to link ADHD to a number of nutritional disorders found some evidence among some children of potential links with deficiencies of essential fatty acids, iron and zinc.⁶⁹ However, there remains a need for more clinical trials of longer duration before any conclusions can be reached. Permanently eliminating a number of foods may be harmful and professional advice should be taken from a registered dietitian before significant dietary changes are attempted.

There is some anecdotal evidence that certain vitamin, mineral, or omega-3 supplements can help to treat ADHD. The evidence is not conclusive and the safety of high doses of supplements is unproven. It would seem prudent to ensure that those with ADHD are given a varied and balanced diet, including oily fish rich in omega-3 fats once a week (eg. mackerel, herring, trout or salmon) if fish is eaten.

New evidence does, however, suggest that some artificial food colours may impact negatively on the behaviour and concentration of some children, and current advice from the Food Standards Agency is that, if a child shows signs of attention deficit hyperactivity disorder (ADHD), eliminating the colours sunset yellow (E110), quinoline yellow (E104), carmoisine (E122), and allura red (E129) from their diet might have some beneficial effects.¹¹⁷

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Chapter 3

Principles of good nutrition

This chapter provides information on the importance of good nutrition and physical activity for children, young people and adults.

The nutrient-based standards for groups of people discussed in chapter 10 of this report are expressed as the amounts of energy (calories) and nutrients that are needed for good health. The term ‘nutrients’ refers to the substances in food and drink which humans need in order to function, grow and repair (for example, after illness or injury). The term nutrients includes:

- fat
- carbohydrates
- protein
- vitamins
- minerals
- water.

Most foods contain a variety of nutrients so it is the *balance* of different foods within a person’s eating pattern that determines whether the recommendations for ‘healthy eating’ are met. It is important for everyone to have a diet that contains a variety of foods if they are to obtain all the nutrients their bodies need. There are no magic foods or food supplements that can compensate for a poor diet. Eating well is not complicated and does not mean that people have to eat unusual or expensive foods. Advice on good nutrition can be obtained from a dietitian or a registered public health nutritionist (see page 151).

Energy (calories)

Why we need energy

We all need energy to function and be active. The body gets energy from fat, carbohydrate, protein and alcohol, but most energy needs are met by fat and carbohydrate. Children and young people also need energy for growth and development.

Energy is measured in kilocalories (kcal) or kilojoules (kJ). 1kcal equals approximately 4.2kJ, and 1,000kcal equals approximately 4.2MJ.

Where does energy (calories) come from?

The nutrients fat, carbohydrate and protein, as well as alcohol, all provide the body with calories. (For more about these nutrients, see pages 37-40.)

Recommendations for a healthy diet are often expressed as what proportion of energy should come from each of those nutrients. Most of our energy should come from carbohydrates (found in foods such as bread, potatoes, pasta and rice). There are also recommendations for the different types of carbohydrates, including the proportion of total energy that should come from sugars. (See *Carbohydrates* on page 38.)

The importance of physical activity

The energy we need every day is determined both by a basic level of requirement to keep our bodies functioning (called the Basal Metabolic Rate or BMR) and by the amount of physical activity that we do (for example moving around, walking or exercising). People who are inactive have lower energy needs and will need less food to maintain their body weight. It becomes much harder to get all the nutrients needed for good health if people are inactive and have a poor appetite.

Overweight and obesity have become a growing problem in the UK. Overweight is as much a problem of doing too little activity as of eating too much. People who are overweight should be encouraged to increase their activity levels and eat healthily. Information about strategies to prevent and reduce overweight is given in chapter 5.

Fat in the diet

Fat provides the most concentrated form of energy in the diet. It provides 9kcal per gram of fat, compared with 4kcal per gram for protein and carbohydrate.

There are basically two types of fat found in foods:

- **saturated fats**, which are mainly from animal sources, and
- **unsaturated fats**, which are found mainly in plants and fish. The unsaturated fats include monounsaturated fats and a group called polyunsaturated fats.

Some fat in the diet is essential and fat in foods is also associated with the uptake of fat-soluble vitamins – vitamins A, D, E and K (see page 41).

Diets that are high in total fat and saturated fat are associated with high blood cholesterol levels, which are a major risk factor for coronary heart disease. People are encouraged to use unsaturated fats in cooking and as spreading fats, and to cut down on the amount of food that is high in saturated fat.

Omega-3 fats (derived from oil-rich fish) are thought to be beneficial for heart health. **Omega-6 fats** are found in cereals and grains and the average amount of these in the British diet is thought to be enough. To ensure there is a balance between omega-6 and omega-3 fats in the diet, people are encouraged to increase their intake of oily fish to 1 portion a week. Some claims have been made about the ability of omega-3 fats to improve behaviour and learning. This is discussed on page 32.

Trans fats are a particular type of fat that is found in some manufactured foods that use hydrogenated oils. The trans fats found in foods containing hydrogenated oils or fats are harmful and have no known nutritional benefits. They raise the type of cholesterol in the blood that increases the risk of coronary heart disease. Some evidence suggests that the effects of these trans fats may be worse than the effect of saturated fats.

Foods it is found in

Unsaturated fats

Monounsaturated fats

Olive oil and rapeseed oil

Avocado

Nuts and seeds (almonds, cashews, hazelnuts, peanuts and pistachios)

Some margarines and spreads are made from monounsaturated fats.

Polyunsaturated fats

Corn oil, sunflower oil and soya oil

Nuts and seeds (walnuts, pine nuts, sunflower seeds and sesame seeds)

Some margarines and spreads are made from polyunsaturated fats.

Omega-3 fats

Fish oil

Oily fish such as herring, mackerel, pilchards, sardines, salmon, trout and fresh tuna

Other omega-3 fats can be found in oils such as rapeseed oil, soya oil, walnuts and almonds, pumpkin seeds, organic milk and green leafy vegetables. However, there is no evidence that these omega-3 fats protect against heart disease.

Saturated fats

Butter

Hard cheese

Fat in meat and poultry

Meat products (such as sausages, processed meats, and meat pies)

Biscuits

Cakes

Cream

Lard

Dripping

Suet

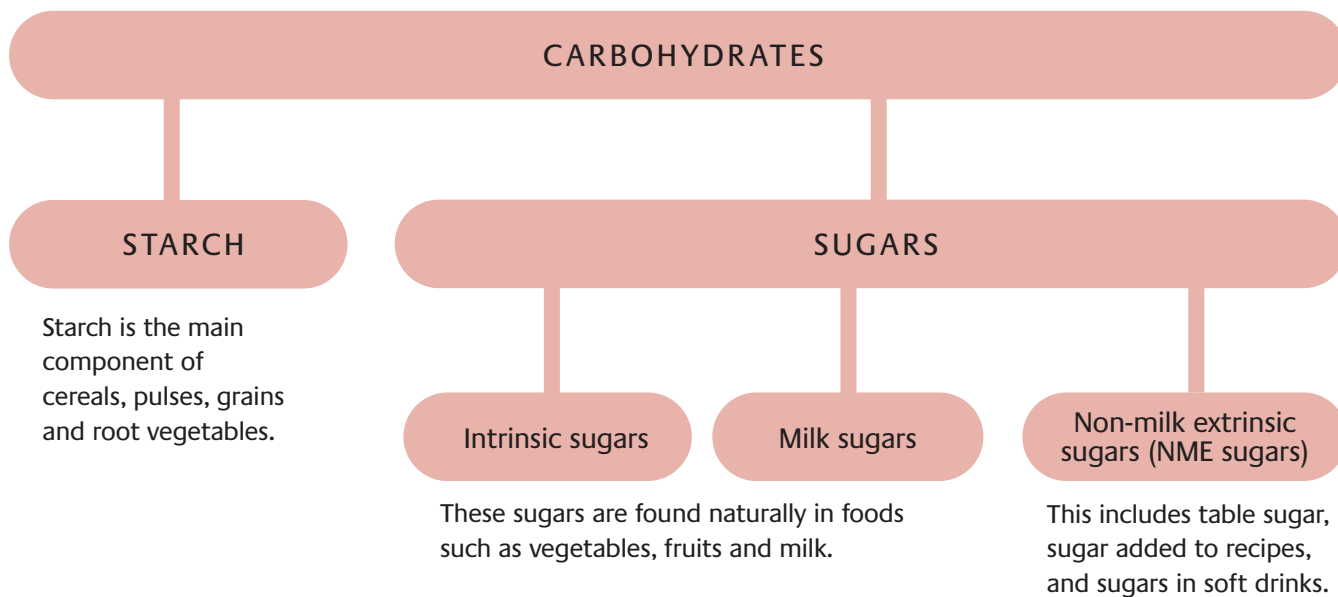
Ghee

Coconut oil and palm oil

Trans fats

Some pastries, cakes, biscuits, crackers, deep-fried foods, take-away foods, and ice cream desserts.

Foods that have 'hydrogenated oils' or 'hydrogenated fat' in the list of ingredients are likely to contain trans fats.



Carbohydrates is the term used to describe both **starch** and **sugars** in foods. Carbohydrates provide energy.

The term **sugars** is often assumed to describe something white and granular found in sugar bowls, but in fact the sugars found in foods can be quite variable. In order to clarify the roles of different sugars in health, the sugars in foods have been distinguished as:

- intrinsic sugars
- milk sugars, and
- non-milk extrinsic sugars (or NME sugars).

What are they?

Foods they are found in

STARCH

Starch is the major component of cereals, pulses, grains and root vegetables (for example yam) and tubers (such as potatoes). Most people can visualise starchy foods when they think of flour and potatoes.

All types of bread and rolls
Chapattis and other flat breads
Rice and other grains
All types of pasta and spaghetti
Noodles
Breakfast cereals
Potatoes
Yams
Plantains

SUGARS

Intrinsic sugars and milk sugars

Intrinsic sugars and milk sugars are the sugars found naturally in foods such as milk, vegetables and fruits.

Fruits (but not fruit juices)
Vegetables
Milk and dairy products contain milk sugars (lactose).

Non-milk extrinsic sugars

Non-milk extrinsic sugars – or NME sugars – is the term used for those sugars which have been extracted from a root, stem or fruit of a plant and are no longer incorporated into the cellular structure of food. NME sugars therefore include table sugar, sugar added to recipes (for example, cakes and biscuits) and sugars found in confectionery, soft drinks and fruit juices. Honey and syrups are also included in this group.

The recommendation to reduce the energy in the diet provided by NME sugars is mainly to prevent tooth decay.¹ The other concern is that foods high in NME sugars often provide calories but few other nutrients and that NME sugars can contribute to the development of obesity. This is particularly true for drinks such as squashes and fizzy drinks, sweets, and also highly sweetened breakfast cereals, biscuits, cakes and sweetened snacks.

We don't need NME sugars for energy. We can get all the energy we need from other carbohydrate foods.

Table sugar
Honey
Sweets
Chocolate
Cakes
Biscuits
Soft drinks
Squashes
Fruit juice

Glycaemic index refers to the speed with which carbohydrate foods increase the level of sugar in the blood after they are eaten. It is suggested that foods with a low glycaemic index keep you fuller for longer and may be beneficial for people with diabetes and those who are overweight.² Many foods which have a low glycaemic index are also high in fibre, such as higher-fibre cereals, oats, whole grains, fruits and vegetables.

Fibre

Why we need it

Fibre (also called non-starch polysaccharides or NSP) is food material from cereal and vegetable foods which is not broken down in the small intestine of humans. Fibre is particularly important to prevent constipation and other bowel disorders. Some types of fibre known as soluble fibre are important for lowering blood cholesterol levels.

Foods it found in

Wholemeal bread
Wholegrain breakfast cereals
Pulses (peas, lentils and beans – including baked beans, kidney beans and butter beans)
Dried and fresh fruit and vegetables

Soluble fibre is found in fruit, oats and beans and pulses.

These foods provide good sources of other nutrients too.

Protein

Why we need it

Protein is needed for growth and the maintenance and repair of body tissues. Most people in the UK have plenty of protein in their diets.

Foods it is found in

Milk
Meat, poultry and fish
Eggs
Cheese
Tofu
Pulses such as peas, lentils and beans (including baked beans, kidney beans, and butter beans)
Nuts and seeds
Cereal foods such as bread and rice

Alcohol

Alcohol provides energy (7kcal per gram) and alcoholic beverages can make a substantial contribution to daily energy intakes among regular consumers. Alcohol affects all the parts of the body it comes into contact with: the stomach, gut, brain and especially the liver. Alcohol affects brain activity. The first thing to be switched off are our inhibitions, which can make people behave in a way they would not normally, and this can lead to risk-taking behaviours.

Men are advised to drink no more than 3-4 units of alcohol a day, and women to drink no more than 2-3 units of alcohol a day. Women who are planning a pregnancy or who are pregnant should avoid having alcohol.

1 unit of alcohol is equivalent to 10ml of alcohol – for example, half a pint of ordinary-strength beer or lager, half a glass of wine, or a pub measure of spirits.

Vitamins

Fat-soluble vitamins

Vitamin A
Vitamin D
Vitamin E
Vitamin K

These are stored in the body. Vitamin A in food can be destroyed by heat or by oxidation if left exposed to the air.

Water-soluble vitamins

Some of the most important water-soluble vitamins are:

B vitamins: thiamin, riboflavin, niacin
vitamin B₆
vitamin B₁₂
folate
vitamin C

These are not stored in the body. They are water-soluble, so they are more likely to be destroyed by heat or by oxidation if left exposed to the air.

Vitamins are often divided into two groups: those that are fat-soluble and those that are water-soluble. Some vitamins are found predominantly in animal foods – for example vitamin B₁₂ and vitamin D (see pages 43 and 42). Others are found predominantly in foods of vegetable origin – for example vitamin C.

It is important to get enough of each vitamin. However, having too much does not bring any benefit and may be harmful. Most people should be able to get all the nutrients they need by eating a varied and balanced diet. If anyone chooses to take supplements containing vitamins and minerals, it is important to know that taking too much, or taking them for too long, can cause harmful effects. Current advice about safe intakes of vitamins and minerals can be found at: www.eatwell.gov.uk/healthydiet/nutritionessentials/vitaminsandminerals.

Many vitamins are not stored in the body and are also more likely to be destroyed if foods containing them are overcooked or exposed to sunlight or air for long periods. This is why it is important to prepare vegetables close to the cooking time and not to overcook them.

Why we need it

Foods it is found in

(See also Appendix 2.)

Vitamin A

Vitamin A is often thought of as the ‘anti-infection’ vitamin as it plays an important role in maintaining the immune system. It is also essential for growth, which is why children need relatively more vitamin A than adults. Vitamin A is also associated with good vision in dim light as retinol is essential for the substance in the eye which allows night vision.

Experts now believe that carotene has a much wider role than just as a means to produce vitamin A. It may protect the body from internal damage to the cells, which could lead eventually to heart disease or the development of cancer. There is no evidence that supplements of carotene are protective, so it is important to include good sources of carotene in the diet.

Vitamin A comes in two forms:

- retinol, which is only found in animal foods, and
- carotene, the yellow or orange pigment found in fruit and vegetables (both those coloured yellow or orange and in many green ones where the orange colour is masked by chlorophyll pigment).

Vitamin A is found in:

- liver*
- liver pâté*
- carrots and other orange foods such as sweet potatoes
- mango, melon and apricots (dried or fresh)
- green leafy vegetables such as spinach, watercress and broccoli
- tomatoes
- red peppers.

Vitamin D

Vitamin D is needed for healthy bones and teeth. Prolonged deficiency of vitamin D in children results in rickets, the main signs of which are skeletal malformation (such as bowed legs) with bone pain or tenderness and muscle weakness.

People who rarely go outside in the summer, those who always cover their skin when they do go out, black and ethnic minority groups, adults aged 65 years or over, pregnant and breastfeeding women and children under the age of 4 are at risk of vitamin D deficiency. For more information about vitamin D and those groups recommended to take vitamin D supplements, see page 47.

Oily fish such as tuna, salmon and pilchards

Egg yolk

Liver*, liver pâté *

Some fortified breakfast cereals

Margarines

Vitamin E

Vitamin E is involved in a number of body processes and protects cell walls as it acts as an antioxidant.

Plant oils such as soya, corn and olive oil

Nuts and seeds

Wheatgerm in bread and cereals

Vitamin K

Vitamin K is important for bone health, wound healing and blood clotting.

We can make vitamin K in the body but it is also found in green leafy vegetables such as broccoli and spinach, and in vegetable oils and cereals. Small amounts can also be found in meat (such as pork) and dairy foods (such as cheese).

* As these foods can contain high levels of vitamin A, it is suggested that they are not eaten more than once a week. Anyone who is pregnant should avoid eating liver and liver pâté (and avoid dietary supplements which contain vitamin A), as very high vitamin A intakes may damage the fetus.

Why we need it

Foods it is found in

(See also Appendix 2.)

B vitamins – thiamin, riboflavin and niacin

Thiamin, riboflavin and niacin are particularly important for the brain and nervous system. The body also needs these vitamins to be able to use the energy (calories) in food.

Thiamin and niacin

Bread and other foods made with flour
Breakfast cereals
Pork (including bacon and ham)
Offal such as liver* and kidney
Oily fish
Yeast extract (such as marmite)
Nuts
Potatoes

Riboflavin

Milk and milk products such as yoghurt and cheese
Meat, offal* and poultry
Oily fish (such as tuna, salmon or sardines)
Eggs

Folate

Folates are a group of compounds, found in foods, which collectively are known as ‘folate’ or ‘folic acid’. Folate is an essential vitamin for many body processes, including forming red blood cells, making new cells, and using protein in the body. Deficiency can lead to a particular type of anaemia known as megaloblastic anaemia. Also, low folic acid intakes at conception and in early pregnancy are associated with an increased risk of neural tube defect births (such as spina bifida).

Green leafy vegetables and salads
Oranges and other citrus fruits
Liver
Yeast extract
Foods which have been fortified including breakfast cereals and some breads

Vitamin B₆

Vitamin B₆ is the name given to a whole group of substances that are commonly found in both animal and vegetable foods and which are involved in a number of body processes involving amino acids (the protein building blocks).

Bran flakes
Red meat
Poultry
Liver*
Oily fish
Potatoes
Bananas
Nuts
Peanut butter
Dried fruit
White fish

Vitamin B₁₂

Vitamin B₁₂ interacts with folate and vitamin B₆. Together these vitamins help the body to build up its own protein, especially for nervous tissue and red blood cells.

All foods of animal origin, for example: meat, white fish, eggs and milk.

Some other foods are fortified with vitamin B₁₂, such as fortified breakfast cereals, and drinks such as fortified blackcurrant drinks. Some yeast extracts also contain this vitamin.

If someone avoids all animal products, it is important to make sure that they include a source of vitamin B₁₂ in their diet.

* See footnote on page 42.

Why we need it

Foods it is found in

(See also Appendix 2.)

Vitamin C

Vitamin C has an important role in preventing disease and maintaining good health. The body needs vitamin C to produce and maintain collagen, the foundation material for bones, teeth, skin and tendons. It is also important in wound healing. It is suggested that vitamin C also has a role as an antioxidant vitamin in preventing damage to cells and tissues. Vitamin C also helps the body to absorb iron in the diet if both nutrients are present in the same meal.

Most fruit and vegetables and fresh juices.

Good sources include:

- citrus fruits such as oranges
- green vegetables such as broccoli and green peppers
- potatoes
- blackcurrants and strawberries.

Some drinks are also fortified with vitamin C.

Minerals

Iron

Iron is an essential part of the pigment in red blood cells called haemoglobin, which carries oxygen. A deficiency in iron will cause anaemia. In a person with anaemia, the blood transports less oxygen for the body's needs and so limits the person's ability to be physically active.

People with anaemia may become pale and tired and their general health, resistance to infection, and vitality will be impaired. Sometimes there are no apparent symptoms and anaemia may be undetected. Iron deficiency during periods of rapid brain growth during childhood can impair brain function and iron-deficient children do less well in both motor and mental development tests. Sufficient iron in pregnancy is also important to ensure a healthy term baby.

Some women may have higher needs for iron and may require an iron supplement. Always seek advice from a medical practitioner about iron supplementation and keep iron supplements (as with all medicines and vitamin supplements) out of the reach of children.

There are two forms of iron in foods:

- haem iron, and
- non-haem iron.

Haem iron is found in foods of animal origin such as beef, lamb, chicken and turkey, liver and kidney, and in some fish such as sardines and tuna. Haem iron is absorbed into the body more easily than non-haem iron.

Non-haem iron is found in foods of plant origin including cereal foods like bread, pulses (such as peas, beans and lentils), dried fruits and green vegetables. It is also found in fortified breakfast cereals.

Calcium

Calcium is needed for building bones and keeping them strong, for transmitting nerve impulses and muscle actions and for many other body functions. Adequate calcium intakes (and vitamin D production) during childhood, adolescence and young adulthood are essential for long-term bone health. Older people are advised to ensure they have good sources of calcium in their diet every day.

Milk
Soya drink fortified with calcium
Yoghurt
Cheese and cheese spread
Bread
Tinned fish (eaten with the bones)
Tofu
Egg yolk
Pulses such as beans, lentils and chick peas
Green leafy vegetables
Dried fruit
Oranges
Sesame products

Zinc

Zinc plays a major role in the functioning of every organ in the body. It is needed for growth and development, and for normal metabolism of protein, fat and carbohydrate, and it is associated with insulin, the hormone which regulates the body's energy.

Zinc is also involved in the immune system, the use of vitamin A, and in wound healing.

Meat, fish, shellfish
Eggs
Milk
Cheese
Wholegrain cereals
Pulses
Tofu
Nuts
Sesame seeds

Why we need it

Foods it is found in

(See also Appendix 2.)

Sodium

Salt (sodium chloride) is the main source of dietary sodium. Sodium is essential for fluid balance, but too much sodium is associated with raised blood pressure in later life, and this is a risk factor for heart disease and stroke. There is also evidence that people who are obese may be particularly sensitive to the effect that salt has in raising blood pressure.

People who regularly eat snack foods such as crisps or salted nuts, processed meats (such as salami or ham), cheese and tinned foods such as beans or spaghetti in sauce are getting far more salt than they need.

Foods to which salt is added in processing or preparation – for example, sauces, soups, processed meat and fish products, some canned foods, bacon, ham, sausage, smoked cheese or smoked fish, crisps and other snacks, and some cereal foods. (For example, some breakfast cereals and breads are very high in salt, and many biscuits and other bakery products also have a high salt content.)

Take-away and fast foods such as pizzas, burgers and coated chicken products are also likely to be high in salt.

Fresh meat and poultry, and all fresh and frozen fruit and vegetables, are low in sodium.

Other minerals

Copper

Copper is an essential component of many substances which control body functions. We do not yet know whether the health of those with low intakes is affected. No tests are yet available to make this assessment.

Copper is found in a wide variety of foods, particularly in vegetables, fish and liver.

Iodine

Iodine helps to make thyroid hormones necessary for maintaining the metabolic rate. Iodine deficiency is now rare in the UK but is still common in many areas of the world.

Milk
Fish

Magnesium

Magnesium is important for the development of the skeleton and for maintaining nerve and muscle function.

Cereals including bread
Green vegetables
Nuts

Phosphorus

About 80% of the phosphorus in the body is present in the bones, and phosphorus, with calcium, provides rigidity to the skeleton.

Phosphorus is found in all plant and animal cells, so people will get enough phosphorus as long as they eat a varied diet.

Potassium

Potassium helps to regulate body fluids and blood pressure and also has a role in nerve and muscle function.

A large range of foods contain potassium and it is particularly abundant in:

- vegetables
- potatoes
- fruit and fruit juices.

Selenium

Selenium is involved in the mechanism which protects the body from damage inside the individual cells due to oxidation. Low intakes of selenium are associated with increased risks of heart disease and some cancers.

Cereals
Meat
Fish
Brazil nuts

Water

Water is the main constituent of the body and forms 50%-60% of body weight. Water is vital to many functions in the body including the maintenance of cell structure, the physical transport of other nutrients and oxygen through the body via the bloodstream, the transport of white blood cells to fight infection via the lymphatic system, and enabling the body to get rid of waste products via the excretory systems, such as through the formation of urine. Water is lost from the body as urine, in faeces and by evaporation from the skin and lungs, and more water is lost from the skin and lungs in high temperatures, at high altitude and when the air is dry. The amount of water required by the body can vary markedly depending, for

example, on dietary factors, physical activity level, environmental conditions, metabolism and health status. There is evidence that dehydration among people with learning disabilities in residential settings is common.³ To ensure people are adequately hydrated it is currently recommended that adults should have at least 1.2 litres of fluid a day (about 6 glasses)⁴ but older people or people who are prone to constipation should be encouraged to have at least 1.5 litres a day (about 7 to 8 glasses). If someone breathes through their mouth, sweats a lot or has a high temperature, they will have increased requirements for fluid and should seek advice on the amount appropriate to their needs. (See also *Drinks* on page 84.)

The Balance of Good Health

Food is an important part of our lives. In order to get all the nutrients needed for good health, it is essential to eat a variety of different foods every day. The Government's *Balance of Good Health* plate below shows the five food groups and the balance to aim for.

Balance of Good Health

Fruit and vegetables

Eat at least five portions of fruit and vegetables a day.

Bread, other cereals and potatoes

Eat lots of these.



Meat, fish and alternatives

Eat moderate amounts of these. Choose lower fat versions whenever you can.

Foods containing fat and foods containing sugar

Eat only small amounts of foods containing fat. Look out for lower fat alternatives. Don't eat foods containing sugar too often.

Milk and dairy foods

Eat or drink moderate amounts of these. Choose lower fat versions whenever you can.

Snacks as well as meals count towards the healthy balance.

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Preventing diseases: heart disease, bone disorders, cancer and infections

Coronary heart disease and stroke

What do we know about coronary heart disease and stroke among people with learning disabilities?

High-fat diets and increasing lifespan of people with learning disabilities, combined with obesity and low activity levels, have been linked to the reported increases of coronary heart disease seen in people with learning disabilities.⁵ Heart disease is the second highest cause of death in people with learning disabilities (accounting for between 14% and 22% of deaths⁶), but the rate is lower than that seen in the general population, possibly due to reduced life expectancy.⁷

Stroke is the third most common cause of death in the UK and the most common cause of severe disability,⁸ but there do not appear to be any statistics directly relating to the incidence of stroke among people with learning disabilities. The current high levels of salt habitually consumed by the UK population increase the risk of high blood pressure, which increases the risk of stroke and premature death from cardiovascular disease (coronary heart disease and stroke). It is currently recommended that the adult population as a whole would benefit from reducing their intake of salt from about 10g a day to 6g a day.⁹

What can help to prevent coronary heart disease and stroke?

Eating a diet which is rich in fruits and vegetables and wholegrain cereal foods, and which has moderate amounts of fat, sugar and salt, is recommended for reducing the risk of coronary heart disease. Everyone is encouraged to have oil-rich fish (such as salmon, trout, herring, mackerel or sardines) at least once a week. Useful information about how to eat well to protect your heart can be found on the British Heart Foundation website www.bhf.org.uk.

Bone disorders

What do we know about bone disorders among people with learning disabilities?

Fractures and vitamin D insufficiency are relatively common in people with learning disabilities, although there is not necessarily a correlation between the two.^{10,11} People with learning disabilities are also reported as having high prevalence of low bone mineral density, and those who are immobile are reported as being at greater risk of both low bone mineral density¹² and vitamin D insufficiency.¹⁰ Low

levels of vitamin D are particularly common among those with learning disabilities in long-term care wards,¹³ suggesting that people who may be less likely to go outside are at particular risk. Taking oral vitamin D supplements has been found to restore normal vitamin D levels among those with low levels of the vitamin,¹⁰ and it has been suggested that this be considered for people with little exposure to sunshine.¹³ Research among children with Down's syndrome who had low vitamin D status has shown that adequate exposure to sunshine restores their vitamin D levels.¹⁴

Osteoporosis is an abnormal loss of bone density. It is generally associated with post-menopause, a sedentary lifestyle and long-term use of steroids. It is also linked to poor diet, small body size, Down's syndrome, under-activity of the ovaries or testes, and high phosphate levels in females.¹¹ The reduction of oestrogen at menopause means that women (particularly those with Down's syndrome) are at increased risk of osteoporosis. One study of hospital patients found that those with learning disabilities had poorer bone density than patients without learning disabilities¹⁵ – suggesting that those with learning disabilities are at greater risk of osteoporosis.

Low bone density has also been found in children and adults with cerebral palsy, particularly if they are chairbound. This may be due to low calcium intakes,¹⁶ decreased exposure to the sun, immobility, and drug interactions, all of which make vitamin D metabolism less effective.¹⁷

What can help to prevent bone disorders?

To minimise the possibility of low bone density, people with learning disabilities should be encouraged to be as mobile as possible, to spend time outside in the summer sunshine safely, and to ensure adequate vitamin D and calcium intakes. Anyone with a learning disability who has little regular exposure to summer sunshine would benefit from vitamin D supplementation, as would young children, and pregnant and breastfeeding women. All those who live in residential care and all older adults (aged 65 years or more) should also be considered for vitamin D supplementation. Families, friends, support staff, and people with learning disabilities themselves, are encouraged to seek advice from a medical practitioner on the most suitable form of vitamin D supplementation, since some over-the-counter medicines may be of variable strength or may not be easily tolerated.

People with learning disabilities who are at an increased risk of falling are at particular risk of fracture, and a holistic approach to their care with careful risk assessment from a multi-disciplinary team as part of the care planning is required to ensure that sufficient preventative strategies

are put in place and that adequate calcium and vitamin D intakes are ensured.

Cancer

What do we know about cancer among people with learning disabilities?

In the past it has been reported that the incidence of cancer is lower among people with learning disabilities than the rest of the population, but that the types of cancer experience differ.¹⁸ However, more recent evidence suggests that among people with Down's syndrome the overall risk of cancer is the same as for the rest of the population,¹⁹ and that some people with learning disabilities are at particular risk of certain types of cancer.²⁰ Some individual cancers are more common among people with learning disabilities (eg. leukaemia and testicular cancer in people with Down's syndrome), while others are less common (eg. breast cancer in people with Down's syndrome). For people who have both a learning disability and mental ill health, rates of some cancers may be higher. For example, women with schizophrenia are one and a half times more likely to get breast cancer than other women, and people with schizophrenia are almost twice as likely to get bowel cancer.²⁰ A higher proportion of cancers in people with learning disabilities affect the intestinal tract such as the oesophagus, stomach and gall bladder²¹ and there is evidence that cancers of the intestinal tract are linked to lower intakes of fruits, vegetables and fibre²² and higher rates of *helicobacter pylori* infection which can cause gastritis, and peptic and gastric ulcers.²³ Mortality rates from stomach cancer have been reported to be higher among people living in community settings than among the general population. This may be due to a greater prevalence of *helicobacter pylori* infection which is more commonly observed among people who have been moved from institutions to residential or community care than among the general population.

What can help?

The possibility of *helicobacter pylori* infection should be considered in health checks. A diet rich in fruits, vegetables and higher-fibre carbohydrates, with moderate amounts of fat and alcohol, is also recommended to prevent cancer.

Infections, immune function and recovery from illness and surgery among people with learning disabilities

What do we know about these issues in people with learning disabilities?

Infections are common among people with learning disabilities and respiratory infections have been reported to be more common among people with Down's syndrome,²⁴ Prader-Willi syndrome²⁵ and among those with more severe disabilities where swallowing difficulties may lead to aspiration.²⁶ Urinary tract infections have been reported to affect 5.6% of women with learning disabilities, with the highest prevalence among those aged 55-64 years.²⁷ Living in a group setting has also been linked to a greater risk of infections.

What can help?

It is well established that good nutrition plays an important role in the immune system and that optimum nutrition is associated with shorter hospital stays and fewer infections among hospitalised patients.²⁸ There is significant evidence that adequate nutrient intakes are essential for those recovering from illness and surgery as tissue repair requires increased energy and nutrients.²⁹ The nutrients particularly linked to the immune system are zinc and vitamin C. For more on these see page 44.

KEY MESSAGES

Eating well

- Children, young people and adults with learning disabilities should wherever possible be encouraged by family, friends and support staff to eat a varied diet. They should eat foods from each of the four main food groups every day to ensure they get all the nutrients they need. The four main food groups are:
 - bread, pasta, other cereals (such as rice), and potatoes and other starchy roots (such as yam)
 - fruit and vegetables
 - milk and dairy foods such as yoghurt and cheese
 - meat, fish and meat alternatives such as eggs, peas, beans and lentils, soya and nuts.
- Fruit and vegetables are particularly important for good health. Everyone should be encouraged to eat at least 5 portions of a variety of different fruits and vegetables every day.
- Most people in the UK eat too much fat, saturated fat and sugar. Foods which are high in fat and sugar (particularly snacks) can contribute to overweight and obesity if they are eaten frequently or in large amounts. Many people with learning disabilities, and in particular those who are overweight or obese, should be encouraged to replace fatty and sugary foods, drinks and snacks with more fruit and vegetables and other lower-fat and lower-sugar alternatives.
- Most people in the UK eat too much salt and this can contribute to high blood pressure, which is a risk factor for coronary heart disease and stroke. Most people are encouraged to reduce the amount of high-salt foods and snacks they eat and to reduce the amount of salt they use in cooking and at the table.
- Adults are encouraged to eat a portion of oily fish each week – for example, salmon, trout, mackerel, herring or sardines – since the long-chain fats in oil-rich fish have been shown to help with heart health. There is no equivalent food suitable for vegetarians, but a diet which is rich in wholegrain cereals, peas, beans and lentils, vegetables and fruit will contribute to a diet low in fat and saturated fat and high in complex carbohydrates and fibre which is recommended to prevent heart disease.

Bone health

- To minimise the possibility of low bone density, people with learning disabilities should be as mobile as possible, spend time outside in the summer sunshine safely, and have adequate vitamin D and calcium intakes.
- Anyone with a learning disability who has little regular exposure to summer sunshine, young children, pregnant and breastfeeding women, those who live in residential care and all older adults (aged 65 years or more) should be considered for vitamin D supplementation. Where this is the case, advice should be sought from a medical practitioner.
- People with learning disabilities who are at increased risk of falling and fracturing their bones should be assessed by a multi-disciplinary team to ensure that sufficient strategies are put in place to prevent falls and that adequate calcium and vitamin D intakes are ensured.

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Chapter 4 **Nutrition through the lifespan for children, young people and adults with learning disabilities**

This chapter looks at some of the nutritional factors which may impact on children and adults throughout their lifespan – as infants, young children, teenagers, and as adults.

There is very little data which describes typical food and nutrient intakes among people with learning disabilities. There is, however, considerable evidence to suggest that adults with learning disabilities are more likely to be either underweight or overweight than the general population, and body weight issues are looked at in detail in chapter 5. Gastrointestinal disorders, swallowing difficulties and oral health also impact throughout the lifespan and are dealt with in detail in chapter 6.

Infants

The nutritional needs of infants are very specific, and advice about infant feeding is available from midwives, health visitors and other health professionals. Exclusive breastfeeding is the best way to feed babies, and for the first 6 months a baby can receive all his or her nutritional requirements from breast milk alone. Supporting women to breastfeed and finding innovative ways to ensure that all infants receive breast milk, regardless of their mother's disability or any disability in the child, should be seen as a priority. Breast milk is hygienic, easily digested and nutritionally unique, and contains important antibodies to help babies fight infections. Breastfeeding can also protect women from some diseases of later life.¹ Women with learning disabilities should be offered specific and tailored support to help them breastfeed their infants if they wish to do this. Some infants with learning disabilities may have feeding difficulties and this may lead to 'failure to thrive', which means they are not growing as well as other children of their age. Mothers of learning-disabled infants should be aware that they may experience feeding difficulties and should be offered tailored support to help with breastfeeding as well as emotional and practical support if breastfeeding is unsuccessful. For information on resources on breastfeeding, see page 155 in Appendix 4.

Learning disability manifests itself in the developing child as slower development through typical milestones – for example, a failure at 6 months to show interest in their surroundings or to attempt to sit up and grasp objects. Diagnosis of learning disability is rarely possible, and with a few exceptions, unwise in the first 6 months of life. The most important exception is infants born with Down's syndrome.

Once learning disability has been confirmed, a multi-disciplinary team of health professionals will be able to support the family, and where there are dietary-related problems a paediatric dietitian will be consulted. Too little or too much weight gain may be seen if babies are weaned too early, or weaned onto the wrong types of foods, or if they are fed inappropriately during their first year. Weaning means the introduction of complementary foods to babies in addition to milk. It is currently recommended that babies are weaned at about 6 months of age. When complementary foods are introduced, the following points are important.

- No salt should be added.
- No sugar should be added.
- The first foods recommended are: smooth rice or oat cereals; potato or other root vegetables; a variety of fruit and vegetable purées; and puréed beans, peas, lentils, meat or fish.

- A variety of tastes should be introduced and, as babies become more confident at taking food from a spoon, soft, minced and chopped food can be given rather than purées, as well as finger foods for babies to chew on such as rice cakes or pieces of vegetable or fruit.

It is important that parents are given guidance on inappropriate foods, and on portion sizes and mealtime behaviour and that they are aware of safety issues such as never leaving a baby or child alone with food.

It is important that all parents, guardians and other carers, regardless of their own disability or any disability recognised in their child, receive careful and individually tailored advice on nutrition for babies in the first year of life. This is particularly important if one or both parents have a learning disability.

For information on vitamin drops for infants, see page 53. For more detailed information on infant feeding and weaning, see the Caroline Walker Trust publication *Eating Well for Under-5s in Child Care* (details on inside front cover).

Children

Eating well and being active in the early years are essential for proper growth and development. This is true for all children, regardless of whether they have a learning or physical disability or not. It is the responsibility of everyone who cares for and supports young children that the children are exposed to good experiences around food and encouraged to develop positive attitudes to good nutrition and physical activity. It is recommended that all parents and other carers of children with learning disabilities, and all parents with learning disabilities themselves, are given appropriate information on eating well for their children, to ensure that they can establish appropriate eating habits and prevent underweight or overweight and other nutritionally-related health problems in later years. Some of the key points to consider when helping children to eat well are outlined below.

Children with learning disabilities

Various research studies have examined the nutritional status of children with learning disabilities. Children with disabilities and neurological impairment (conditions which impact on the brain and spinal cord, including cerebral palsy, brain injury and epilepsy) have been shown to have nutritional problems, and in particular insufficient energy intake which can impact on growth.² Stunting (being shorter than would be expected) and wasting (being thinner than expected) have both been reported in children with disabilities.² Micronutrient deficiencies – including

Key issues for eating well among children

Children should be encouraged to eat a varied diet. They should eat foods from each of the **four main food groups** every day. The four main food groups are:

- bread, other cereals and potatoes
- fruit and vegetables
- milk and dairy foods, and
- meat, fish and meat alternatives such as eggs, peas, beans and lentils, soya and nuts.

Fruit and vegetables are particularly important for good health. Children should be encouraged to have at least 5 portions of a variety of fruits and vegetables a day.

Vitamin C is important in maintaining good health and may have a role in helping the body to absorb iron if both nutrients are present in the same meal. Children should be encouraged to eat foods containing vitamin C at meals. Vitamin C is found, for example, in most fruit and fruit juices, potatoes, broccoli and other green vegetables, tomatoes and peppers.

It is recommended that children aged 1 to 4 years should receive **vitamin drops** containing vitamins A, C and D.

The **iron** and **zinc** intake of children is lower than currently recommended and there is evidence to suggest that low iron and zinc status is common in this age group. Children should therefore eat a diet that is high in iron-rich and zinc-rich foods such as meat, poultry and fish, as well as cereals and some vegetables. Children who do not eat meat should have a varied diet containing foods such as cereals, pulses (peas, beans and lentils), vegetables and fruits.

The intakes of the type of **sugars** in the diet which most contribute to tooth decay are higher than recommended among children. If children have sugary foods and drinks, these should be given with meals rather than as snacks between meals. Children do not need sugary foods or drinks – such as sweets, chocolate, soft drinks or honey – for energy. Starchy foods – such as potatoes, bread, rice, pasta and yam – are better sources of energy as these foods contain other important nutrients too.

Children should be encouraged to be **physically active** and it is important to fit activity into children's daily routines throughout the year. Physical activity helps to ensure that children eat enough food and get all the nutrients they need. It also builds up muscle strength and overall fitness, develops physical skills such as balance and coordination, and provides a release for children's energy.

deficiencies of calcium, vitamin C, vitamin A, riboflavin and thiamin – have been reported in children with developmental disability and may be under-recognised.³ Nutritional problems are more likely among children with more severe disabilities and, where there are feeding difficulties and children rely on a milk-based diet, it is more likely that they will get insufficient amounts of other nutrients, particularly iron.² Children with learning disabilities may have some particular difficulties around eating and drinking, such as difficulty controlling food or fluid in their mouth, mouth sensitivity (where the child has an exaggerated response to touch in the mouth or around the face), or difficulty managing cutlery. Advice on managing eating difficulties can be found in chapter 9. Parents of children with disabilities and eating difficulties have reported that meat, fruits and vegetables are often avoided and this can have a particular impact on iron and zinc intakes.² For information about the importance of iron and zinc see page 44.

It is recommended that all children between 1 and 4 years receive daily vitamin drops (containing vitamins A, C, D). These are free to beneficiaries under the Healthy Start scheme. Information on vitamins can be obtained from health visitors or the Healthy Start website on www.healthystart.nhs.uk.

Children with learning disabilities want to be treated like other children and to be included in ordinary activities.⁴ All children with special needs should be encouraged to eat the same healthy diet and, wherever possible, do this in the same way as other children they are with. Advice on helping very young children to eat well can be obtained from a paediatric dietitian (see *Where to get advice about eating well* on page 151).

For more information on drinks for children, see page 84. For information on healthy eating for children up to the age of five and for school-aged children, see the Caroline Walker Trust publications *Eating Well for Under-5s in Child Care* and *Eating Well at School* (see inside front cover).

Teenagers

The teenage years are characterised by a move to greater independence for almost all children as they forge their own identities and make more decisions about their own lifestyle. Teenage is often seen as a time of rebellion and experimentation with food and this may impact on food choices leading to, for example, irregular eating habits, increased snacking or grazing, missed meals, unconventional meals and an increase in the consumption of fast food, soft drinks and confectionery as teenagers become more financially responsible for their food choices.⁵ Many young people with learning disabilities will be faced with the same pressures as other teenagers to adopt a more risk-taking lifestyle and it has been suggested that teenagers with low self-esteem and less hope for their own futures are more likely to adopt behaviours which put their health at risk.⁶

As young people with particular health needs grow older and move away from specialist child healthcare provision, family, friends and support staff may find it more difficult to access services which will help to support older teenagers and young adults to eat well and be active. Teenagers are at risk of weight gain when they have greater access to food and if they become less active, so this can be a crucial time to develop good eating habits and do regular physical activity where possible, both of which will help to prevent other physical health difficulties. It is important that each person's nutritional needs are considered whenever their health is reviewed. If young people develop a circle of friends or supporters in their teenage years, it is useful if those friends and supporters are aware of the importance of healthy eating and activity so that they can encourage the young person to eat well and be active.

Pregnancy

It is widely acknowledged that a healthy diet during pregnancy optimises the health of the mother and the infant. There are some important nutritional and health messages associated with pregnancy and all women should be offered appropriate advice on eating and drinking well throughout their pregnancy. For women with learning disabilities, it is important that the advice is specifically tailored to their particular condition and geared to their level of understanding.

It is very important that women with learning disabilities attend all the appointments made available to them with health professionals throughout their pregnancy so that they can be supported appropriately. Those with learning

disabilities should be enabled to access that support. Those caring for or supporting women with learning disabilities who are or who may become pregnant should ensure that medical advice is, at all times, accessible and accessed.

Women with learning disabilities who are planning a pregnancy, and those who may become pregnant (that is, if they are sexually active and not using contraception) should take a daily supplement of 400 micrograms of folic acid before pregnancy and during the first 12 weeks of pregnancy. Women who have a history of neural tube defect or diabetes mellitus, or who take anti-convulsant drugs, should talk to a health professional about the amount of folic acid they need, as they have greater needs than other women. Folic acid is essential for the early development of the fetus and for preventing the development of neural tube defects such as spina bifida. (See *Folate* on page 43.)

Women should take a supplement of vitamin D during pregnancy. Vitamin D is essential for ensuring healthy bones for both the mother and the infant. Advice should always be sought from a health professional on which vitamin D supplements are appropriate and how much of any supplement the woman should take.

Women who receive Income Support or income-based Jobseeker's Allowance, and some women who receive family tax credits, are entitled to free vitamins – which contain folic acid, vitamin C and vitamin D – as part of the Healthy Start programme. More information about who is eligible for free vitamins and about food vouchers in pregnancy can be found on www.healthystart.nhs.uk.

Women who are pregnant may also need extra iron and advice should be sought from a medical practitioner.

There are also recommendations about which foods to avoid during pregnancy and women with learning disabilities who are pregnant should be helped to make good choices about food and be given accessible and clear information about the foods they should avoid while pregnant. Pregnant women should be advised not to drink alcohol when they are planning a pregnancy or when pregnant. If they choose not to follow this advice, they should limit their alcohol to no more than one glass of wine once or twice a week.⁷

For women with learning disabilities who are planning a pregnancy, pregnant or breastfeeding, drugs should be prescribed cautiously and regular drug reviews carried out, in order to minimise the risk of harm to the fetus or child. Those who prescribe or recommend pharmaceutical drugs to a breastfeeding mother should have access to consistent, accurate and regularly updated information on the drug and levels that will pass to the baby, from an expert or a specialist text or source.

Women who are overweight or obese before they conceive have an increased risk of complications during pregnancy and birth which pose health risks to both the mother and baby.⁸ Pregnancy may be associated with a permanent increase in maternal body weight, and it has been reported that mothers who have a higher body mass index (BMI) pre-pregnancy and who gain significant weight during pregnancy are more likely to be heavier after pregnancy.⁹ Women who are overweight at the start of pregnancy should be given accessible advice, tailored to their needs and circumstances, on how to eat sensibly during pregnancy and after they have given birth. All women should be encouraged and supported to breastfeed their infants (see page 52). Breastfeeding women should be advised that losing weight through a combination of healthy eating and regular physical activity will not affect the quantity or quality of their milk.

For information on resources on pregnancy and breastfeeding, see page 155 in Appendix 4.

Parenthood

There is little information about the challenges faced by parents in ensuring healthy food choices for their children, but it is generally acknowledged that the number of parents with learning disabilities is rising and that their needs are not adequately addressed.¹⁰ Parents with learning disabilities are far more likely than other parents to have their children removed from them and permanently placed outside the family home. Many learning-disabled parents will not be in employment and their children will be born into low-income households. Appropriate help and support should be provided to learning-disabled parents to ensure they know what an appropriate diet for their children is when they are infants and small children, and in later years know how to prepare food for their children and how to budget. For more information on children up to the age of five, see the Caroline Walker Trust publication *Eating Well for Under-5s in Child Care* (see inside front cover).

The menopause

Women with learning disabilities have the same menopausal symptoms as other women, but generally experience the menopause earlier – particularly those with Down’s syndrome. The symptoms of the menopause can be particularly distressing for women with learning disabilities as they may lack the cognitive ability or education to understand the implications of the menopause or why they are experiencing symptoms such

as hot flushes and anxiety. Hormone replacement therapy (HRT) is frequently prescribed to relieve the symptoms of the menopause, but some women with learning disabilities are unlikely to be able to make an informed decision about the treatment.¹¹ Research has shown that most women with learning disabilities are influenced by the beliefs of those who care for them about what can aid the symptoms – for example, being given evening primrose oil in the misguided belief that it will relieve symptoms.¹¹ Maintaining a healthy weight, eating a diet rich in fruits and vegetables and being as active as possible may help to mitigate some of the symptoms associated with the menopause.

For information on coronary heart disease, bone disorders and cancer, see page 47.

Old age

Older people with learning disabilities are likely to be living in a variety of settings: a few people remain in long-stay hospitals; some live in group homes, and some in their own homes or in sheltered accommodation; and some people live in residential care designed for all older people. Some ‘younger’ older people are living with their families. Some continue to use specialist services for people with learning disabilities which allow them to ‘age in place’ and remain in familiar surroundings with people they know. Others move to using generic services for older people, although often at an earlier age than for other older people.¹² The increased longevity of people with learning disabilities and their growing numbers will put additional stresses on family carers in particular and it is essential that adequate support is planned for both older carers and the people they care for. There will also be an increasing number of older people with learning disabilities from ethnic minority groups in the coming years, and it is important that the needs of this group around food are built into care planning strategies both in the community and in residential care.

Older people with learning disabilities are at risk of the same age-related physiological changes as the general older population and the nutritional needs of older people have been summarised in the Caroline Walker Trust report *Eating Well for Older People*. There is some evidence that, as people with learning disabilities age, many behavioural problems and disorders appear to decrease, and increases in behaviour problems tend to be associated with the onset of dementia rather than with the learning disability itself.¹³

Older people are at greater risk of depression and this may be a particular problem among those with learning disabilities if they have poor communication or verbal skills. In the general older population there is usually a good outlook once depression is treated, but there is some evidence that, among older people with learning disabilities, mental ill health can be more persistent.¹³ The mental health needs of older people with learning disabilities have been reported to be overlooked and unmet and this is likely to be an increasing problem as this population ages.¹³

Many older people with learning disabilities have very limited social networks and few opportunities to use ordinary leisure provision in the community. Many people with learning disabilities in residential care for older people have impoverished lives with few opportunities to get out, and are socially isolated.¹⁴ This is in marked contrast to the experiences of many non-learning-disabled people who, as they grow older, take up new hobbies and other leisure pursuits. People with learning disabilities need support to share these opportunities and it is essential that learning disability services are better equipped to meet age-related needs.

Provision for people with learning disabilities who develop dementia is a key area of concern. People with Down's syndrome are at greater risk of developing Alzheimer's disease and will do so at a younger than average age.¹⁵ However, in the case of people with learning disabilities other than Down's syndrome, the prevalence of Alzheimer's disease and other forms of dementia are no greater than for the rest of the population. A number of studies and action research projects are currently underway

to identify ways in which family carers and residential and day services can best support people with dementia.¹² The nutritional needs of older people with dementia, who may have more problems with eating and drinking, have been considered in the report *Eating Well for Older People with Dementia*. (Details of this and other useful resources about growing older with a learning disability are given on page 154.)

End of life

Caring for people at the end of their lives is an important role for health and social care professionals. End-of-life care requires an active, compassionate approach that treats, comforts and supports individuals who are living with or dying from progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement. One of the key elements to support people at the end of their lives is to find out what their preferences and wishes are in relation to how they would like to be cared for. End-of-life planning for people with learning disabilities should be given the same care and attention as it is for any other member of society. Useful information on end-of-life planning can be found at <http://www.endoflifecare.nhs.uk/eolc>. There are frequently specific issues around food and drink at end of life and it is essential that issues around nutrition and hydration and overall patient comfort at end of life are carefully discussed with all those involved in end-of-life planning for an individual.

KEY MESSAGES

Nutrition and pregnancy

- All pregnant women should ensure that they attend all the appointments made available to them with health professionals throughout their pregnancy, so that they can be supported appropriately. Pregnant women with learning disabilities should be enabled to obtain and attend such appointments and sufficient support should be provided at those appointments to ensure that they can access the information or recommendations made on how to eat well and on the foods they need to avoid while pregnant.
- Women with learning disabilities who are planning a pregnancy, and those who may become pregnant (that is, if they are sexually active and not using contraception) should take a daily supplement of 400 micrograms of folic acid before pregnancy and during the first 12 weeks of pregnancy. Women who have a history of neural tube defect or diabetes mellitus, or who take anti-convulsant drugs, should talk to a health professional about the amount of folic acid they need, as they have greater needs than other women.
- Women should take a supplement of vitamin D during pregnancy. For pregnant women, Healthy Start vitamins, which contain vitamin D (as well as folic acid and vitamin C), are available free to beneficiaries through the Healthy Start scheme. Women who are not entitled to free vitamins are advised to consult a health professional about the appropriate vitamin D supplement to take during pregnancy.

- For women with learning disabilities who are planning a pregnancy, or who are pregnant or breastfeeding, drugs should be prescribed cautiously and regular drug reviews carried out, in order to minimise the risk of harm to the fetus or child.
- Pregnant women with learning disabilities should be counselled about the importance of avoiding alcohol during pregnancy since this has been associated with increased risk of a baby being born with a learning disability.
- Women with learning disabilities who are overweight at the start of pregnancy should be given accessible advice, tailored to their needs and circumstances, on how to eat sensibly during pregnancy and after they have given birth.

Infant nutrition

- Supporting women with learning disabilities to breastfeed, and finding innovative ways to ensure that all infants receive breast milk – regardless of their mother’s disability or any disability in the child – should be seen as a priority. Breast milk is hygienic, easily digested and nutritionally unique, and contains important antibodies to help babies fight infections. Breastfeeding can also protect women from some diseases of later life. Women with learning disabilities should be offered specific and tailored support to help them breastfeed their infants if they wish to do this.
- All parents and carers of infants with learning disabilities should be given advice and on-going support on infant feeding and weaning so that they can establish appropriate eating patterns in their children which will promote good nutritional health in later life.
- All parents who have learning disabilities themselves should be given clear, accessible advice and on-going support on how to feed and wean their infants appropriately.
- Breastfed babies over 6 months of age and all children between 1 and 4 years should receive daily vitamin drops (containing vitamins A, C and D). Vitamin drops containing vitamins A, C and D for children from the age of 6 months until their 4th birthday are available free to beneficiaries under the Healthy Start scheme (www.healthystart.nhs.uk).

Nutritional needs of children and young people

- All parents and other carers of children with learning disabilities, and all parents with learning disabilities who have children themselves, should be given appropriate information on eating well for their children, to ensure that they can prevent underweight and overweight and establish appropriate eating habits for their children to prevent nutritionally-related ill health in later life.
- Children with learning disabilities who eat a poor variety of foods – for example, because they are very selective or because they have eating difficulties – may be at greater risk of nutritional insufficiency, and care should be taken that sources of important nutrients such as vitamin A, vitamin C, iron, zinc and calcium are included in the diet regularly.
- The teenage years can be a critical time for weight gain or dietary change among young people with learning disabilities as they gain greater independence in food choice. Young people with learning disabilities should wherever possible be encouraged to be active and eat a varied diet.

For information on drinks for children and young people, see page 84.

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Chapter 5 **Weight management**

This chapter looks at identifying underweight and overweight, why people with learning disabilities may be vulnerable to abnormal body weight, and how this can be managed.

Identifying underweight and overweight

There is considerable evidence that many people with learning disabilities have inappropriate body weights – either underweight or overweight. However, it is not always easy to tell if people are too thin, and it can be difficult to know if a person’s weight gain is impacting on their health and wellbeing. In order to measure people’s body weight we rely on some simple measurements which we describe below.

Growth charts

Growth charts are used to ensure that children are growing appropriately. Special growth charts (height, weight and head circumference) are available for boys and girls with Down’s syndrome from birth to 5 years, based on data from around 1,100 healthy children with Down’s syndrome living in the UK and Ireland.¹ There are also specific height charts available for children with Turner syndrome from the same source.

Body mass index

Deviations from ‘ideal weight’ are most commonly defined in terms of body mass index, or BMI. This is calculated by dividing a person’s weight (in kilos) by the square of their height (in metres). The classification of weight among adults by NICE (the National Institute for Health and Clinical Excellence) is shown in Table 1 below. This classification accords with the World Health Organization classification of overweight and obesity.²

Table 1 Classification of weight among adults

Classification	BMI (kg/m ²)
Underweight	Less than 18.5
Normal weight	18.5-24.9
Overweight	25.0-29.9
Obese	30.0 or over
Class I	30.0-34.9
Class II	35.0-39.9
Class III	40.0 or over

Source: NICE, 2006³

The use of BMI as a measure of fatness does not take into account fat distribution or differing body composition (for example, the percentage of muscle).⁴ There are no predetermined correction factors available specifically for use with those with Down’s syndrome, who tend to be shorter compared to the general population.⁵ Also, BMI may not be appropriate for those who are disabled through missing or withered limbs, who have muscle wasting or who have abnormal anatomy or body functions.⁶ However, BMI remains the measurement of choice for the population as a whole.

Waist measurements

Another simple way to show health risks associated with overweight is to take waist measurements. This can often be the most straightforward way of alerting someone to their increased body weight, although care has to be taken with anyone who may have an inappropriate waist measurement for other reasons (eg. related to the use of medicines or to another illness). Also, these measurements have not been validated in a learning-disabled population, so they should only be seen as a general guide. The measurement of waist circumference is also a measure of risk for conditions such as coronary heart disease.

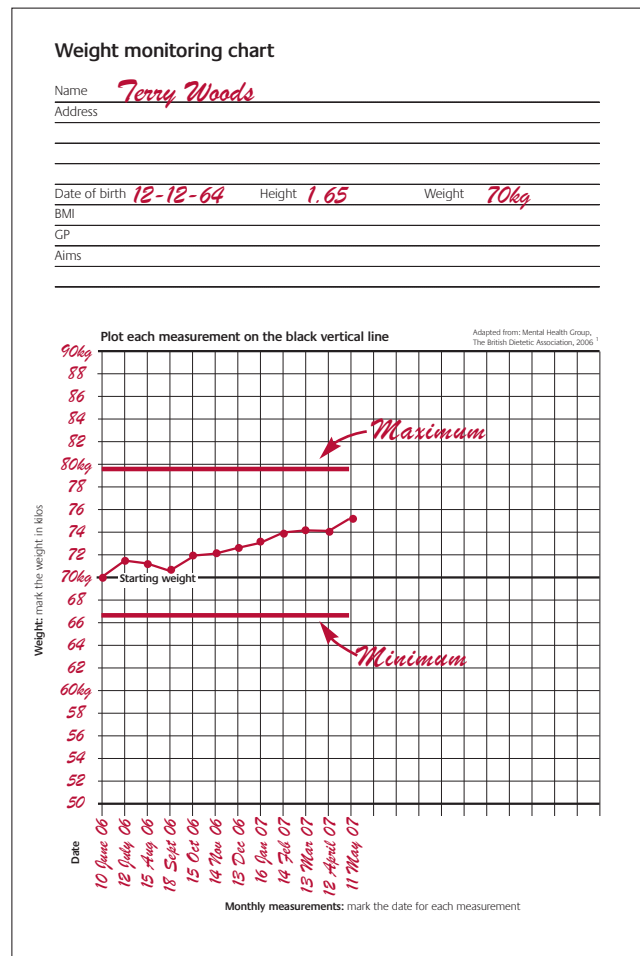
The correct position for measuring the waist is at the level of the belly button. The waist circumference measurement

for men and women at which there is an increased relative risk is defined as follows:

	Healthy waist	Risk to health
Men	Up to 40 inches (102cm)	40 inches (102cm) or more
Women	Up to 35 inches (88cm)	35 inches (88cm) or more

Tools to help monitor weight

It is important that support staff are able both to easily monitor weight change and to act on changes appropriately. There are a number of tools to help with this and we suggest that tools are used both to measure weight and to consider nutritional status (see page 154). A simple tool has been developed for use with people with learning disabilities. It allows support staff to plot a person’s weight on a chart and, with input from a health professional, lines can be added which show when attention should be sought for an inappropriate weight. An example of this simple weight chart is shown below, and a blank version of it with instructions for completing it is given in Appendix 3.



It is important that scales used to measure people are accurate and where possible sitting scales should be used, should be checked regularly and should not be moved. It is useful if there are discussions with each person about how frequently weighing should take place and whether weights will always be taken with clothes on or off. For people who are chronically constipated, constipation can add 0.5kg to 1.5kg of weight and this should be considered when potential weight loss or weight change is considered.

It has been suggested that a person is potentially at risk of malnutrition if they have unplanned weight loss of 5%-10% in the past 3 to 6 months, and is at significant risk if they have lost more than 10% of body weight in the past 3 to 6 months.⁸ This would mean, for example:

- If someone of 60kg had unintentionally lost 3kg in the past 4 months (equivalent to 5% of weight), they may be at risk of malnutrition and should be monitored carefully.
- If someone of 50kg had unintentionally lost 5kg in the past 3 months (equivalent to 10% of weight) they are at high risk of malnutrition and advice should be sought from a medical practitioner as a matter of urgency.

It is important to remember that, even if people appear to be normal weight or overweight, they can be at risk of malnutrition if they lose a significant amount of weight unintentionally.

Underweight

What do we know about underweight among people with learning disabilities?

A study of 1,542 adults in supported accommodation found that 14% of those with learning disabilities were underweight (with a BMI less than 20)⁶ and a review of 25 studies by Gravestock⁹ concluded that between 35% and 72% of those with severe learning disabilities were significantly underweight (with a BMI less than 17). This was mostly confined to those who were immobile, or unable to feed themselves or tolerate solid foods, or who exhibited regurgitation, rumination or chronic vomiting. It has been common for severe undernutrition to go unrecognised by support staff and health professionals, particularly when it has been longstanding (“They have always been thin.”)¹⁰ Thinness can appear to be resistant to obvious practices like offering more food (“No matter what we do we can’t get weight on them. They are just like that and always will be.”)

It has also been suggested that maintenance of low weight among people with learning disabilities has been continued because expectations are based on long-standing

experience of underweight and even that some support staff accept smallness and resist change as the person they care for may be easier to manage if he or she remains underweight.¹⁰ Challenging the perception of what are normal body weights for people with learning disabilities is essential and it is important that health professionals in particular are given clear information on the ‘normal’ growth and development that should be expected among people with learning disabilities, and the importance of intervention if an individual is below a healthy body weight for their height.

Why does underweight matter?

Significant underweight is associated with increased susceptibility to infection and reduced ability to perform physical tasks.¹¹ Undernutrition is related to increased mortality, increased risk of bone fracture, increased risk of infections and an increased risk of specific nutrient deficiencies which can lead to a variety of health-related conditions that can greatly affect quality of life. Sudden death from respiratory illness typifies the end-of-life story for people who have insufficient food intake.¹⁰ People who are underweight will have weaker muscle tone which can impact on their ability to do everyday tasks and may impact on eating itself. People who are underweight are less likely to be active and this may impact on appetite and, as they are more prone to infection, there is a typical cycle of poor food intake, illness, reduced appetite and further reduced food intake that can lead to chronic undernutrition.

What to do if someone is underweight

It is possible to reverse undernutrition with careful and patient assistance with eating and drinking or with nutrition support (see next page). It is essential that all support staff are alert to undernutrition and are trained to spot the signs that food intake is inadequate as early as possible. The main strategies to reverse undernutrition are:

- keeping weight records and following up if there is unexplained weight loss or if weight drops below an agreed cut-off point for the person
- keeping records of food eaten and wasted
- investigation of any underlying medical problems which might be related to weight loss
- increasing physical activity among those who are able, in order to increase appetite and interest in food (see page 66)
- improving techniques to support people who have eating difficulties (see page 108)
- offering small meals regularly (for example six small

- meals a day) – sometimes called ‘little and often’ eating
- exciting the appetite by making food look good and taste good and ensuring meals are served at appropriate times, in a calm and happy atmosphere (see page 82)
- dietary enrichment and supplementation (see pages 134 and 135)
- artificial nutrition support (see below).

Nutrition support

When an individual has significant difficulties with eating and drinking and is no longer able to maintain his or her body weight by eating and drinking normally, they may be offered some form of nutrition support. This can be in a modified oral form if they have difficulties with chewing or swallowing, or it can be through a tube, where liquid food passes straight into the stomach. In extreme circumstances where there is disease of the gut or very serious illness, individuals may be offered parenteral nutrition support where nutrients are passed directly into the blood supply.

The use of non-oral feeding among people with learning disabilities has been an issue of debate among health professionals, and decisions about how to feed people who have significant disability is one of the most difficult for professionals to confront.¹² Many people in whom the issue of artificial nutrition support arises are unable to communicate their own wishes and may not have relatives able to speak on their behalf, making it essential that issues surrounding nutrition support are discussed openly with all concerned. There is evidence that nutrition support via gastrostomy can be an effective way of improving the weight and nutritional status of children with cerebral palsy,¹³ but there remains some controversy about gastrostomy feeding, especially in people with dementia.

A common view is that the current evidence fails to show that gastrostomy feeding among people with dementia has a favourable outcome.¹⁴ The criticisms are based on work among patients with dementia showing that: gastrostomy feeding fails to lengthen survival;^{15, 16} prognosis worsens after tube insertion;¹⁷ there is a higher complication rate;¹⁸ and outcomes are poor in malnourished patients.¹⁹ However, there remain many unanswered questions:

- *Is survival a relevant outcome measure?* Survival will be unchanged against the background of a progressive, untreatable condition. The survival curves are parallel for people with dementia and people in the general population who have gastrostomies,¹⁷ suggesting that it is the dementia that reduces survival, not the insertion of a tube.

- *When does dysphagia become an issue?* Dysphagia (swallowing difficulties) occurs early in many progressive neurological conditions, including Alzheimer’s disease, challenging the usual view that this is a terminal symptom.²⁰
- *Is early dysphagia being identified?* Dysphagia is often missed because of poor screening so, when it becomes obvious, it is already at an advanced stage.²¹
- *Are tubes being inserted too late?* Any delay in identifying dysphagia means that malnutrition may already have developed when the tube is inserted, and there is evidence that malnourished dementia patients do less well after a gastrostomy is inserted than those who are not malnourished.²²
- *Is the re-feeding syndrome being recognised?* This syndrome is caused by an imbalance of electrolytes in the body when food is suddenly reintroduced after a period of starvation and is often ignored in research about people with learning disabilities, even though this syndrome can be a cause of death.²³

There is also debate about the risks associated with the surgical procedure required for the insertion of a gastrostomy and the possible increased risk of respiratory problems.^{24, 25} There are also concerns about the loss of the eating experience when nutrition is provided artificially, and the lack of support given to families and caregivers before and after the intervention. While these areas still require rigorous debate and further research, there is compelling evidence that maintenance of nutritional status through artificial nutrition support for many individuals can lead to better health and may improve quality of life and extend life.

For many children and adults the addition of nutrition support does not mean an end to eating and it is important that it is not viewed as an either/or scenario in many cases. Where the provision of food and drink is extremely time-consuming (more than 45 minutes per meal for example), oral nutrition can become very fatiguing for both the person involved and the caregiver. Nutrition support alongside oral support can significantly reduce the time spent helping someone to eat. Following advice from a speech and language therapist there may be no need to deny the person the social aspects of eating or the pleasant tastes of foods and drinks.

Gastrostomy tubes can be hidden under clothing and also allow the accurate administration of medication. There are likely to be fewer battles over nasty-tasting medicine as medicines given through the gastrostomy bypass the tastebuds altogether. It has been reported that, while nutritional intake may be effectively maintained among children with a gastrostomy, parents of children with

learning disabilities require considerable support before and after the insertion of the gastrostomy, and that this is frequently inadequate.²⁶

Living with artificial nutrition support

People with either naso-gastric tubes or gastrostomies will often rely on the support of family carers and support staff to manage their artificial nutrition support, ideally with back-up from a dietitian or nutrition support nurse. Training should always be given so that family, friends and support staff know how to manage tube-feeding and solve any practical problems people may have. For information on organisations which can offer advice, see *Organisations* in Appendix 4.

Some people may find living with a gastrostomy straightforward but some may find that it impacts on aspects of daily life. One small study reported that 90% of parents of children with learning disabilities were happy with the tube-feeding regimen for their child, but that some parents would have liked more support when their child first needed a gastrostomy. The commonest difficulties dealt with by parents in this study were vomiting, leakage, infection, diarrhoea and nausea.²⁷

In order to make life with a gastrostomy as normal as possible, especially for children, it is worth considering the following:

- Feeding regimens should consider the individual's lifestyle, and feeding should not dominate each day.
- Individuals may choose to join in with the social aspects of mealtimes and children and young people in particular should be encouraged to do this wherever possible.
- Oral intake of food and drink at meals may still be possible but should only be given under the guidance of a speech and language therapist and dietitian.
- It is important that oral hygiene continues even if food and drink are not consumed orally (see page 75).
- If people fiddle with their PEG, try a close-fitting vest or provide another distraction. Also, profile button tubes can be fitted which sit snugly on the skin surface.

People may feel self-conscious about their tube and feel tied down by the gastrostomy. Talking to other people can help and there are a number of organisations that might be able to offer support (see *Organisations* in Appendix 4). Useful troubleshooting tips for dealing with the difficulties associated with gastrostomy feeding can be found at <http://www.ich.ucl.ac.uk/factsheets/families/F000380/gastro5.html>

Overweight and obesity

What do we know about overweight and obesity among people with learning disabilities?

When the total amount of calories in the food and drink taken in exceeds that expended by the body, any excess is stored as body fat. Obesity is defined as a condition in which the stores of body fat have increased to a level which impairs health. Obesity in the general population is rising rapidly and predictions suggest that the current estimate of 22% of men and 23% of women²⁸ being obese will rise to 25% of all adults in the UK by 2010.²⁹

Numerous studies have looked at overweight and obesity in those with learning disabilities. In 2000, Gravestock reviewed 25 research studies, with samples varying from 35 to 2,202 people, which included people in hospital and in residential units. In most studies the rate of obesity among those with learning disabilities was higher than the rate among people without learning disabilities at that time. In 2000 it was reported that 13% of men and 24% of women with learning disabilities over 18 years of age living in supported accommodation were obese³⁰ and this had risen to 27% of men and women with learning disabilities over 16 years of age in supported accommodation in the north of England in 2005.⁶ A recent study in Ireland reported that almost 70% of people with learning disabilities had a BMI greater than 25, with 30% of subjects having a BMI of more than 30.³¹ Almost all studies report greater rates of obesity among women than men, and significantly greater levels of obesity among women with learning disabilities than women in the general population.⁴

Evidence also suggests that people with intellectual disabilities will experience obesity at a younger age than the general population⁴ although there is little information available about rates of obesity in children and young people with learning disabilities. Research currently ongoing in Northern Ireland looking at children with learning disabilities in comparison with those of a similar age in mainstream schools is already showing significantly higher levels of overweight and obesity among children in special schools, suggesting that overweight in children with learning disabilities is also greater than for the child population as a whole.³²

Obesity is more common among those with Prader-Willi syndrome and other genetic syndromes such as Cohen syndrome and Barder-Biedl syndrome.³³ Studies have reported an increased prevalence of obesity in people with Down's syndrome,³⁴ but more recent evidence from one study reported that, while women with Down's syndrome had a higher rate of obesity, this was not true for men with

Down's syndrome⁴ and it is likely that obesity among the majority of people with Down's syndrome is linked to lifestyle factors rather than the condition itself. People with Down's syndrome are more likely to have thyroid disease that can lead to overweight, and screening for thyroid disease is important for people with Down's syndrome.

Why is obesity higher among some people with learning disabilities?

It has been suggested that the increased rates of obesity among young adults with learning disabilities are linked to living in poorer households, increased dependence on others, lower levels of activity and overfeeding to compensate for boredom, social isolation and behavioural problems.⁵ Obesity may be higher in young people with learning disabilities when they leave school as many find it difficult to move into employment or continuing education, or to access some purposeful activities.³⁶ Propensity to weight gain can be compounded by using food as a reward or comfort, or by an eating disorder. For example, recent evidence suggests that about 13% of service users with a learning disability in South London had a diagnosable binge eating disorder associated with obesity.³⁷ Children and adolescents with learning disabilities are four times more likely to have an emotional disorder and this is more common among girls and those who live in poverty.³⁸ In the general population, increasing rates of obesity and poor nutrition have been linked to: a lack of understanding of what constitutes a balanced diet; limited access to fresh fruit and vegetables, a sedentary lifestyle;³⁹ a diet high in fat and sugar,⁴⁰ particularly sugary drinks;⁴¹ environments which contribute to and do not discourage obesity;⁴² portion sizes;⁴³ and behaviour patterns.⁴⁴ Studies have reported that people with learning disabilities living in residential care, who rely on their support staff for advice and help with their diets and lifestyle, are also subject to these factors.^{4, 6, 30, 45, 46}

The health consequences of overweight and obesity

It is known that overweight (BMI 25-29.9) and obesity (BMI 30 or above) in the general population are linked to an increased risk of developing coronary heart disease, type 2 diabetes, certain cancers, stroke and osteoarthritis.^{40, 11} Being overweight can also contribute to skin infections, which can develop into abscesses if not treated. There is also social stigmatisation associated with being overweight which means that fatter people, and particularly fatter children, can be viewed very negatively by their peers and by society.⁴⁷ Type 2 diabetes is described in more detail opposite. For information on the other conditions mentioned above, see page 47.

Type 2 diabetes

Between 70% and 80% of those with type 2 diabetes are either overweight or obese, and overweight and obesity are therefore considered important risk factors for developing the disease.⁴⁸ The number of people in the UK with type 2 diabetes is rising,⁴⁸ and it is estimated that 9% of those with learning disabilities have type 2 diabetes⁴⁹ compared to 4% of the general population.⁴⁸ Maintaining a normal weight status (BMI 18.5-24.9) combined with regular physical activity is strongly associated with a reduction in the risk of developing type 2 diabetes.

Being diabetic may be particularly problematic for some people with learning disabilities. They might experience difficulty adjusting to, or understanding the reasons for and importance of diet and lifestyle changes. However, many people are able to learn to manage their diabetes with support. It is important to ensure that diabetes is taken seriously, as a failure to manage the disease properly can result in further medical problems, such as blindness, nerve damage resulting in possible amputations, and an increased risk of atherosclerosis leading to an increase of kidney failure, heart disease, and stroke.⁵⁰ In some people with learning disabilities, the responsibility for managing the diabetes is likely to rest with their family, friends and support staff, and a diagnosis of diabetes can in some circumstances encourage support staff to find out more about eating and drinking well and pay greater attention to the foods and drinks made available. For most people with diabetes, the diet of choice is the diet encouraged for the population as a whole – namely a diet that is rich in fruit, vegetables and wholegrain carbohydrates, and lower in fat, saturated fat, sugar and salt. Special diabetic products and strict dietary regimes are unlikely to be necessary. For support on how to eat well with diabetes, contact Diabetes UK (see *Organisations* in Appendix 4).

Managing overweight

In simple terms, weight management means balancing the amount of energy that is consumed (as calories) with the amount of energy that we use up (in normal body processes – the basal metabolic rate – and in any activity that we do). Weight reduction therefore requires either energy intake to go down, or energy expenditure to increase, or some combination of the two. Weight maintenance requires a consistent balance of input of expenditure and intake.

There is, however, no simple solution to weight gain as the large numbers of the population who are currently overweight would testify. Preventing overweight involves:

- eating well and
- being active.

Focusing on weight itself is often unhelpful and being thin, but not eating well, not exercising, or using smoking to manage weight does not lead to good health. Promoting healthy body weight and body image is particularly important for young people who need to be given positive messages about health and to realise that people come in all shapes and sizes. Family, friends and support staff need to be sensitive to body shape dissatisfaction and ensure they do not make derogatory comments about their own or other people's body shape and do not aim for unrealistic media images of body shape and weight.

Weight loss interventions

A recent review of weight loss interventions for people with learning disabilities⁵¹ reported that moderate weight loss can be achieved and that the factors that related to weight reduction included the teaching of behavioural techniques (that is, how to manage meals, portion sizes and eating patterns), the involvement of support staff, increased physical activity and the sharing of nutritional and health information. Adults with learning disabilities often collaborate in their decision-making with support staff and this review highlighted the importance of motivated and aware support staff in supporting people to manage their weight.

There is evidence that the health knowledge and skills of adults with learning disabilities can be increased⁵² and in particular that equipping participants of a weight loss

programme with an understanding of the health risks of obesity is necessary in order to reinforce behavioural changes in the longer term.⁵³

However, it is not easy to lose weight and it may be particularly difficult for people with learning disabilities if they have mobility difficulties or are chairbound or bedbound. It is therefore useful to consider the following questions before starting attempts at weight loss, and to be realistic about what can be achieved:

Is it really necessary for the person to lose weight?

If health and mobility are not affected by a person's weight and it is stable, then be cautious before recommending weight loss. If someone has a BMI of between 25-30, but eats well, is active and their weight is stable, intervention may be counter-productive and impact on quality of life. If someone is over the age of 65, extreme caution should be taken in encouraging weight loss unless there is a clear rationale for doing this.

Is weight increasing rapidly?

If someone is gaining weight rapidly and consistently – for example, if they have gained 3kg (half a stone) or more per year for a number of years – this may well require intervention to maintain weight. It can be more successful to encourage weight maintenance than weight loss to start with and this can seem more achievable.

Have there been any lifestyle changes that can be compensated for?

Simple changes in lifestyle can often trigger weight gain. If someone changes their place of education, work or transport route this can mean a decline in small amounts of regular activity. If someone walks 15 minutes to a bus stop twice a day, this adds up to 150 minutes' exercise over five days and losing this regular activity can tip the balance in terms of weight maintenance and weight gain. Encouraging small, regular amounts of exercise every day is often preferable to, and more realistic than, a weekly visit to a gym. Three short 10-minute walks a day often seem more achievable than a more vigorous exercise plan. For more information on physical activity, see page 66.

Have there been any changes in eating pattern?

Weight gain may be related to a change in eating habits that might be triggered by a change of residence, a change in lifestyle or a change in the people who are offering care and support. Be alert to simple changes or additions to the diet that might be related to changing circumstances, as it is often small changes to daily patterns that can trigger weight gain.

What weight is ideal?

It may be more constructive to aim for an achievable and comfortable weight than aiming at an 'ideal' weight whose achievement would require considerable discomfort and sacrifice. To keep the need for weight loss in perspective, it is important to balance a healthy body weight with a person's need for quality of life and the circumstances in which they may be living.

Physical activity

Why is physical activity important?

Inactivity can be disabling. As well as being implicated as one of the reasons for the increase in obesity among people with learning disabilities, inactivity is reported to double the risk of coronary heart disease.⁵⁴ This is particularly relevant for people with learning disabilities as they have more risk factors for coronary heart disease than the general UK population.³⁰ Physical activity builds muscle strength and overall fitness, encourages better mobility and balance, increases appetite and burns up calories.⁵⁴ Exercise is also important for preventing constipation and osteoporosis. There is also significant evidence to show that activity can be beneficial in treating depression⁵⁵ and this might be particularly important for many people with learning disabilities. Activity is important for underweight people too, as it helps to increase appetite.

Simple, practical tips to help people who may wish to lose weight or not gain weight

- Aim to have 5 portions of fruit and vegetables every day and make this a priority when menu planning (see page 86).
- Offer water as a drink. Place personalised and fun bottles of tap water in the fridge each day and encourage people to drink from these.
- If people are frequently hungry and impatient while waiting for meals to be served or prepared, offer slices of fruit or vegetables such as carrots and peppers to eat while waiting rather than biscuits or crisps.
- Follow the guidance in this report for good choices for snacks and drinks (see pages 83 and 84) and look at the example eating plans in chapter 11 to see how much food in a week people typically need to get all the nutrients they need.
- Look at portion sizes carefully: people may be used to disproportionately large portion sizes of food and may eat them because they are given to them. Using smaller plates can be helpful in reducing portion sizes.
- Home-made vegetable soup is filling yet low in calories and contributes to vegetable intake.
- After the main course, offer fruit routinely and then dessert if the person is still hungry.
- Simple changes in the kitchen can be helpful. For example: switching to semi-skimmed milk and reduced-fat spreads; using less oil in cooking; grilling rather than frying some foods; buying leaner meats and using smaller quantities of them; buying fewer ready-prepared foods; and avoiding pies and pastries. See the food-based guidance in chapter 10 for more tips.
- If food is eaten for comfort, be sensitive to the relationship the person may have with food. If people are able to, encourage them to talk about their feelings and how their food intake and mood are related. Among those with less severe learning disabilities it may be possible to find non-food ways of stimulating a feeling of wellbeing, such as encouraging people to take up hobbies and pastimes that are creative, taking walks with family, friends and support staff, having a haircut or massage, or spending time in the garden. (See page 156 for information about therapeutic horticulture.)

What do we know about physical activity levels among people with learning disabilities?

Studies have consistently reported that people with learning disabilities have low activity levels.^{4, 6, 30, 45, 54}

Why are people with learning disabilities often inactive?

Physical disabilities and illnesses can create extra obstacles to exercising at all ages. Among younger people with learning disabilities there is an increased risk of epilepsy, sensory disorders, underweight and overweight, congenital heart disorders and neurological problems, all of which can be barriers to exercise.⁵⁶ Among older people with learning disabilities, impaired mobility, respiratory problems, arthritis, deafness and heart disease are common health problems that will impact on physical activity.⁵⁷ Adults with learning disabilities are often prevented from being physically active due to financial difficulties, transport barriers or a shortage of staff.⁵⁸ People with learning disabilities in residential care may have even more limited opportunities for community leisure or to be active as part of tasks of daily life or employment.⁵⁹ Secondary attitudinal barriers may also impact on the activity patterns of people with learning disabilities. Individuals may be less motivated themselves, they may be less encouraged to be active, may have overprotective family, friends and support staff, and staff in leisure facilities may not be aware of the age-appropriateness or safety of different forms of activity.⁶⁰

Perceived barriers to being active reported by people with learning disabilities include:⁶¹

- Insufficient support staff and resources to enable physical activity
- Location, availability and accessibility of leisure services
- Personal finance and budgeting
- Lack of choice and autonomy
- Lack of time
- Poor weather conditions preventing outdoor activities
- Perceived safety of local environment
- Concern over injury or health problems made worse by activity
- Overprotection and negative attitudes to activity by support staff.

Work and activity

In a survey of adults with learning disabilities in England carried out in 2003/04, only 17% had paid employment and another 6% had unpaid work.⁶² Increased work activity may help to increase activity levels, as may involvement in community activities or volunteering activities where

people spend time outdoors being active. It has been suggested that, when lack of exercise is combined with unemployment, there is likely to be apathy and boredom which can contribute to mental ill health and behavioural disorders.⁶³

What can help?

The recommendation for the general adult population is do at least 30 minutes' moderate-intensity activity a day on at least five days of the week.⁵⁴ For children and young people the recommendation is at least one hour's activity a day.⁵⁴ While these are the ideal recommendations, any activity is beneficial and if people have been inactive, they should be encouraged to start at a level of activity they feel comfortable with and gradually build up the duration and intensity of activity. Where people with learning disabilities also have physical disabilities which make movement difficult, it is important that they are given as much help as possible to be as active as they can be, even if this involves only very limited chair-based movement.

The key to achieving and maintaining a more active lifestyle for people with learning disabilities is to find activities which they personally enjoy, which can be easily incorporated into their routine and which fit in with other activities of daily living. There is some evidence that drop-out rates for exercise programmes among people with learning disabilities are lower when the programmes are structured and supervised.⁶⁴ There have been demonstrated benefits among young children with Down's syndrome from a simple jumping exercise routine to promote motor and balancing skills.⁶⁵ There is some evidence that structured programmes such as 'Activate' produced by the Health Promotion Agency in Northern Ireland, which encourages exercise and healthy eating, can help to reduce weight in the longer term (more than one year) among people with learning disabilities.⁶⁶

Regular active games, walking, swimming, social dancing, climbing stairs, cycling, gardening, housework, DIY and chair, bed and wheelchair exercises can all be used to simply increase activity levels. Where practical, children and young people with learning disabilities should be encouraged to do moderate-intensity activity – for example, playing with their friends in a playground, swimming or playing football – for at least an hour a day.

Activities must:

- consider safety issues associated with a particular disability or health condition
- take place in a safe, supportive environment to minimise the risk of injury and to promote confidence and avoid unnecessary feelings of embarrassment
- take account of an individual's needs.

Activities might include specific mobility, stretching and strengthening exercises. Postural awareness, balance and coordination are important considerations.

Appropriate medical advice should always be sought before a person with learning disabilities begins an exercise programme.

There is evidence that health practitioner input with people with learning disabilities can significantly improve activity levels and reduce levels of obesity.⁶⁰ Home-based programmes are an important option and can supplement other activities. Home-based programmes should be self-determined but are more effective when they are tailored to the person, when someone acts as a supporter and when they are preceded by an initial introductory and training phase.⁶⁷ People with learning disabilities may find

activity more enjoyable if they do this with others, and support staff should consider taking part in activities with service users wherever possible.

Eating after activity

It is common for people to over-eat after they have exercised as they believe that activity burns up a significant number of calories. While being active is important for those who want to maintain their weight or lose weight, it is important that the amount of calories burnt is kept in perspective. Encourage those who have done exercise to drink water rather than sweetened drinks or sports drinks, and avoid additional snacks other than fresh fruit after activity unless these have been specifically recommended by a health professional or there is concern about underweight or excessive weight loss.

KEY MESSAGES

Undernutrition

- It is important that children, young people and adults with learning disabilities are offered a good variety of foods that they will accept and which ensure their nutritional needs are met. Where people with learning disabilities have small appetites or eating difficulties, it may be difficult for them to eat enough food to obtain all the nutrients they need. Support staff therefore need to be aware of the importance of adopting strategies to encourage sufficient food intake.
- It is essential that all those who support people with learning disabilities are alert to undernutrition and are trained to spot the signs that food intake is inadequate as soon as possible and to take appropriate action by informing the person's medical practitioner.

Healthy body weight

- Support staff should be able to monitor weight change easily and to act on changes appropriately. All residential settings should have weighing scales, preferably sitting scales, for monthly weight checks. The scales should be checked appropriately. Support staff should be shown how to act on the weight data recorded, and there should be an appropriate chart in each person's care plan which highlights when action is needed because of significant weight change.
- Challenging the perception of what are normal body weights for children, young people and adults with learning disabilities is essential. It is important that health professionals are given clear information on the growth and development that should be expected among people with learning disabilities and on the importance of intervention if an individual is below or above a healthy body weight for their height.
- Where weight gain is rapid and avoidable, or where someone is very heavy for their height and where a careful assessment has been made by a dietitian or medical practitioner that weight maintenance or weight loss would be beneficial, individuals with learning disabilities should be supported to reduce the amount of calories they eat and to be more active.

Physical activity

- Everyone should be as active as possible as physical activity builds muscle strength and overall fitness, encourages better mobility and balance, increases appetite and burns up calories. Activity also helps prevent constipation, coronary heart disease and osteoporosis, and has been associated with better mental health.
- Where practical, children and young people with learning disabilities should be encouraged to do moderate-intensity activity – for example, playing with their friends in a playground, swimming or playing football – for at least an hour a day. Adults should aim to do, or build up to, at least 30 minutes' moderate-intensity activity a day on at least five days of the week.

- Where people with learning disabilities also have physical disabilities which make movement difficult, it is important that they are given as much help as possible to be as active as they can be, even if this involves only very limited chair-based movement.
- People with learning disabilities may find activity more enjoyable if they do this with others, and support staff should consider taking part in activities with service users wherever possible.

Nutrition support

- People who receive some or all of their nutrients through a naso-gastric or gastrostomy tube will often rely on support staff to help manage their artificial nutrition support, ideally with back-up from a dietitian or nutrition support nurse. Training should always be given so that support staff know how to manage tube feeding and solve any practical problems people may have.

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Chapter 6

Gastrointestinal disorders, swallowing difficulties and oral health

This chapter looks at gastrointestinal disorders and swallowing difficulties which can affect many people with learning disabilities throughout the lifespan. It also looks at the importance of maintaining good oral health.

Gastrointestinal disorders

‘Gastrointestinal disorders’ includes conditions such as constipation, diarrhoea and coeliac disease. There are also some specific structural problems associated with Down’s syndrome in particular, such as small bowel obstruction, abnormalities of the anus, and Hirschsprung’s disease. Details of these conditions and their management can be found on the Down’s syndrome association website www.downs-syndrome.org.uk.

Constipation

What do we know about constipation among people with learning disabilities?

Constipation is a common complaint in people with learning disabilities and is mainly caused by a lack of fibre, and by dehydration and inactivity. One study identified 69% of people with learning disabilities living in residential care as being constipated.¹ Major tranquilisers, opioid analgesics, anti-convulsants, and any drug with anti-cholinergic effects (drugs given for tremor and shaking) produce constipation as a side effect.² Constipation has also been linked to the use of anti-epileptic drugs.¹ Other factors contributing to constipation include thyroid disorders, weak bowel muscles, anxiety, over-use of laxatives, food refusal, severe learning disabilities and lack of mobility. People with cerebral palsy are at particular risk of constipation because of abnormal gastrointestinal motility.³ Failure to report lack of bowel movements, or inability to communicate pain or discomfort, might result in constipation going unnoticed in some people with learning disabilities. This could lead to rectal and womb prolapse, ulcers, hernias, and changes in behaviour if people cannot communicate their discomfort and pain.

What can help?

To avoid constipation it is important that people are **as mobile as possible**, have **sufficient fluid** and have **sufficient fibre in their diet**. All of these can be difficult for some people with learning disabilities. Support staff should also be aware that some people may be at particular risk of constipation because of the drugs they take or the particular conditions they have. Support staff should be alert to signs which may indicate constipation, such as a reluctance to go to the toilet, obvious discomfort, long periods spent in the toilet, a change in eating habits, unexplained diarrhoea, or unexplained challenging behaviour, including smearing faeces. Constipation should always be considered when food is refused.¹

Fluid and hydration. How much fluid?

There is debate about the amount of fluid needed and it is difficult to estimate a general requirement, because of the wide variability within and between individuals.

To ensure people are adequately hydrated it is currently recommended that adults should have at least 1.2 litres of fluid a day⁴ (about 6 glasses) but older people or people who are prone to constipation should be encouraged to have at least 1.5 litres a day (about 7 to 8 glasses).⁵ If someone breathes through their mouth, sweats a lot or has a high temperature, they will have increased requirements and advice should be sought on the amount appropriate to their needs.

Fluid can be in the form of drinks but also in foods such as soups, milk puddings, jellies, yoghurt, mousses, gravy, sauces, ice cream and ice lollies. Taking small amounts of fluids regularly throughout the day may be necessary. Those who have swallowing difficulties may need to have thickened fluids (see page 133) and it may be more difficult to provide enough drinks each day. Make sure that there is a good choice of different hot and cold drinks available, as people may become fatigued of the same drinks. If it is safe, some people with eating difficulties may find that ice lollies or sorbet in cones provide an alternative source of fluid. Some people may find it easier to drink through a straw and some find cold drinks easier to tolerate than hot drinks. For more information about drinks, see page 84.

Fibre

Foods that are high in fibre include bread, cereals, fruits and vegetables and pulses. Increasing the amount of fibre eaten can help to alleviate constipation, but it must be done carefully. Fibrous foods are bulky and can reduce the energy density of the diet, and some people may find that sudden increases in fibre intake cause bloating and wind. It is recommended that fibre intakes are increased very gradually to start with, by increasing fruit and vegetable intakes, then by adding in peas, beans and lentils, and then higher-fibre cereal foods such as wholemeal breads or higher-fibre cereals. When increasing the amount of fibre in the diet, it is important also to increase fluid intake.

Some people with advanced disease (such as cancer) or functional (dysmotility) dyspepsia will struggle with high-fibre diets. Also, in people with poor appetites, care should be taken that the diet does not become too bulky or unpalatable.

Here are some suggestions for simple ways to increase fibre intakes, for those who are able to increase their fibre intake safely:

- Puréed tinned peaches, apricots or mango as a sauce served with ice cream or sorbet
- Dried fruit added to cakes and desserts
- Using rhubarb, blackberries, plums and other fruits in desserts, or stewed with custard or ice cream or sorbet
- Dried fruit such as apricots, raisins and dates can be eaten as fruit snacks with meals.
- Baked beans
- Canned beans and lentils puréed into soups
- Houmous as a sandwich filling or on toast
- Sweetcorn and peas added to stews and casseroles
- Mixing some brown flour into white when baking
- Using wholemeal pasta in pasta dishes

- Using brown rice in rice dishes
- Switching to higher-fibre white bread if wholemeal bread is not liked.

For more information on foods high in fibre see page 40, and for information on menu planning see page 127.

Activity

The importance of being as active as possible is discussed on page 66. Even for those who are chairbound or bedbound, simple exercises may help to reduce constipation and everyone should be encouraged to be as active as they can be. Support staff should always be aware that a sudden loss of mobility due to an accident or worsening of a longstanding condition is likely to be associated with constipation and they should make sure that, if a person's level of activity changes, the person gets adequate fluid and fibre as a priority.

Medicines

If a diagnosis of constipation is confirmed and any underlying conditions have been investigated, constipation should be managed in the first instance by increasing mobility, and increasing fluid and fibre intakes. Where these simple measures are ineffective or impractical (for example, because people are immobile or take medicines which contribute to constipation), a short course of laxatives may relieve symptoms and restore normal bowel function. The most commonly used laxatives are:

- bulk-forming (for example, ispaghula husk or methylcellulose)
- softeners or lubricants (for example, docusate sodium)
- osmotic laxatives (for example, lactulose or macrogols)
- stimulant laxatives that directly stimulate colonic nerves to cause movement of the faecal mass (for example, senna or bisacodyl).

Laxatives should be chosen on a case by case basis according to symptoms and side effects, but a common combination is a stimulant (eg. senna) and a softener (eg. docusate or low dose lactulose). Using combinations allows low doses and volumes to be used (eg. senna syrup 10mls, and lactulose 10mls at bedtime), and also allows the stimulant and softening laxatives to be adjusted individually for the best response. Combinations avoid the need to use high doses of lactulose alone, which can cause bloating and fluid shifts into the gut.

There is insufficient evidence at present to recommend the more expensive macrogol laxatives over other well-established, less expensive combinations of stimulant and softening laxatives.⁶ Particular care should be taken over the use of macrogol laxatives which must be mixed with exactly the recommended volume of water to be effective,

eg. 125ml per sachet of full strength macrogol.

Children and young people who are constipated should seek advice from a dietitian or medical practitioner on the amount of fluid and fibre appropriate to their needs.

Diarrhoea

Diarrhoea can be caused by a bacterial infection, can be a side effect of medication, can be caused by poor bowel control or food intolerance, can be spurious (overflow as a result of constipation), or can be stress-related. Food poisoning is the most common cause of diarrhoea, and anyone with diarrhoea lasting more than 48 hours should have a stool specimen sent to bacteriology for testing. Diarrhoea can also be a symptom of bowel disorders such as ulcerative colitis, Crohn's disease or coeliac disease and lactose intolerance. Lactose intolerance means having an inherited reduction in the amount of the enzyme lactase available to digest the lactose in milk and dairy products. It is more common in people from Asia, Africa, South America and Mediterranean countries. Diarrhoea has also been reported as a common side effect of antibiotics when used in conjunction with tube feeding.

What can help?

Finding out the underlying cause of diarrhoea will help with its management. If difficulties are associated with tube feeding, seek advice from a registered dietitian. (For more on managing problems with tube feeding, see page 62.) If problems are caused by infection, ensure that everyone is aware of the importance of food hygiene and hand washing (see *Food hygiene and safety* on page 92).

If someone is lactose intolerant, they may be able to tolerate a small amount of milk products in the diet but, if milk and milk products are excluded or reduced, care must be taken to ensure that the diet still contains enough calcium. (For good sources of calcium, see page 44.)

If someone appears to have a food intolerance or condition which requires a special diet, this should be undertaken with advice from a registered dietitian.

People who have diarrhoea should be encouraged to have a diet which has sufficient fibre. For some people, simply restricting the amount of sweetened drinks (including apple juice) consumed each day may help reduce the severity of diarrhoea. People who have diarrhoea will need extra fluids and, if the diarrhoea is severe and prolonged or if it occurs in a child, it is essential that medical advice is sought so that the person does not become dehydrated. It is important also to ensure that the person with diarrhoea does not actually have constipation, as this can be very serious if faeces become impacted. (For more on constipation, see page 72.)

Coeliac disease

People with Down's syndrome or Turner syndrome are more likely than the rest of the population to have coeliac disease.⁷ Coeliac disease means that gluten (a protein found in wheat, rye, barley and oats) cannot be tolerated, and this may cause diarrhoea and malabsorption of nutrients, which can lead to osteoporosis and iron deficiency. It is also possible to have coeliac disease which has more vague symptoms such as tiredness, mouth ulcers, constipation or abdominal pain, and it is important that those at high risk are considered for regular screening.⁷

Once diagnosed, people require a gluten-free diet for life, and advice on how to manage this should be given by a registered dietitian.

Swallowing difficulties

What do we know about swallowing difficulties among people with learning disabilities?

There is a high incidence of dysphagia (eating, drinking and swallowing difficulties) among people with learning disabilities.⁸ Health risks associated with dysphagia include poor nutritional status, dehydration, asphyxiation and aspiration (breathing in of food particles to the lungs) which can lead to respiratory tract infections – the leading cause of death among people with learning disabilities.⁹ Dysphagia not only results in a reduced ability to swallow food and drink safely, but also leads to inadequate food intake, and this may result in either general undernutrition or not getting enough of some specific nutrients. Problems resulting from eating and drinking difficulties are not always obvious and the gradual changes that accompany eating difficulties may go undetected or be accepted as part of the person's normal condition.¹⁰

Swallowing difficulties – what can help?

Intervention to manage dysphagia is a multi-disciplinary approach usually coordinated by specially trained speech and language therapists who both assess swallowing difficulties and train support staff and family carers in management techniques. Family carers can be very expert in positioning to aid swallowing and avoid choking and it is important that support staff work in partnership with family and friends where appropriate so that their valuable experience is not lost. The need for training of **all** support staff who support people with learning disabilities in recognising, understanding and managing dysphagia is

Signs and symptoms of a swallowing problem in people with learning disabilities

- Coughing and/or choking before, during or after swallowing
- Recurrent chest infections
- Difficulty in controlling food and drink in the mouth
- Change in breathing patterns
- Unexplained weight loss or chronic low body weight
- 'Wet voice' – sounding gurgly when someone speaks
- Hoarse voice
- Drooling
- The person reports difficulty and/or painful chewing and/or swallowing or feelings of obstruction in the throat.
- Heartburn
- Frequent throat-clearing
- Change in eating pattern – for example, eating more slowly or avoiding foods or meals
- Constipation
- Repeated urinary tract infections

Adapted from: *Nutrition Support for Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition* (see www.rsceng.ac.uk).¹¹

however considered critical.⁸ An inter-professional dysphagia framework is now available which consists of competencies which can be developed by a range of practitioners to enhance their skills in this field.¹²

Management of swallowing difficulties can involve:

- modifying the texture of food and drink (for example, offering a soft textured diet or a puréed diet – see page 133)
- altering the position of the person while he or she is eating (see page 107)
- use of specialised equipment and eating aids (see page 106)
- training for people with learning disabilities themselves on how to manage their dietary requirements and eat and drink safely, and
- training for support staff about how to support people

to eat and drink safely.

There is evidence that there needs to be on-going support for people with learning disabilities themselves to help them understand the reasoning behind the management strategies suggested.¹³ There can be conflicts between foods that people with dysphagia want to have and safety issues. Support staff need to be trained to handle these conflicts sensitively and to ensure that as far as possible altered textured food looks and tastes appealing.

The following factors can all contribute to difficulties in supporting people with dysphagia to eat and drink:¹⁴

- Lack of sufficient staff or of well trained staff, high staff turnover and lack of consistent care.
- Insufficient time allowed for people who are being helped to eat to process and swallow their food in comfort.
- One-to-one help with eating and drinking may mean that meals and drinks have to be given in shifts and at odd times of day.
- Maintaining a good posture may be difficult.
- Getting consistent food textures can be difficult.
- Mealtimes can be very long, and it can be difficult to pace meals and drinks throughout the day.
- Food can get cold if mealtimes are lengthy.
- Constantly monitoring food and drink intake may prove problematic.
- Encouraging people to eat and drink slowly can be difficult and can lead to conflict if the person resents interference in how they manage their eating occasions.

Those who are at high risk of dysphagia should be assessed for vulnerability and their care plans updated accordingly. The involvement of a speech and language therapist with specialist knowledge of swallowing disorders is critical in creating a management strategy and in training the person himself or herself, as well as his or her family, friends or support staff.

A person with dysphagia will often be unable to swallow tablets or other medication or supplements and it is important that medication reviews take swallowing difficulties into consideration.

For more information on texture modification of food and drink, see page 133. Strategies to help deal with difficulties around eating and drinking can be found on page 108. The importance of staff training is considered on page 100.

For information on mouth sensitivity (where the person has an exaggerated response to touch in the mouth or around the face), see page 109.

What to do if someone chokes

If someone does choke:

- First check whether the casualty has a mild or severe case. Ask 'Are you choking?' If the person can reply, cough or breathe (or in a baby's case cry) then the advice is to encourage the person to cough.
- If a person can't speak, cough, cry or breathe, treat the incident as severe choking and follow the procedures from current first aid training, which is likely to include giving blows between the shoulder blades in the first instance.

Other useful advice includes:

- Try to remove any loose bolus of food from the mouth. Call other staff for help. (If the person resists, he or she may injure you, rendering you unable to help. Also, other people may try to stop you if they misunderstand your intentions.)
- If the person is wearing dentures, remove them. (The person may not understand that you are helping and in fear may bite you.)
- Stay calm. Talk to the person and reassure him or her. Encourage big, deep coughs rather than shallow irregular ones if possible.

When the choking episode is over, try to reassure in a calm voice. The experience of choking is a very frightening one. Try to work out what caused the choking so that a similar incident can be prevented in the future.

Oral health

What do we know about oral health among people with learning disabilities?

Poor oral health can adversely affect the intake of a balanced diet – especially of foods that require chewing (such as fruit and vegetables) – and can result in the consumption of soft foods that are easily swallowed. Good dental health is also linked to happiness and good general health and poor teeth can impact on self-esteem, confidence and socialisation.¹⁵

- Diets which are high in sugar lead to the development of dental caries (dental decay).

- Poor dental hygiene and the build-up of plaque causes periodontal disease (gum disease).
- Direct acid attack of the teeth (particularly from acidic drinks such as fruit-based drinks) causes tooth erosion.

People with learning disabilities have a higher level of untreated dental decay, more prevalent gum disease, more tooth extractions and poorer dental hygiene than the general population.^{16,17} All research studies report uniformly poor standards of oral hygiene and plaque control and poorer periodontal health in children with learning disabilities.¹⁸ Little is known about the oral health of adults with mild learning disabilities since many are not in contact with dental services, but studies in day centres and residential settings report higher levels of untreated disease than in the general population.¹⁹ Infections of the mouth lining occur easily and can cause considerable distress and difficulties with eating and drinking (eg. thrush in the mouth, cold sores and mouth ulcers).

Suggestions for the reasons behind the high levels of poor oral health include difficulties accessing dental services due to people's challenging behaviour, or lack of NHS treatment.¹⁷ Studies have also demonstrated a lack of knowledge, support and training about oral health available to family, friends and support staff of people with learning disabilities.²⁰ Oral health care is often given a low priority by support staff²¹ and there is a shortage of training particularly in community-based and residential accommodation.²² Family and friends may be able to provide useful information on how to handle oral care.

Historically, it has been reported that people with Down's syndrome have a lower prevalence of caries due to late tooth eruption and abnormal tooth formation. However, more recent studies have shown that while caries incidence is lower among people with Down's syndrome, it is not as low as it used to be since a higher percentage of people with Down's syndrome are now living in the community setting rather than in institutions and have more access to foods and drinks that can cause caries (dental decay).²³

People with Down's syndrome are more likely to suffer from bruxism (grinding teeth) and gum disease. The tongue can be large relative to the size of the oral cavity and this can be a cause of badly aligned teeth.²⁴ Gum disease can be severe in children with Down's syndrome, even when oral hygiene is of a good standard. Hennequin et al²⁵ have reported that, in France, people with Down's syndrome had more oral health problems compared with their siblings and that, with age, the prevalence of chewing difficulties did not improve; the prevalence of bleeding gums and breathing through the mouth increased; but tongue protrusion decreased. In Sweden, a longitudinal study of oral health of adults with learning disabilities found that

those with Down's syndrome had higher average annual loss of tooth-supporting bone compared with those people with other diagnoses.²⁶

Poor oral hygiene and gum disease can put people at risk of transfer of bacteria into the bloodstream during some surgical or dental procedures. If the bacteria lodge in damaged or abnormal heart valves, life-threatening infection of the heart can result. Good oral health, of both teeth and gums, is therefore essential. In children with a learning disability, who may be slow to clear food or who may 'pouch' food in their mouth, as has been reported for some children with autistic spectrum disorder (ASD),²⁷ there is a need for good oral hygiene both at home and at school.²⁸

People with learning disabilities have fewer dentures provided for them than people in the general UK population, and those who do have them have increased problems with them related to poor dental hygiene.²⁹

Frequent food and drink consumption allows little time for remineralisation of the teeth between snacks or meals and therefore those who may need to eat or drink 'little and often' should pay particular attention to their oral health.²⁸ People who require higher-energy food supplements between meals and those who take sugar-based medication will also have an increased risk of dental decay. People who take medication which causes dry mouth are also at greater risk of tooth decay. There may be some conflict between health professionals, family, friends and support staff when conflicting messages around oral health are given, for example, when high-sugar snacks are recommended between meals to increase energy intake. It is important that health professionals consider the consequences of their recommendations on other health messages and seek advice on how to manage this most effectively.

Tooth erosion is a progressive, irreversible loss of dental enamel usually caused by acids other than those produced by plaque bacteria. Erosion can lead to a reduction in the size of teeth and to tooth destruction. One of the main causes of tooth erosion is the frequent consumption of fruit juices, fruit drinks and fizzy drinks. Even those marked as 'low-sugar', 'no added sugar' or 'diet' can cause tooth erosion. Gastro-oesophageal reflux, vomiting and rumination can also contribute to tooth erosion.

A person with learning disabilities suffering dental pain may be unable to express discomfort and may exhibit a change in behaviour such as loss of appetite, unwillingness to participate in activities, sleeplessness, irritability or self-harm. It is important for family carers, friends and support staff to be alert to such changes and to find out if mouth or tooth pain is a possible cause of behaviour change.

Oral health – what can help?

If dental services are to respond to the needs of all members of a community it is important that community dentistry teams are trained and confident in treating people with learning disabilities. Extensive recommendations and guidance on how to ensure that people with learning disabilities receive appropriate oral health care have been written by the Faculty of Dental Surgery and the British Society for Disability and Oral Health (see page 154).

The recommendations made in this report relate specifically to simple oral hygiene and the role of food and drink in oral health, but the Expert Working Group strongly recommends that staff in all community dental services have disability awareness and communication skills training. It also recommends that training in the provision of dental care to people with learning disabilities should be included in the undergraduate curriculum for dentists. All those who support and care for people with learning disabilities should be offered training on the importance of oral health and how to help people to clean their teeth.

Tips on oral health

- All children, young people and adults with learning disabilities should visit the dentist twice a year.
- Good daily oral hygiene is essential, including brushing the teeth twice a day with fluoride toothpaste. (See *Toothpastes* below.)
- If brushing is not completely effective, dentists may recommend that a mouthwash or chlorhexidine gel is used after brushing.
- Parents, guardians or support staff should help with brushing of teeth for children under the age of 8 years, and anyone who may have difficulty in brushing their teeth independently.
- If helping someone to brush their teeth, use the procedure suggested in the box on the next page.

Toothpastes

The best toothpastes to use are those which contain fluoride, as these are effective in preventing dental decay. In guidance soon to be published by the Department of Health, it is recommended that all children and adults with disabilities should brush their teeth twice a day with a pea-sized amount of toothpaste (1350-1500ppm fluoride). All children and adults should be encouraged to spit out excess toothpaste when they have finished brushing, but not rinse their mouths with water.

Food and drink

Limiting the intake and frequency of consumption of sugary foods and drinks is the most important way of preventing tooth decay:

- The only drinks that should be given in a bottle are milk and water.
- Sugar should never be added to milk for infants or children.
- It is particularly important to ensure that drinks other than milk or water are not given at bedtime. This is because the mouth produces less saliva during sleep, which means that teeth are at greater risk of damage.
- As far as is possible, keep food and drink that have sugar in them to mealtimes only.
- Milk, water, and tea or coffee (without sugar) are the only drinks which will not damage teeth between meals. For information about good choices of snack foods between meals, see page 83.
- Medicines where possible should be sugar-free.

For details of resources about oral health for people with learning disabilities and general information on good dental health, see Appendix 4.

How to help someone to clean their teeth

- Always explain what you are going to do first. Brushing someone else's teeth is an invasive procedure and can be frightening.
- Make sure the person is relaxed, comfortable and well supported.
- Encourage the person you are assisting to do as much as they are capable of themselves. Prompt, encourage or assist as necessary.
- Support staff should wear latex-free gloves when helping with toothbrushing and stand behind the person, slightly to one side.
- Partial dentures should be removed before cleaning natural teeth.
- Gently draw back the lips with the thumb and forefinger on one side of the mouth to gain access to the upper teeth.
- Using a small, soft brush with the appropriate toothpaste, brush the teeth and gums using short, scrub motions and try to brush the outer, inner and biting surfaces of all teeth to ensure all plaque and food debris have been removed.
- Carefully brush all the teeth in the mouth, trying to reach all areas. If cooperation is limited, it may be necessary to brush different areas of the mouth at different times.
- If necessary, help the person to rinse their mouth afterwards. A straw can be useful to help the person rinse his or her mouth. If recommended by the dentist or dental hygienist, use mouthwash or chlorhexidine gel.
- If someone has no natural teeth, it is still important to clean the gums and the inside of the mouth daily with a soft toothbrush or gauze to maintain good oral health.
- Record the toothbrushing session on an appropriate oral healthcare plan.
- If any changes to the mouth are noticed, contact the person's dentist.

Adapted from the British Society for Disability and Oral Health and the Faculty of Dental Surgery, 2001 ³⁰

Artificial sweeteners

Some health professionals are in favour of products with artificial sweeteners which do not contribute to tooth decay, especially for those people with a tendency towards obesity. Others have concerns about the metabolism of sweeteners – particularly of aspartame – in children with syndromes which may compromise the phenylalanine-tyrosine-dopamine-serotonin metabolic pathway. Aspartame causes significant increases in plasma phenylalanine, and probably brain phenylalanine, and therefore has the potential to interfere with neurotransmitter production.²⁸ There is also some concern that, if people get used to sweet tastes through the use of artificially sweetened foods, this will not help them to make long-term, permanent, beneficial changes to their diet to reduce high intakes of sugar. Moderation in the use of artificial sweeteners and in the amount of artificially sweetened foods and drinks included in the diet would therefore seem prudent.

KEY MESSAGES

Constipation

- All those who support people with learning disabilities should be alert to signs which may indicate constipation, such as a reluctance to go to the toilet, obvious discomfort, long periods spent in the toilet, a change in eating habits, unexplained diarrhoea, food refusal, or unexplained challenging behaviour.
- To avoid constipation it is important that adults are as mobile as possible, have sufficient fluid and have sufficient fibre in their diet. Children and young people who are constipated should seek advice from a dietitian or medical practitioner on the amount of fluid and fibre appropriate to their needs.

Dysphagia (swallowing difficulties)

- Dysphagia should always be considered when there are unexplained eating or breathing difficulties, changes in eating patterns, distress associated with eating, or recurrent chest infections.
- Those who are at high risk of dysphagia should be assessed for vulnerability and their care plans updated accordingly. The involvement of a speech and language therapist with specialist knowledge of swallowing disorders is critical in creating a management strategy and in training the person himself or herself, as well as his or her family, friends or support staff.
- Medication reviews of a person with dysphagia should take into account swallowing difficulties, as the person may be unable to swallow tablets or other medication or supplements.

Oral health

- All children, young people and adults with learning disabilities should visit the dentist twice a year.
- Cutting down on the amount of sugar eaten, and on how frequently sugary foods and drinks are consumed throughout the day, will help to prevent dental decay.
- Good daily oral hygiene is essential, including brushing the teeth twice a day with fluoride toothpaste. Children under the age of 8 years and anyone who may have difficulty in brushing their teeth independently should be helped when brushing their teeth.
- Support staff should be offered training on the importance of oral health and how to help someone clean their teeth.
- All those who support people with learning disabilities should be alert to changes in behaviour such as loss of appetite, unwillingness to participate in activities, sleeplessness, irritability or self-harm, and should find out if mouth or tooth pain is a possible cause of the behaviour change.

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Chapter 7

How to eat well throughout the day

This chapter looks at some of the practical issues to consider when helping people to eat well, and their importance when planning menus and food service for people with learning disabilities.

Food for all

Eating together, having special foods or avoiding particular foods are all intimately related to aspects of people's family life, cultural and religious beliefs. It is important to value the contributions which different cultures and nationalities make to the variety of foods eaten in the UK today. While many people who have settled in the UK still try and preserve many of their traditional food patterns, within each family, and for each individual, food choice will be unique and it is essential to treat everyone as an individual when finding out about their food choices and preferences.

Food-related customs

Over the page is a brief summary of some of the differences in food choice commonly observed by those from different religious and cultural groups.

	Jewish	Hindu*	Sikh*	Muslim	Buddhist	Rastafarian**
Eggs	No blood spots	Some	Yes	Yes	It varies	It varies
Milk/yoghurt	Not with meat	Yes	Yes	Yes	Yes	It varies
Cheese	Not with meat	It varies	It varies	Possibly	Yes	It varies
Chicken	Kosher	It varies	It varies	Halal	No	It varies
Mutton/lamb	Kosher	It varies	Yes	Halal	No	It varies
Beef and beef products	Kosher	No	No	Halal	No	It varies
Pork and pork products	No	Rarely	Rarely	No	No	No
Fish	With fins and scales	With fins and scales	It varies	It varies	Some	Yes
Shellfish	No	It varies	It varies	It varies	No	No
Butter/ghee	Kosher	It varies	It varies	It varies	No	It varies
Lard	No	No	No	No	No	No
Cereal foods	Yes	Yes	Yes	Yes	Yes	Yes
Nuts/pulses	Yes	Yes	Yes	Yes	Yes	Yes
Fruits/vegetables	Yes	Yes***	Yes	Yes	Yes	Yes
Fasting****	Yes	Yes	Yes	Yes	Yes	Yes

* Strict Hindus and Sikhs will not eat eggs, meat, fish, and some fats.

** Some Rastafarians are vegan.

*** Jains have restrictions on some vegetable foods. Check with the individuals.

**** Fasting is unlikely to apply to young children.

The eating environment

Creating a calm eating environment where individual needs at mealtimes can be met can make an important contribution to encouraging people to eat well. Inadequate or inappropriate nutrition in those with learning disabilities can be partly due to environmental factors which are commonly reported in residential care. Mealtimes are often hurried and staff are frequently untrained in nutrition and constrained by finances and cooking abilities. This can result in residents not getting a nutritionally balanced diet.^{1,2,3} It is important to ensure that people arrive at mealtimes ready for the eating occasion, for example having had the opportunity to go to the toilet and wash their hands, or collect their hearing aid, glasses or dentures, and having been informed of the eating occasion ahead. Ensuring everyone has the correct cutlery and crockery for their needs and the appropriate seating is also important.

In residential and day care settings, support staff should also consider how the choice of tables and layout of the

room impact on people's mealtime experience. Wherever possible:

- People should choose where they sit and whom they sit with.
- People should have the opportunity to serve themselves the amount of food that they would like, from serving dishes brought to the table.
- Tablecloths, colourful table mats, matching crockery and table napkins can all help to make mealtimes more enjoyable and give them a sense of importance and occasion.
- Mealtimes should be protected and other routine tasks and visits should be avoided during planned meals.

For people with learning disabilities who may have sensory disabilities, using cues to stimulate appetite may be particularly important. The smell of food being prepared, the sound of food preparation and service, and the sight of laid tables may help to orientate people to the mealtime ahead.

Food should be appetising and attractively served, to ensure that people enjoy their food. This is particularly important if the food has its form or texture changed for people with swallowing difficulties.

To make mealtimes a time of pleasant social sharing, and as good practice, staff should sit with the people they support during meals and snacks, and where appropriate share the same foods and drinks.

Mealtimes offer an opportunity for support staff to model eating skills and to encourage social interaction and conversation. To encourage this, distractions such as television are best avoided during mealtimes.

Eating patterns, and timing of meals and snacks

When people with learning disabilities are living in their own home, they are likely to be able to choose when to eat and drink and will find patterns of eating and drinking which suit their lifestyle and routines. In residential accommodation, the national minimum standards for care homes for adults give clear guidance that mealtimes should be flexible and that a range of food and drink should be available at all times. (See Appendix 1.)

Additional guidance for care settings has also been produced by the British Dietetic Association⁴ and by the National Association of Care Catering.⁵ The timing of meals and snacks throughout the day should be organised to fit around the needs of the individual being supported. Some people may need frequent small meals and snacks throughout the day.

It is important to ensure that everyone has enough time to eat and drink and that, where necessary, food is kept warm safely during the meal for those who eat and drink slowly.

Breakfast

Breakfast is an important meal for two main reasons. Firstly, many breakfast foods are a very good source of fibre and other important nutrients. Secondly, if breakfast is missed, it is more likely that people will be tempted by other snack foods later in the day.

Breakfast cereals can be a useful source of nutrients. The best breakfast cereals to choose are those that are high in fibre and low in salt, sugar and fat and those that are fortified with extra vitamins and minerals: for example, puffed wheat, wheat flakes, weet bisks, shredded wheat

and some crisped rice cereals and mueslis. Look at the labels to choose those that are lower in salt and sugar. (See page 120 for details of how to check if foods are high in fat, salt and sugar.) Most breakfast cereals can be eaten as a finger food, or they can be eaten with milk, yoghurt, fresh or dried fruit or fruit juice. Fresh fruit juice at breakfast is recommended, as vitamin C may help iron absorption (see page 44), but other fresh or dried fruits or vegetables can also be served (eg. tinned tomatoes or baked beans). For those people who have a good appetite in the morning that recedes as the day continues, breakfast should be seen as an opportunity to consume a significant amount of energy and other nutrients, and a range of foods should be offered, rather than just traditional breakfast foods.

Snacks

It is important that nutritious snacks are offered regularly to people who have small appetites and who therefore need to eat frequently or 'little and often', to those who may need to eat a greater amount of calories per day, or to those who are fussy or selective eaters or who are growing rapidly. Snacks should be viewed as mini-meals and should be as varied and nutritious as meals.

For those people with learning disabilities who are gaining weight or who have been advised to lose weight, snacks that are high in fat and sugar (such as confectionery, savoury snacks, soft drinks, cakes, biscuits and ice cream) should be kept to a minimum as these frequently contribute significant extra calories to the diet.

For many people, snack foods are limited to biscuits and crisps but snacks can and should be varied and planned for. The best snacks are those which provide useful nutrients without adding lots of salt, fat and sugar to the diet. Ideas for good snack choices are given over the page.

Good snack choices

The best snacks are low in sugar and salt. Avoid adding sugar to drinks or yoghurts.

Examples of good snack choices are:

- Dairy foods such as cheese or yoghurt.
- Fresh fruit such as pears, apple slices, satsumas, banana, seedless grapes, slices of melon, mango, pineapple, kiwi, plums, or berries such as strawberries and raspberries. Choose fruits in season and those that are grown locally where possible. The fruit from canned fruit in juice can be added to yoghurt or fromage frais.
- Raw vegetables such as peeled carrots, sweet pepper, tomato, cucumber or celery (all well washed) with dips such as houmous, taramasalata, avocado, salsa or Greek yoghurt with chives.
- Unsalted nuts and seeds may be suitable for some people, but should not be given to anyone who has eating difficulties.
- Home-made plain popcorn, home-made oven-baked potato crisps or sweet potato crisps. (To make potato crisps, put thin slices of potato on a lightly greased baking tray and bake in a hot oven.)
- Biscuits such as crispbreads, oatcakes, breadsticks, cream crackers, matzos, rice waffles or melba toast. Some of these foods can be high in salt, so choose those that are lower in salt where possible (see page 87).
- Any type of bread (use a variety of white, brown, wholemeal, granary or crusty breads, including toast); plain scones, crumpets, English muffins, bagels, pitta bread or sandwiches. Look for lower-salt (low-sodium) versions where available.
- Suitable fillings for sandwiches and toast might be meat (for example, cold roast meats, chicken, ham, corned beef or meat paste), cheese, cottage cheese, fish paste, mashed pilchards, sardines, mackerel, tuna, egg, houmous, roast vegetables, banana, salad or combinations of these.
- Milky drinks and smoothies can be made from a combination of milk, fruit and yoghurt.

Drinks

Drinks are essential in the diet to ensure adequate fluid intakes. They can also provide an opportunity to supplement the diet with additional nutrients. However, drinking too many sweetened or other soft drinks, particularly between meals, can be damaging to the teeth (see page 76). Drinks which contain sugar can also add calories – but few other nutrients – to the diet.

Providing drinks

It is important that everyone has access to adequate fluid intakes throughout the day. To ensure people are adequately hydrated it is currently recommended that adults should have at least 1.2 litres of fluid a day⁶ (about 6 glasses) but older people or people who are prone to constipation should be encouraged to have at least 1.5 litres a day (about 7 to 8 glasses).⁷ If someone breathes through their mouth, sweats a lot or has a high temperature, they will have increased requirements for fluid and should seek advice on the amount appropriate to their needs. (For information on excessive fluid intake, see page 29.) We get some fluid from the food we eat but it is important that drinks of fluid are provided regularly since dehydration can lead to headaches, confusion, irritability and lack of concentration as well as constipation and potentially urinary tract infections. Free, fresh, chilled tap water should always be offered with meals and regularly throughout the day.

Milk

Milk should be the drink of choice for children and young people where this is tolerated, since milk is safe for teeth and contains other essential nutrients. It is important that appropriate milks are chosen for infants and children and advice on this should be sought from a health visitor.

For most people over the age of 5 years, semi-skimmed milk should be the milk of choice as this has reduced amounts of fat and saturated fat. For those people who need to gain weight, whole milk may be appropriate.

Milky drinks before bed can enhance sleep as well as offering additional calories to those who are underweight.

Water

Water quenches thirst and should be the drink of choice between meals when people are thirsty. Free, fresh, chilled tap water should always be offered with meals and regularly throughout the day and should be widely available in any places where people with learning disabilities may live, work or visit. It has been reported that some people do not like giving water to children as they think children

will reject it, that it is 'cruel', and that offering water is a sign of poverty.⁸ It is important therefore that family, friends and support staff are positive about water drinking, make sure that palatable water is always available, and act as good role models for water drinking. Providing interesting and colourful cups and bottles for water drinking may encourage some people with learning disabilities to drink more. Anecdotal evidence suggests that organising water drinks in personalised bottles in the refrigerator each day and encouraging these drinks to be consumed before other drinks are chosen can be motivating for some people with mild and moderate learning disabilities. Other practical tips to encourage water consumption can be found at www.water.org.uk.

Soft drinks

There is a wide range of soft drinks available, most of which are sweetened with sugars, sweeteners (for example saccharin or aspartame) and commonly a mixture of both. They include:

- squashes and other drinks which need to be diluted
- carbonated soft drinks such as cola or lemonade, and
- fruit drinks which are drinks that contain a proportion of fruit juice as well as water and some form of sugar and/or sweetener.

The amount of soft drinks given to children should be limited since these offer little nutritional benefit and may suppress appetite and prevent the child eating more nutritious foods. Children can become conditioned at an early age to the sweet taste of drinks. High intakes of soft drinks have been reported to lead to frequent looser stools, poor appetites and failure to thrive.⁹ Soft drinks containing sweeteners are generally not recommended for children. If soft drinks (such as squashes) containing saccharin are given to under-5s, they should be diluted much more than they would be for an adult – for example, a dilution of 1 part squash to 10 parts water.

Sugary drinks provide additional calories to the diet and this can be significant over time, since high volumes of soft drinks can often be consumed without impacting on appetite. Evidence suggests that consuming a sweetened soft drink every day is linked to increased weight gain and development of type 2 diabetes.¹⁰ One research study estimated that among children the chance of developing obesity increased 1.6 times for each additional sweetened drink consumed a day.¹¹ Swapping some or all sugary drinks for drinks of water may be particularly helpful if people are trying to maintain their weight or lose weight.

Soft drinks containing sugar can be harmful to everyone's teeth, especially if they are drunk frequently or stay in contact with the teeth for too long. If sugary drinks are

given, they should be kept to mealtimes. Soft drinks such as fruit drinks and fruit squashes should not be given at bedtime or during the night as this practice is highly likely to contribute to dental decay.

Soft drinks labelled 'low-sugar' or 'no added sugar' may still harm teeth as they often contain some sugar and they may also be acidic. Any of the following on the label of a soft drink indicates that the drink has sugar added: glucose, glucose syrup, fructose, concentrated fruit juice, sucrose, dextrose, honey, invert sugar, maltose or hydrolysed starch.

Sweetened fizzy drinks such as cola or lemonade are both sugary and acidic. The 'diet' versions of these drinks can also be harmful to teeth even if they do not contain sugar, as the acidity erodes the dental enamel.

Pure unsweetened (100%) fruit juices

Fruit juices are most beneficial when given with meals because, if they are a good source of vitamin C – for example, orange juice or grapefruit juice – this may help the body absorb iron. However, fruit juices have also been shown to be acidic enough to erode dental enamel, so it is best to avoid giving them between meals.

Some fruit juice drinks are available which contain some fruit juice, with added sugar and water. These can often be high in calories and can be an expensive way to buy fruit juice. 150ml of 100% pure fruit juice counts as one of the 5 fruit and vegetable portions each day and makes a better choice.

Cranberry juice

Women with learning disabilities who are prone to urinary tract infections may benefit from drinking a cranberry juice drink regularly since there is some evidence that this can be a useful preventative measure for some people.¹² However, people who take the drug warfarin should avoid drinking cranberry juice or having cranberry products as it may increase the potency of the drug and cause haemorrhage.¹³

Tea and coffee

Tea and coffee are not recommended as a drink for infants or children as the tannic acid they contain reduces the absorption of iron.¹⁴ However, young people and adults are likely to enjoy tea and coffee as these drinks are important in our culture at social occasions and offer comfort and warmth. There is some evidence that, as tea is an important source of compounds such as flavanols and polyphenols, drinking tea can protect against cardiovascular disease, some cancers and osteoporosis when consumed as part of a healthy diet.^{15, 16} While caffeine in tea and coffee has a mild dehydrating effect, this effect is negligible

among habitual consumers and is compensated for by the total amount of fluid in the drink.¹⁷ Sugar added to tea and coffee can damage teeth and contribute to obesity and everyone should be encouraged to reduce the amount of sugar they use in hot drinks over time. If appropriate, people could consider using sugar alternatives that are less damaging to teeth such as fructose or sorbitol, but care must be taken not to have these in large amounts as they can cause diarrhoea.

Caffeine

Caffeine is a commonly consumed drug which is not harmful to most people in moderate amounts. Caffeine is commonly found in tea, coffee, cola beverages and chocolate as well as in some pain relievers or 'energy' drinks. In excess, caffeine can cause anxiety, sleep disruption, restlessness, palpitations, dizziness, nausea, diarrhoea and involuntary trembling. Excess caffeine intake can complicate psychiatric diagnosis and can intensify the side effects of medication given for treating mental ill health or interfere with how effective some medicines are. Over 600mg of caffeine a day is considered an excessive amount and it is quite possible for people to reach these intakes if they drink a large amount of tea or coffee socially (for example, more than 6 mugs of coffee a day). Pregnant women are advised to have no more than 300mg of caffeine a day. Typical caffeine contents are shown below.

Cup or mug of instant coffee	75mg/100mg
Can of cola	38mg
Cup or mug of brewed coffee	100mg/140mg
Can of energy drink	80mg
Cup or mug of tea	50mg/70mg
50g bar of plain chocolate	50mg

Source: www.eatwell.gov.uk¹⁸

Herbal and fruit-flavoured teas

Some herbal and fruit-flavoured teas may contain vitamin C and can be useful hydrating drinks which might make a pleasant change to other hot drinks. Some herbal teas contain 'herbal medicine' which might make claims for health benefits (for example as a laxative, as an anti-diabetes agent or to aid weight loss). In most cases these teas are likely to be harmless but some people may drink these in preference to taking appropriate medication and support staff should be alert to this possibility. Some herbal supplements which may be found in drinks can interfere with the effectiveness of some medicines (see page 89).

Frozen drinks

People who can swallow safely may be able to manage frozen drinks. These provide variety of texture, can be fortified to increase their energy content and can increase fluid intakes.¹⁹ For people who find it difficult to handle cups due to tremor or weak muscle tone, frozen drinks as sorbets or ice pops served in inedible easy-to-hold cones may help to promote independence.

Fruit and vegetables

Eating more fruit and vegetables can significantly reduce the risk of many chronic diseases.²⁰ It has been estimated that eating at least 5 portions of a variety of fruit and vegetables a day (at least 400g a day) could reduce the risk of deaths from chronic diseases such as coronary heart disease, stroke, and certain forms of cancer by up to 20%.²¹ One study of adults with learning disabilities in supported accommodation found that about 80% of participants ate less than the recommended minimum of 5 portions a day.² It has been estimated that diet might contribute to the development of one-third of all cancers, and that higher vegetable consumption would reduce the risk of colorectal cancer and gastric cancer, and there is also some evidence that higher fruit and vegetable consumption may reduce the risk of breast cancer.²² Other health benefits of eating enough fruits and vegetables include delaying the development of cataracts, reducing the symptoms of asthma, improving bowel function, helping to manage diabetes, increasing fibre intake, reducing fat intake, and providing good sources of folate (for example, in green leafy vegetables and oranges).²³

The reason why fruit and vegetables are so beneficial is because of the array of compounds they contain. As well as vitamins and minerals, fruit and vegetables also contain many complex plant components (called phytochemicals), including flavonoids, glucosinilates and phyto-oestrogens. Some of the vitamins and phytochemicals are also antioxidants, destroying free radicals in the body. These free radicals are known to have a role in causing cancer as well as other harmful effects.

It appears that the benefits of fruit and vegetables stem not only from the individual components, but also from the interactions between these components. Dietary supplements containing isolated vitamins or minerals do not appear to have the same beneficial effects as fruit and vegetables themselves. Indeed, in some research studies, supplements were found to cause more harm than good.²⁴

What counts towards 5 a day?

Any fruit or vegetables: fresh, frozen or canned.

150ml of 100% fruit juice. This counts only as 1 portion a day, however much is consumed.

Dried fruit. 1 portion of dried fruit is about a tablespoon of raisins or currants, 3 dried apricots, 2 dried figs or 3 dried prunes. Dried fruit counts only as 1 portion a day.

Examples of how to eat 5 a day

A portion of fruit or vegetables should be 80g or more and a glass of fruit juice about 150ml.

Glass of orange juice
Apple as a snack
Baked beans at lunch
Sweetcorn
Raisins and yoghurt

Glass of pineapple juice
Orange
Vegetable curry (counts as 2 portions)
Tomato salad

Large bowl of fruit salad (counts as 2 portions)
Home-made vegetable soup
Raw carrots as a snack
Bowl of green salad

Rice and peas (peas count as 1 portion)
Callaloo
Glass of orange juice
Tomato salad
Canned pineapple in juice

Vegetable stir-fry (counts as 2 portions)
Cucumber salad
Baked apple
Fruit smoothie

Glass of apple juice
Coleslaw
Dried apricot snack
Frozen mixed vegetables
Pear

Salt

Salt (sodium chloride) is the main source of dietary sodium. Sodium is essential for fluid balance, but too much sodium is associated with raised blood pressure in later life, and this is a risk factor for coronary heart disease and stroke. It is currently recommended that adults have no more than 6g of salt a day and children proportionally less depending on their age.²⁵ Advice on salt and health can be found on the Food Standards Agency website at www.salt.gov.uk.

How to reduce salt in the diet

Three-quarters of the salt we eat is in processed foods such as soups, sauces, ready meals, meat products such as pies and pasties, bacon and ham, take-away foods, savoury snacks, and foods like bread and breakfast cereals. There is no need to stop eating foods which are higher in salt, but it may be necessary to eat them less often and in smaller amounts.

Think about the amount of salt you use when cooking and at the table. Try not to add salt automatically – people should always taste food first.

There are lots of ways to add flavour to food without using salt – for example:

- Add fresh herbs to dishes.
- Use tomato purée to add flavour.
- Marinade meat and fish in advance to give them more flavour.
- Use garlic, ginger, chilli, lemon or lime to add flavour to meat and fish dishes.
- Use spices such as cumin, coriander and turmeric.
- Use black pepper as seasoning instead of salt.
- Roast vegetables such as red peppers, courgettes, fennel, parsnips and squash to bring out their flavour.
- Add fruit to meat dishes to give a naturally sweet flavour (eg. pork and apricots).
- Make your own sauces and gravies and avoid using stock cubes and instant gravy mixes.
- Use a smaller amount of strong cheese in dishes, rather than a larger amount of mild cheese.

There is a lot of practical information on reducing salt in the diet on www.salt.gov.uk

Checking labels

Look at the figure for salt (or sodium) per 100g.

High is more than 1.5g of salt per 100g (or 0.6g of sodium).

Low is 0.3g of salt or less per 100g (or 0.1g of sodium).

If the amount of salt per 100g is in between these figures, the food has a medium level of salt.

Sugar

Diets which are high in sugar contribute to obesity as well as tooth decay, and very sugary foods may contain few nutrients. Most adults and children in the UK eat too much sugar, and people who drink soft drinks regularly or have a 'sweet tooth' are likely to be exceeding the current recommendations for the amount of sugars in the diet (see page 39).

To cut down on sugar:

- Have fewer sugary drinks and snacks. See page 84 for other ideas for nutritious snacks.
- Drink water between meals or unsweetened fruit juice with meals. Fruit juice can be diluted with sparkling water.
- Replace cakes or biscuits with currant buns, plain scones, or malt loaf with low-fat spread, or have fresh fruit instead.
- If people take sugar in hot drinks, or add sugar to breakfast cereal, gradually encourage them to reduce the amount until they can cut it out altogether.
- Choose tins of fruit in juice rather than syrup.
- Choose wholegrain breakfast cereals rather than those coated with sugar or honey.

Checking food labels

When you are checking food labels, you can use the information below as a guide to work out if a food is high or low in sugar, per 100g.

Look for the 'Carbohydrates (of which sugars)' figure in the nutrition information panel on the label.

High is more than 15g of sugars per 100g.

Low is 5g of sugars or less per 100g.

If the amount of sugars per 100g is in between these figures, the food contains a medium level of sugars.

Meat and fish

Meat and meat products are a good source of protein and some vitamins and minerals, particularly iron and zinc. The iron in meat is more easily absorbed by the body than iron from vegetable sources. However, there has been some concern over a possible link between large intakes of meat and some types of cancer and there is evidence that diets with less red meat and less processed meat (for example, the meat in pies, burgers, sausages and cold meats) and more vegetables reduce the risk of colorectal cancer.²² Red

meat should be eaten in moderation, and processed meats should be kept to a minimum.

There is a lot of evidence that including oil-rich fish in the diet can be beneficial in reducing the risk of heart disease.²⁶ However, there is as yet no conclusive evidence that oil-rich fish can improve behaviour and learning. People who eat fish should have 1 portion of oily fish each week – for example, salmon, trout, mackerel, herring or sardines – as these contain protective omega-3 fats. Canned salmon, mackerel, sardines, herring or sild and other oil-rich fish are also good sources of omega-3 fats. Canned tuna fish does not contain enough fat to be included in this category. There is no equivalent food for vegetarians but a diet which is rich in wholegrain cereals, peas, beans and lentils, vegetables and fruit is also likely to be protective against heart disease.

Vegetarian diets

Vegetarian diets can vary in the foods restricted and, if a person says he or she is a vegetarian, it is important to find out what they do and do not eat. Most vegetarian diets exclude meat, some but not all exclude fish, and some may also exclude dairy products or eggs. Vegetarian diets have traditionally been eaten by many people throughout the world, particularly in Asia. Vegetarianism is common among Hindus and some Sikhs and also among Rastafarians and Seventh Day Adventists. Some people may also choose to be vegetarian because they believe the diet is healthier, because they are concerned about the environment, food safety or animal welfare, or because they dislike the taste of meat.

A vegetarian diet can provide all the nutrients needed for good health and it has been shown that vegetarians have diets which are lower in fat and saturated fat and higher in complex carbohydrates and fibre.²⁷ However, it is important not to assume that vegetarian diets are healthy, as some people may remove meat from their diet without consuming suitable alternatives and it is harder to consume sufficient iron and zinc if a good variety of foods is not eaten. Vegetarian diets usually have a high proportion of cereals and the higher levels of fibre and substances called phytates in cereal foods make it harder for the body to use the iron and zinc in foods.

The body absorbs iron more easily from animal sources – such as meat – than from non-animal sources such as cereals or vegetables (see page 44). This means that vegetarians have to take extra care to make sure that they get enough iron. There is some evidence that vegetarian

women in particular have low levels of iron.²⁸ For advice on iron in the diet see page 44.

Zinc intakes may also be lower among vegetarians. Eating a good variety of foods ensures that vegetarians have adequate zinc intakes. Sources of zinc include fortified breakfast cereals, tofu, nuts, peas, beans and lentils, sesame seeds and milk and cheese.

When cooking for vegetarians the following are important.

- Offer suitable meat substitutes at meals (see page 129 for example vegetarian eating plans).
- Respect the right of those who avoid meat and fish to have a diet free of these foods by ensuring that separate cooking pots, utensils and cooking oils are used for meat and non-meat dishes.
- Ensure that vegetarians are not given gravies made with meat juices, or soup made with meat stock.
- Avoid ingredients such as gelatine and animal fats in foods served to people who wish to avoid these foods. (Check the food labels.)

Advice on vegetarian diets can be obtained from the Vegetarian Society (see page 151).

Vegan diets

Vegans generally adopt a diet free of all animal products and will not eat milk, cheese, yoghurt or eggs as well as avoiding meat and fish. It is possible to eat well as a vegan, but care has to be taken and people should always seek advice on how to ensure that they get all the nutrients they need. Vegans need to ensure that they include sources of vitamin B12 and riboflavin (see page 43) in their diet.

Advice on vegan diets can be obtained from the Vegan Society (see page 151).

Vitamin, mineral and herbal supplements

Most people can obtain all the vitamins and minerals the body needs by eating a varied diet. Dietary supplements which contain vitamins and minerals may be useful in some cases where intake of nutrients are low (for example, if the amount of food eaten is very small for some reason) or where there may be increased needs (for example for vitamin D or iron). Advice should always be sought from a medical practitioner or pharmacist before supplements are taken, because high doses of certain vitamins and minerals, and also some herbal supplements, can cause adverse reactions and may interfere with the absorption of other

nutrients. There is no evidence that taking large doses of vitamin and mineral supplements are beneficial to health and there is some evidence that they may be harmful.²⁴

Herbal supplements are often assumed to be safe because they are 'natural' but this alone does not imply safety, and advice should always be sought before taking any type of supplement. A number of herbal supplements can interfere with the effectiveness of medicines. For example: St Johns Wort should not be taken by people on some anti-depressants, digoxin, warfarin or the contraceptive pill; ginseng and ginkgo can interfere with the action of warfarin; evening primrose oil should be avoided by people with epilepsy; and betel nut can worsen asthma and cause a return of movement disorders where drugs have been given to combat these.²⁹

School lunches

Most children with learning disabilities will attend school and some may receive school meals. Schools will be obliged to follow the standards for school meals specified by the appropriate Department for Education in the four countries of the UK. In England, advice on achieving school meal standards can be obtained from the School Food Trust (www.schoolfoodtrust.org.uk). It is hoped, however, that a pragmatic, holistic approach to improving the food available to children with learning disabilities in schools is developed in all four countries of the UK. It is particularly important that schools bring in the necessary changes slowly and with thought, so that pupils are not overwhelmed with new foods and choices. The aim of improving school food across the UK is to ensure that all children and young people are offered a range of healthy and tasty food at school, that they learn more about what eating well means in practice, and that those children who are entitled to free school meals in particular are enabled to meet a significant proportion of their nutritional needs through their school lunch. As schools for children with learning disabilities often cater for a range of complex needs and special diets, it is important that caterers and other staff in these schools are offered tailored training and support to meet the needs of the children and to enable them to work in partnership with families and other carers. For children with complex needs and those with autistic spectrum disorders, it may be very difficult for support staff to fully involve children in school meals, and staff will require specific training on how to handle eating difficulties and in how to support those who are entitled to free school meals effectively. For advice on how to manage faddy and selective eating, which may be more common

among those with autism, see page 108.

For more information on important things to think about when providing food in schools, see the Caroline Walker Trust report *Eating Well at School* (details on inside front cover).

Packed lunches

People may take a packed lunch when they go to school, visit a day care centre, college or other facility, or go on an outing. A survey of packed lunches made for school-aged children showed that almost half of lunchboxes surveyed (48%) contained no fruit or vegetables and that one-sixth of lunchboxes (16%) did not contain a starchy food such as sandwiches, pasta or rice. In addition, foods high in fat, salt and sugar – such as crisps, fat spreads, cheese products, chocolate bars, biscuits and crisps – were served in about 70% of lunchboxes.³⁰

It is important that a packed lunch provides the same variety of foods and nutrients as the meal it might be replacing. A packed lunch should contain:

- **A starchy food.** For example, any sort of bread, pitta bread, chapatti, crispbreads, rice cakes, or wraps. Choose lower-salt breads where available.
- **A meat, fish or alternative.** Alternatives include, for example, egg, cheese, peanut butter, or houmous.
- **One portion of vegetables.** For example, raw vegetables or salad.
- **One portion of fresh or dried fruit** or fresh fruit juice.
- **A drink.** Water, milk or fresh fruit juice are good choices.

The quantity of food provided in a packed lunch will depend on the needs of an individual, and all the other principles outlined in this report should be considered when planning an appropriate packed lunch. Additional snacks such as plain popcorn, breadsticks, unsalted nuts, pumpkin or sunflower seeds, rice crackers or pretzels could be added occasionally and a yoghurt or fromage frais provides a good source of calcium. For people who have higher energy needs, some more energy-dense foods may also be appropriate. See page 84 for more ideas for snack foods, and chapter 11 for general information on menus and menu planning,

Eating out and take-aways

Eating out is an important part of lifestyle for many people and offers the opportunity to socialise, meet friends and take a break from food preparation and clearing up. While there should be no barrier to where people eat out, anecdotal evidence suggests that many people with learning disabilities, and those who care for them, feel more comfortable eating out in more anonymous outlets, particularly fast food restaurants and cafés. Family, friends and support staff should think about varying the choice and variety of foods on offer to the people they support. Habitually eating fast food is likely to mean that intakes of fat, saturated fat, salt and sugar are higher than recommended and this is often the case if fast food meals are treated as snacks rather than as meals. The high energy densities of many fast foods challenge human appetite control systems and promote ‘passive over-consumption’ so that regular consumers are likely to accidentally consume too many calories and therefore gain weight.³¹

Take-aways

There is anecdotal evidence that take-away foods are very popular among some people with learning disabilities, particularly when people gain greater freedom to choose and shop for their own foods. Take-away foods are easy to obtain, the variety of foods on offer is large, they can be relatively cheap to buy and the foods are often very much enjoyed, particularly in social settings, so it is understandable that it is tempting for some people to use these outlets regularly. Many foods available in Chinese and Indian restaurants and take-aways are high in fat and salt. For suggestions for healthier take-away options, see *Tips on eating out and take-aways* on the next page.

For anyone who has eating difficulties, particular care should be taken when ordering take-away food, particularly rice-based dishes, which can cause choking. Individual advice needs to be sought regarding suitable take-away foods for anyone with swallowing difficulties.

Food allergy and food intolerance

Tips on eating out and take-aways

Indian meals

Good choices: Tandoori chicken or other meat or fish (which is cooked in an oven), chicken or other meat or fish tikka (meat on a skewer without sauce), dry curries, vegetable curries, dahl, channa dahl, plain boiled rice, chapatti or roti breads.

High-fat foods to avoid: Papadums and other fried foods such as samosas and onion bhajias, creamy or coconut-based sauces (such as korma sauces), fried rices (such as pilau rice), and breads which have fat added (such as naan bread).

Chinese meals

Good choices: Stir-fries, chicken, vegetable or prawn chop suey, steamed fish, vegetable dishes, boiled noodles and dishes with steamed tofu.

High-fat foods to avoid: Avoid batter (for example sweet and sour chicken, battered bananas or apple fritters), spring rolls and prawn crackers. Avoid fried rice dishes and fried noodles.

Pizza

Choose thin-crust pizzas, and pizzas without cheese in the crust.

Avoid having extra cheese, pepperoni or salami. Add more vegetable or fish toppings instead. Encourage eating a salad with the pizza.

Fish and chip shops

Fish is a good choice but batter is high in fat and eating less or no batter could be encouraged. Choose small portions of chips. Mushy peas or baked beans are a good accompaniment. Avoid pies or battered sausage-type products.

Burger bars

Go for standard rather than 'super-size' options. Choose a plain burger in a bun with a salad. Avoid extra cheese or mayonnaise, thick milk shakes, chicken nuggets or other battered dishes such as onion rings. Avoid French fries.

Food intolerance is defined as a reproducible and unpleasant reaction to a specific food ingredient. A food allergy is a form of food intolerance where there is evidence of an abnormal immunological reaction (a reaction of the immune system). Foods that can cause severe reactions include peanuts, nuts, shellfish, sesame seeds, cow's milk, eggs, citrus fruits, soya beans, wheat and other cereals.

A minority of people experience adverse effects from some foods or food ingredients. Between 4% and 10% of children are estimated to have intolerance to one or more foods, but this is most predominant in the first three years of life.³² Among adults it is estimated that about 1%-2% of people have true food intolerance.³³ There is no data to suggest that food allergy and intolerance are more prevalent among people with learning disabilities.

Food allergies are most likely to occur in children with a family history of allergies such as hay fever, eczema or asthma. True food allergy should always be taken extremely seriously and expert advice sought from a medical practitioner. If someone has a food allergy it is important that everyone understands the importance of avoiding contact with those foods that may trigger a serious reaction and that full information on the food allergy is carefully recorded in care plans, and is communicated to schools, day centres or other places that the person may visit regularly. For sources of advice on how to manage food allergies see *Resources* in Appendix 4.

Some people may also have a food aversion which causes an unpleasant reaction in the body due to emotions associated with a food. People may become convinced that they are sensitive to a food and this can be encouraged by some popular books and unorthodox practitioners.³⁴ People with learning disabilities, and their family, friends and support staff, should be discouraged from attempting to restrict the person's diet due to a perceived allergy or intolerance, as this may make it difficult for them to get all the nutrients they need. This is particularly true if foods such as milk and milk products, or bread and other cereals are avoided. It is not easy to diagnose food allergies and food allergy tests sold on the high street or by unqualified practitioners should be viewed with caution.

Migraine headaches may be triggered by a number of factors including some foods. Alcoholic drinks, chocolate, cheese and citrus fruits have been reported to bring on migraine in some people.³⁴ People should seek advice if they think migraine may be triggered by certain foods.

Food hygiene and safety

Food should always be stored, prepared and presented in a safe and hygienic environment. Extra care is needed when preparing food for people who may be vulnerable to infection, as they may have a lower resistance to food poisoning. Most support staff will need to complete a Food Hygiene Certificate course. For more information on this, contact the local authority's environmental health department.

Support staff need to know about storage of food and leftover food, and thorough cooking or heating of foods. Several useful publications are available from the Food Standards Agency (see *Resources* in Appendix 4). Support staff should obtain these and follow the advice in them. Some of the main points for support staff are given in the box opposite.

It is also important that children, young people, adults with learning disabilities and family, friends and support staff are given information about the importance of basic hygiene measures to prevent infections – for example, not eating food that has fallen on the floor, and washing hands with soap and water before eating meals or snacks and after going to the toilet or handling animals. This is particularly important for people with learning disabilities who are going to become independent and who may have had more limited exposure to food handling in earlier places of residence.

Children under 5 and anyone who has any form of eating difficulty should never be left unattended when eating or drinking, as they may choke.

Food hygiene and safety hints

This information is not designed to replace appropriate training but is here as a reminder of some of the important standard practices.

- Everyone should wash their hands with soap and water before preparing food or helping people to eat. If a handkerchief is used while preparing food, hands should be washed before continuing.
- All work surfaces and utensils used in the preparation of food should be clean.
- Don't leave perishable food at room temperatures for more than 2 hours. Perishable food brought from home, including sandwiches, should be kept in a fridge or cool place below 8°C.
- Pets should not be allowed near food, dishes, worktops or food preparation areas.
- Insulated cool boxes, or a cool box with cool packs, should be used for carrying food when taking people on trips or outings.
- Eggs should be kept in the fridge.
- Food stocks should be rotated, and food beyond its use-by date discarded.
- If food is to be eaten warm, it should be reheated until piping hot (70°C) for 2 minutes and then cooled down before serving.
- Avoid keeping food hot for long periods.
- Cool leftover food quickly, cover and refrigerate, ideally within 1 to 2 hours.
- Fruit and vegetables to be eaten raw should be washed well.
- Whole pieces of nut or chopped nuts should not be given to anyone at risk of choking. Ground nuts can be included in foods where appropriate.
- Allergic reactions can be very serious. There should be a careful plan for choosing a safe and nutritious diet for any individual with a diagnosed food allergy (see page 91).

KEY MESSAGES

The eating environment and timing of meals and snacks

- All children, young people or adults with learning disabilities should be respected as individuals and their food preferences and religious and cultural requirements around food should be accommodated.
- Food should be appetising and attractively served, to ensure that people enjoy their food. This is particularly important if the food has its form or texture changed for people with swallowing difficulties.
- The timing of meals and snacks throughout the day should be organised to fit around the needs of the individual being supported. Some people may need frequent small meals and snacks throughout the day.
- It is important to ensure that everyone has enough time to eat and drink and that, where necessary, food is kept warm safely during the meal for those who eat and drink slowly.
- It is important to ensure that people arrive at mealtimes ready for the eating occasion, for example, having had the opportunity to go to the toilet and wash their hands or collect their hearing aid, glasses or dentures. Where possible, children, young people and adults with learning disabilities should have the opportunity to serve themselves at mealtimes and independence in eating should be encouraged. The appropriate cutlery, crockery, tables and chairs should be available to ensure that everyone is as comfortable and independent as possible.
- To make mealtimes a time of pleasant social sharing, and as good practice, staff should sit with the people they support during meals and snacks, and where appropriate share the same foods and drinks.
- Mealtimes offer an opportunity for support staff to model eating skills and to encourage social interaction and conversation. To encourage this, distractions such as television are best avoided during mealtimes.

Breakfast

- Breakfast is an important meal, firstly because many breakfast foods are a very good source of fibre and other important nutrients, and secondly because, if breakfast is missed, it is more likely that individuals will be tempted by other snack foods later in the day.
- For those who have a good appetite in the morning that recedes as the day continues, breakfast should be seen as an opportunity to eat a significant amount of energy (calories) and other nutrients, and a range of foods should be offered, rather than just traditional breakfast foods.

Snacks

- A variety of snacks should be offered and these should be included in menu plans. Snacks provide an opportunity to supplement nutritional intakes between meals and can be particularly important for those with small appetites or who are fussy or selective eaters, or who are growing rapidly. However, for those people with learning disabilities who are gaining weight or who have been advised to lose weight, snacks that are high in fat and sugar (such as confectionery, savoury snacks, soft drinks, cakes, biscuits and ice cream) should be kept to a minimum as these frequently contribute significant extra calories to the diet.

Drinks

- It is important that everyone is encouraged to drink a sufficient, but not excessive, amount of fluid each day and it should not be assumed that people will necessarily drink enough fluid without encouragement. Most adults need at least 1.2 litres of fluid a day (about 6 glasses) but older people or people who are prone to constipation should be encouraged to have at least 1.5 litres a day (about 7 to 8 glasses). However, excessive fluid (more than 5 litres a day) can be very dangerous and advice should be sought from a medical practitioner if there is concern that someone is drinking excessively.
- Free, fresh, chilled tap water should always be offered with meals and regularly throughout the day and should be widely available in any places where people with learning disabilities may live, work or visit.
- The amount of soft drinks given to children with learning disabilities should be limited since these offer little nutritional benefit and may suppress appetite and prevent children eating more nutritious foods. If soft drinks (such as squashes) containing saccharin are given to the under-5s, they should be diluted much more than they would be for an adult – for example, a dilution of 1 part squash to 10 parts water.

- If sugary, fruit-based or fizzy drinks are given to children and young people with learning disabilities, they should be kept to mealtimes since frequent consumption of soft drinks is related to tooth decay and tooth erosion. Drinks other than milk or water are highly likely to contribute to tooth decay, so they should not be given at bedtime or during the night.

Vitamin, mineral and herbal supplements

- Advice should always be sought from a medical practitioner or pharmacist before any dietary supplements are taken, as high doses of certain vitamins and minerals and some herbal supplements can cause adverse reactions and may interfere with the absorption of other nutrients or with the action of medicines.

See also: page 54 for information on supplements for pregnant women; page 53 for information on vitamin drops for children; and page 47 for information on vitamin D supplements.

Food allergy and food intolerance

- If a child, young person or adult with a learning disability has a medically diagnosed food allergy, this needs to be taken extremely seriously. It is important that everyone understands the importance of avoiding contact with those foods that may trigger a serious reaction. Full information on the food allergy should be carefully recorded in care plans and be communicated to schools, day centres and any other places that the person may visit regularly.
- It is important that food allergies should be medically diagnosed. People with learning disabilities, their family, friends and support staff should be discouraged from attempting to restrict a person's diet due to a perceived allergy or intolerance, as this may make it difficult for the person to get all the nutrients they need. This is particularly true if foods such as milk and milk products or bread and other cereals are avoided.

Food hygiene and safety

- It is important to remind children, young people and adults with learning disabilities, and their family, friends and support staff, about the importance of washing their hands with soap and water before eating meals or snacks and after going to the toilet.
- Support staff should always wash their hands with soap and water before preparing food or before helping people to eat, and after they have blown their nose.
- Support staff should seek information about food hygiene and safety, and requirements for training, from their local authority's environmental health department.
- Support staff need to ensure they know how to store food safely, handle leftover food, and cook and heat food appropriately.
- Children under 5 and anyone who has any form of eating difficulty should never be left unattended when eating or drinking, as they may choke.

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Chapter 8

Encouraging eating well

This chapter provides information on some practical strategies that can be adopted, to help encourage eating well among people with learning disabilities.

Some of the information in this section relates to residential care environments and to the role of support staff, but much is also relevant to other living arrangements and household types. Just as for all members of society, there is no one right way to support people to eat and drink well. This section aims to open up debate on some of the issues and to suggest some strategies that may help.

Philosophy of care: rights and responsibilities

It is a fundamental human right that everyone should have access to food and drink that is both nutritionally adequate and culturally acceptable, and it is important to work together to ensure that people with learning disabilities are supported to make choices and understand the importance of eating well. Person-centred care aims to ensure that the individual remains the most important person in determining how they are supported, and promotes the rights of everyone to maximum independence and choice.

Mental Capacity Act 2005

A policy of maximising choice is not new in services for people with learning disabilities, but has become a central theme in all four UK countries over the last 20 years.¹ Some people with learning disabilities need information and explanation of how food choices can impact on their health and wellbeing, so that they can make a more informed choice. Others may need greater support in making choices or managing food and drink that is appropriate to their health needs. Some people may at times find it difficult to make choices at all. The Mental Capacity Act 2005, which came into force in 2007, is an important piece of legislation which will change how decision making may be handled for some people with more severe learning disabilities.

The terms of the Act are likely to affect everyone involved in caring for someone with a learning disability, whether formally or informally, if at some time the person with a learning disability lacks the capacity to make a particular decision or take a particular action for themselves at the time the decision or action needs to be taken. The Act sets out a single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time. It is a 'decision-specific' and 'time-specific' test. No-one can be labelled 'incapable' simply as a result of a particular medical condition or diagnosis. Section 2 of the Act makes it clear that a lack of capacity cannot be established merely by reference to a person's age, appearance, or any condition or aspect of a person's behaviour.

The Act is supported by a Code of Practice which provides guidance to anyone who is working with and/or caring for people over the age of 16 who may lack the capacity to make particular decisions. The Act is underpinned by five key principles:

- *A presumption of capacity.* Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.
- *Individuals being supported to make their own decisions.* A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
- *Unwise decisions.* Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
- *Best interests.* An act done or decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests.
- *Least restrictive option.* Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

The Act also establishes a new court, the Court of Protection, a new Office of the Public Guardian and a new Independent Mental Capacity Advocate service which will employ Independent Mental Capacity Advocates or IMCAs. An IMCA will be someone appointed to support a person who lacks capacity but has no-one to speak for them, such as family or friends. The IMCA makes representations about the person's wishes, feelings, beliefs and values, at the same time as bringing to the attention of the decision-maker all factors that are relevant to the decision. More information about the Act and the Code of Practice and a series of publications have been produced by the Department of Constitutional Affairs (see *Resources* on page 155).

Taking responsibility for health

People taking responsibility for their own health is now part of most government public health strategies^{2,3,4,5} and people with learning disabilities should be encouraged to take the same responsibility for their own health as other people in society. However, access to health facilitators is essential for people with learning disabilities, so that people who may be less able to act as 'expert patients' in a system which increasingly expects well informed, articulate consumers, do not become further disempowered. It is also important to remember that many people with learning disabilities may live in poor households and may experience inequalities in their environment and their health. It is important that access to services is made equally available to all, and that all support staff are trained to support those who may live in poorer households.

Helping people make good choices

During the research for this report, the author met people who worked with learning-disabled people and who had very different views on the concept of choice. For some, allowing an individual to drink six cans of cola a day if they chose to do so was seen as 'individual choice and a person's right'. Others, however, argued that guidance on choice is needed where the choices made can have a negative impact on health. To restrict food and drink choices among people with learning disabilities when these are not restricted to other members of society would seem unfair. To allow someone to become overweight and ill, and in some cases to put their lives at risk, when they may be unable to consider the consequences of their actions might, however, seem even more unfair. There is a changing mood in terms of free choice of food and drink in

the UK, as the consequences of unlimited choice impact significantly on the nation's health. For example, the Government is acting to restrict food choice in schools since it has had to conclude that many children and young people fail to make good choices on their own in an environment of unlimited choice and that their vulnerability to food-related ill health requires legislation.

A recent review suggested that among the main factors influencing choice and decision-making around food for people with learning disabilities are past experiences, an awareness of the range of choices, and the role of carers in supporting and encouraging choice.⁶ The authors of that review conclude that directing choice-making around food, without encouraging unhealthy eating, is an essential component of a duty of care for vulnerable adults. In order to support people with learning disabilities to make good choices around food and drink, it is essential that family, friends and support staff are confident themselves about what eating well means. We hope that the information in this report will be useful in helping people to find out more about eating well and that appropriate on-going training of support staff will be supported by employers (see page 100).

Most people are likely to have strong opinions about foods and drinks they like and dislike and will have routines and patterns of eating which they prefer to follow. It is not the role of support staff to dictate what better choices might be, but people with learning disabilities have the same right as anyone else to be given relevant information about their health and the impacts of their choices on their health.

A variety of foods and drinks should be made available to everyone and support staff should be trained and supported to help people with learning disabilities make informed choices. Where there are communication difficulties around food and drink choices and eating, support staff should be encouraged to develop skills in interpreting people's wishes.

Each person will have different requirements around food and drink and therefore it is important to be sensitive to any restrictions that might be necessary (for example in food texture) when talking about dietary change.

Family, friends and support staff may find the following suggestions useful when considering how to encourage people to consider the choices they make:

- Sharing snack times and mealtimes with other people provides an opportunity for discussion and people may be more tempted to try new foods and drinks if other people around them are enjoying them.
- Keep a record with the service user of their typical eating and drinking patterns over a few days and use this to talk about the foods and drinks they like, the quantities they

have and their preferred routines, to see if they are actually enjoying their current choices.

- Use pictures or photographs of different types of foods and drinks, in different portion sizes, to encourage people to think about new foods and drinks or the balance of foods and drinks they have.
- There are a number of games available, some of which might be suitable for some people with learning disabilities. These can be a useful springboard for discussion. (See page 153.)
- Small changes over time are likely to be more effective. If people consume large amounts of one particular food or drink (for example, if they are large consumers of fizzy drinks throughout the day), suggest that one drink is swapped for an alternative to start with. Gently distracting someone from a food or drink habit which may be harming their health by spending time with the person and sharing an alternative can be effective.
- Ensure that food being offered as an alternative is attractively presented. Using colourful plates with good contrast to the food can be helpful.
- If people need to lose weight, consider some of the strategies outlined on page 65.
- Look at food labels together and explain how to make choices between similar products.

There are a number of behavioural learning routes which might be helpful in encouraging people with learning disabilities to make positive changes to dietary habits which may be detrimental.

Fading involves gradually replacing some foods or drinks with others. This could take the form of slowly reducing the amount of sugar in tea and coffee, diluting squashes more over time until water becomes the drink of choice, or replacing some biscuits on a plate with fruit and slowly changing the proportions offered.

Replacement can be used as a method of helping those who have very limited food choices to expand the number of foods they eat. For example, if someone only likes to eat chips, then other root vegetables can be cut into the same shape and cooked in the same way and be introduced among with the chips and, if accepted, the proportion can be gradually increased.

Association can also be used to encourage change. Sometimes people associate pleasant experiences with particular foods. For example, someone may associate eating crisps with enjoying television-viewing as a child. It may be possible to reverse this by introducing other foods in similar situations to create other positive associations.

Role modelling is a powerful social learning tool and family, friends and support staff should be encouraged to

eat in a social situation with people with learning disabilities as much as possible, even when someone may need help with eating. Eating together is an important part of social inclusion in most cultures and can also be an important part of the day for sharing information and news.

Organisational culture

In residential care, other supported living arrangements and day care it is essential that there is a commitment to good nutrition and an awareness of the wider role of food and drink in contributing to wellbeing and quality of life. Managers and staff at all levels need to demonstrate their commitment to good nutrition so that it becomes part of the organisational culture of the place of residence. Commitment to eating well may mean that staff shifts, staff training and staff support are all reconsidered in the light of the needs of residents for support in eating and drinking. In order for an organisation to work effectively as a team to support eating well, it is essential that all staff understand why it matters and know how to assess whether people are eating and drinking adequately. More information on staff training can be found below.

The overall ethos of care should be person-centred and therefore the accumulation of information from each person, and from their relatives and friends, about their food and drink preferences, desired meal patterns and choices around where and when to eat are an essential tool for all staff in ensuring continuity of care. This information should be recorded, shared with all support staff, and regularly updated. For those offering respite care, it is essential that family, friends and support staff, as well as the person himself or herself, are given the opportunity to discuss how a change in living arrangement may impact on their usual eating and drinking routines so that everyone can work together to ensure that there is continuity of care.

Staff training and support

It is essential that all staff are valued and that their significant contribution to the support of people with learning disabilities is acknowledged. The importance of staff training cannot be over-emphasised. In order that people with learning disabilities are supported to eat and drink well, it is essential that everyone who supports them, paid or unpaid, has a clear idea about what eating well means in practice and that appropriate training is on-going for all staff regardless of whether they are permanent, temporary, employed through an agency, or are voluntary.

It is important that anyone who supports those who need assistance with eating is trained to help in a sensitive and efficient way. Helping someone with eating difficulties to eat and drink well can be complex and stressful and it is essential that staff are given sufficient support from colleagues when this is challenging. Support staff may be reluctant to help with eating and drinking if they find this distressing, and they may need support from another person, peer group support sessions, or specialist help and support.

Currently there is insufficient training on nutrition and health in the National Vocational Qualifications for Health and Social Care (and equivalent Scottish Vocational Qualifications) typically undertaken by those who work as support staff for people with learning disabilities. While there is scope within the level 2 NVQ/SVQ for good practice to be taught, the modules on providing food and drink and helping individuals to eat are optional and the level of information given is very dependent on the training centre. Ad hoc investigation of a number of training centres found that there was frequently no contribution to training or assessment by a dietitian or registered public health nutritionist. There is no unit on eating and drinking at NVQ/SVQ level 3 and no specific unit available on eating and drinking for people with learning disabilities. NVQs, SVQs and other appropriate social care qualifications are important training opportunities for support workers and other staff. Qualifications at all levels should contain an appropriate section on nutrition and eating well which allows students to understand the information in this report.

Additional on-going training on nutrition should be organised by employers for all those who support people with learning disabilities in their care, to supplement the training they receive elsewhere. Where training in eating well is given in a group setting, this should be given or be supported by a registered dietitian or registered public health nutritionist.

Involving and listening to family and friends

Food and drink can be an emotive issue and sometimes it can be difficult to reconcile the wishes of family members and friends with changes in choices or routines that support staff may wish to put in place to encourage eating well. Some family members and friends may have strong beliefs about the need for particular foods and feel strongly if access to certain foods and drinks is limited or if changes are made to the types of ingredients or basic foodstuffs used. This can be difficult for support staff who are trying

to make positive changes, and upsetting for families and friends who believe they have the individual's best interests at heart. Below are some suggestions which may be a helpful starting point for staff discussing food and drink issues with families and friends.

Think about making small changes over time. It may be easier to phase in changes to the menus or daily food and drink routines little by little, discussing and reviewing changes as you go along and ensuring that the views of the person with learning disabilities, and of their families and friends, are taken into consideration.

Make change familiar. Talking about the changes you want to make and focusing on the positive aspects – perhaps by offering tasting sessions, providing leaflets or other information to service users and their families and friends that support the changes you want to make – will allow the novel to become more familiar and less threatening.

Listen and allow people to discuss ideas. No-one likes change that is forced on them, yet most people respond favourably to change they create themselves. Provide enough background information and a forum for people to reflect on and discuss the implications of the changes you desire, and encourage family and friends to make their own suggestions.

Ensure everyone in the organisation is on side with the changes so the messages given are united and everyone shares a clear vision of what you are trying to achieve.

Avoid confrontation and keep things in perspective. Eating and drinking well means having a variety of food and drink over a period of time, so think in terms of the bigger picture rather than demonising any particular foods or drinks that may be a source of conflict.

Food as a treat or reward

Food has a significant role in many people's lives and the use of food as a treat, reward or consolation, or the withholding of food as punishment, are measures most people will be familiar with from their own lives and the lives of others. It is of course never acceptable to withhold food or drink from anyone, but support staff may be less immediately aware of how often food and drink are used as treats and rewards. Some support staff offer food and drink that they consider as 'treats' to compensate a person with learning disabilities for what they may consider difficult circumstances or conditions. This may mean, for example, that some support staff offer sweets and soft drinks more frequently to people with learning disabilities than they would to other people they cared for, or that relatives and

friends visiting people with learning disabilities might be more likely to bring fizzy drinks, sweets, biscuits and cakes as treats to comfort the person. It is important that anyone who supports a person with learning disabilities considers the needs of the individual in a holistic way and thinks about how best to support them to good health.

A person with learning disabilities who is overweight or who has dental health problems may not be best supported with sweet treats but might enjoy fruit, fruit juice or non-food gifts from friends and relatives. It may be useful for the person with learning disabilities to work with a supporter to come up with a list of treats that they would enjoy which are also health-promoting and which they could ask people to donate instead of sweet treats. For example, this could be a trip or outing, music or a film, or household or garden equipment. For people on low incomes, some types of fresh and dried fruit can be expensive and supporters could find out the varieties that would be particularly enjoyed and offer those as treats and gifts.

Rewards are often given to encourage good behaviour or to reward people if they have done well in a particular task. Rather than giving sweets, chocolates and sweet snacks such as biscuits to reward good behaviour, rewards can be given in the form of smiles and praise ('soft rewards') or as small inexpensive items such as stickers or badges ('hard rewards'). Most people enjoy both soft and hard rewards and it is important to make all people feel proud of their achievements, however small.

Engaging with health and other professionals

There are a number of health professionals who are likely to be involved in the support of people with learning disabilities. Children with learning disabilities usually have their care coordinated by a paediatrician. For adults, most health authorities across the UK have a team providing specialist health and social care to people with learning disabilities living in the community. These are commonly called Community Learning Disability Teams (CLDT), but names may differ in some areas. The teams are multi-disciplinary and may include members from social care, the health service and mental health trusts. CLDTs employ a wide range of specialists including community learning disability nurses, occupational therapists, physiotherapists, psychiatrists, psychologists, social workers, speech and language therapists, dietitians, hearing and visual therapists, pharmacists, psychologists, challenging behaviour workers and psychiatric nurses. However, the

access of individuals and families to all these specialist services is likely to vary across the country and it is important that people with learning disabilities remain in contact with their GP throughout their life span.

Some of the key personnel in supporting eating and drinking are outlined below.

Speech and language therapists (SLTs) help with eating and drinking difficulties, providing assessment and intervention for those with swallowing difficulties. This includes the development of strategies to enable safer eating and drinking developed in partnership with the person with a learning disability, family, friends and support staff and other members of the multi-disciplinary team.

Occupational therapists (OTs) offer support and guidance to help individuals maintain independence and have a number of key roles in supporting eating well. OTs can advise on the immediate eating environment at mealtimes, and the use of appropriate equipment to aid eating and drinking. They can also advise on positioning to promote function, comfort and safety, support staff on how to handle mealtimes, and work with individuals to promote independence.

Dietitians can assess nutritional status and intake and give advice on changes to the diet to improve energy and nutrient intake, as well as offering specialist dietary advice for specific medical conditions. Dietitians can also advise on menu planning, recipe development and cooking practices and offer training to support staff and others on eating well. Dietitians work with other health professionals to advise on artificial nutrition and texture modification for people with swallowing difficulties.

Physiotherapists help and treat people of all ages with physical problems caused by illness, accident or ageing. Physiotherapy sees human movement as central to the health and wellbeing of individuals. Physiotherapists identify and maximise movement potential through health promotion, preventive healthcare, treatment and rehabilitation and can offer advice on positioning, activity and improving mobility for people with learning disabilities.

Community learning disability nurses are involved in planning programmes of care for an individual, skills development, and teaching basic skills. They provide nursing care in a variety of settings, and offer support and counselling to family, friends and support staff. The amount of training on nutrition that nurses will have received is likely to be variable and nurses may welcome additional up-to-date, on-going training on eating well.

Psychologists within learning disability services can support staff and service users in understanding and managing eating and mealtime behaviour, issues around body image

and self-esteem, identity, anxiety and other factors which might contribute to disordered eating.

In addition **social workers** have a key role in organising and monitoring services and support, and **pharmacists** play an increasingly important role in managing medication and providing advice on interactions between certain drugs and foods.

Who can give nutrition advice?

The term nutritionist is not a protected term and therefore many people offer nutrition advice even when they are not qualified to do so. Advice on nutrition should be sought from a registered dietitian (RD) or a registered public health nutritionist (RPHNutr). For details of where to access these professionals, see page 151 in Appendix 4.

Health action plans and annual health checks

Health action plans

A health action plan for each individual should be compiled to explain their health needs. These plans should be drawn up by the individual supported by a health facilitator, which may be someone from their community learning disability team, a relative, partner, carer or friend. The aim of the health action plan is to provide an accessible, living document. It can be considered as the health section of their person-centred plan and should include information about nutrition and health. The health action plan should be made as accessible for the individual as possible. Drawings, photos, work books, drama and group work can all be used to increase the health literacy of people with learning disabilities so they can participate more fully in planning for their own health. People may also have more conventional patient-held medical records that they can share readily with health professionals and take to appointments. For more information on health action planning, see page 155.

Annual health checks

GPs should proactively offer people with learning disabilities an annual health check using tools developed as part of the *Primary Care Service Framework for the Management of*

Health for People with Learning Disabilities (see www.primarycarecontracting.nhs.uk/204.php). This should look at a range of indicators related to nutritional health such as body weight, weight change, bowel health, oral health, specific medical conditions such as diabetes and coeliac disease, difficulties around eating and drinking, and any other issues that may be related to any of the conditions discussed in this report. Reviewing medication is also important, particularly where medication impacts on nutritional status (see page 30). Health professionals need particular skills in assessing the needs of people with learning disabilities as well as skills in how to communicate with those with limited communication skills. Good liaison between medical practitioners, specialist learning disability teams and other health professionals should be fostered to ensure that the annual health check is part of a holistic approach to health planning for each individual.

Children, young people and adults with learning disabilities should also visit their dentist twice a year.

Introducing material on eating well as part of assessment and care pathways

It is important that social care professionals and those involved in assessing, planning for and otherwise helping people with learning disabilities recognise that there are stages in the assessment and care pathway where they can introduce in an appropriate way material about nutritional and dietary needs. There may well be opportunities to talk about eating well during:

- person-centred planning
- carer and user assessments
- case reviews, and
- day service curriculum.

Resources which might be used to discuss issues around food and nutrition can be found on page 153.

Food knowledge and skills of people with learning disabilities

Many people with learning disabilities wish to acquire new skills or improve existing skills. This may be to enhance employment prospects, to allow them to lead more independent lives or because they enjoy learning purely for its own sake. Opportunities to learn also provide people

with new experiences and the chance to meet new people and make new friends. The provision of learning opportunities for people with learning disabilities is likely to vary across the UK as different colleges, learning and skills councils and local education authorities (LEAs) offer different opportunities to begin, continue and extend learning. Some areas will provide considerable high-quality provision for people with learning disabilities, while others may provide very little. It is recommended that all learning and skills councils should accredit courses in nutrition and health and basic cookery for all people with learning disabilities, and make training accessible for family, carers and other supporters where appropriate. Special courses should be made available for people with learning disabilities from ethnic minorities, who are likely to be under-represented in post-school education. Courses should also be made available for those people with learning disabilities who are parents (or who wish to or are likely to become parents), to help them understand the importance of good nutrition in the development of their children and to provide healthy food choices for them.

There are a number of activities that may enhance the food experience for people with learning disabilities and details of a number of games and other activities are given on page 153.

Growing clubs and therapeutic horticulture

Gardening is an activity that many people enjoy at home and which can encourage people to spend more time outdoors being active.

Social and therapeutic horticulture has been defined as the process by which individuals may develop wellbeing through actively being involved in growing plants. This has been used as therapy and for rehabilitation among people with a range of disabilities. There is evidence that this can be a useful and effective form of health and social care provision for people with learning disabilities⁷ and that people benefit from a break in their usual routines and from being outside. Benefits are reported in social networks, education and training, relaxation and restoration, and self-confidence and self-esteem. Many service users also enjoy consuming the food grown and this can contribute to better health. For more information about therapeutic horticulture, contact Thrive (see page 156).

KEY MESSAGES

Philosophy of care – rights and responsibilities

- Managers and support staff should be aware of the code of practice of the Mental Capacity Act 2005 which presumes that anyone over the age of 16 has the right to make his or her own decisions and must be assumed to have the capacity to do so unless proved otherwise, and that people should be supported to make their own decisions and choices.

Helping people make good choices

- A variety of foods and drinks should be made available to everyone and support staff should be trained and supported to help people with learning disabilities make informed choices. Where there are communication difficulties around food and drink choices and eating, support staff should be encouraged to develop skills in interpreting people's wishes.
- Courses on nutrition and health and on basic cookery for people with learning disabilities, and for their friends and family, should be made available. Special courses for those people with learning disabilities who are parents should also be made available.

Organisational culture

- In all settings it is essential that there is a commitment to good nutrition and an awareness of the wider role of food and drink in contributing to wellbeing and quality of life. Managers and staff at all levels need to demonstrate their commitment to good nutrition by ensuring everyone receives adequate training and support.
- Efforts should be made to find out about the food preferences and eating patterns of people with learning disabilities – including those who move into new or residential settings, regardless of how long they will stay there. This information should be recorded, shared with all support staff, and regularly updated.
- People with learning disabilities should be encouraged to include information about food and nutritional health in their health action plan which is compiled to explain their health needs, and in all care plans.

Staff training and support

- The importance of staff training cannot be over-emphasised. In order that children, young people and adults with learning disabilities are supported to eat and drink well, it is essential that everyone involved in supporting them has a clear idea about what eating well means in practice and that appropriate training is on-going for all staff, regardless of whether they are permanent, temporary, employed through an agency or involved in a voluntary capacity.
- It is important that anyone who supports those who need assistance with eating is trained to help in a sensitive and efficient way. Helping someone with eating difficulties to eat can be complex and stressful and it is essential that staff are given sufficient support from colleagues when this is challenging.

Involving and listening to family and friends

- A real partnership between families, friends and support staff is essential so that everyone works together to ensure that each individual eats and drinks in a way that they prefer and which is appropriate, safe and health-promoting. In residential and day care settings it is important that adequate notice of, and the reasons for, changes to meals and snacks are given to everyone so that people can comment on and discuss the changes before they are introduced.

References

- 1 Royal College of Nursing (2005) *Real Choice in the Health Service*. London: RCN
- 2 Department of Health (2004) *Choosing Health. Making Healthy Choices Easier*. London: TSO
- 3 Welsh Assembly (2005) *Designed for Life*. Cardiff: Welsh Assembly Government
- 4 Department of Health, Social Services and Public Safety (2002) *Investing for Health*. Belfast: DHSSPS
- 5 Scottish Office (1999) *Towards a Healthier Scotland*. Edinburgh: Scottish Office
- 6 Smyth CM and Bell D (2006) From biscuits to boyfriends: the ramification of choice for people with learning disability. *British Journal of Learning Disabilities*; 34: 227-236
- 7 Sempik J, Aldridge J and Becker S (2003) *Social and Therapeutic Horticulture: Evidence and Messages from Research*. Reading: Thrive; and Loughborough: Loughborough University



Chapter 9

Monitoring nutritional status and dealing with eating difficulties

This chapter looks at ways of monitoring the nutritional status of people with learning disabilities. It also looks at how to help people maintain independence in eating, and strategies for dealing with common eating difficulties such as extreme faddy or selective eating, food refusal, and difficult eating behaviours.

Monitoring nutritional status

Knowing whether someone is eating inappropriately requires some measure of their nutritional status and this is most frequently done by monitoring a person's weight change over time and recording any changes in food and drink consumption. It is not easy to spot malnutrition and often long periods of insufficient food intake or inappropriate food intake will manifest itself very late as a sudden illness such as pneumonia or a fracture. Being alert to changing food patterns is essential if poor eating and drinking are to be recognised before malnutrition impacts on health and wellbeing.

There are a number of tools that health professionals commonly use to screen the nutritional status of people both in a range of community settings and in hospital. Details of some of these are given on page 154 in Appendix 4. While these have an important place in managing assessment of nutritional status in some residential settings, it is often necessary for staff to have training to use them effectively. It is therefore essential that all support staff are able to make simple assessments that might alert them to changes in the nutritional status of those they care for.

Simple warning signs of changes in nutritional status

These include:

- unexpected weight loss or weight gain (as discussed in chapter 5)
- changes in eating habits, or drinking or eating more or less than usual
- food or drinks left over at mealtimes and from between-meal snacks
- loss of independence in eating
- difficulties with swallowing
- observed fatigue, apathy, or disinterest in activities
- pale skin, thin or sparse hair, spoon-shaped nails, or cracks around the mouth.

A simple nutrition checklist can be useful in helping support staff to recognise nutrition-related problems among people living in the community and an example of a simple checklist is shown in Appendix 3.

If there is concern that someone is not eating well, ask the person's GP for a referral to a registered dietitian, or consult with the community learning disability team.

Maintaining independence in eating

It is generally agreed that help with eating, while sometimes essential, can lead to a loss of self-esteem and a sense of powerlessness and dependency.¹ Those who are able to eat independently, even if this is by hand only, should be encouraged to do so to maximise independence and dignity. If independent eating skills are not encouraged, there may be a rapid decline to dependence.² The use of finger foods can help people to maintain and

recover eating skills and has the advantage of boosting self-esteem and independence as well as allowing people to eat at their own pace.¹ (For more on finger foods, see page 132.)

Practical aids to eating and drinking

There are a number of helpful aids to eating that some people with learning disabilities may find useful for feeding themselves, or which family, friends and support staff can use to help people to eat and drink more effectively. Occupational therapists can advise on suitable aids which might include the following.

- Different shaped cups, with one or two handles, of different weights, materials, transparencies and designs. Cups should not shatter or break if they are bitten.
- A transparent cup can be helpful when helping someone to drink so the carer can see how much liquid is taken.
- Cutlery of differing shapes, sizes, depths and materials. Cutlery should not shatter if it is bitten. Solid plastic cutlery or plastic-coated metal might be better for people who have a bite reflex when cutlery is placed in their mouth. Shorter-handled cutlery is easier to manage and handgrips or irregularly shaped handles may help someone in using a utensil.
- Plates and bowls which do not slip, have higher sides to prevent spillage, or which are angled to make access to food easier.
- Insulated crockery which keeps food hot if mealtimes are lengthy.
- Non-slip mats which support crockery.
- Straws which can help those with a weaker suck or which have different widths.
- Automated eating systems such as *Neater Eater* which allow people to feed themselves even when movement is very limited.

For details of sources of specialist eating and drinking equipment, see page 156.

Helping people to eat

Staff involvement and commitment to successful mealtimes are critically important factors in ensuring that people with learning disabilities eat well.

While it is essential that those who can fully or partly eat independently are encouraged and enabled to do so, those who need help with eating must be treated sensitively. The

perspective of helping people to eat rather than ‘feeding’ them is essential. Mealtimes should be seen as a therapeutic time for activity involving physical, sensory, emotional and social stimulation. Speech and language therapists can recognise and help with eating difficulties (see page 102). Verbal prompting during eating to ‘Open your mouth,’ ‘Chew,’ or ‘Swallow’ has been suggested as particularly helpful.³ If direct verbal prompting fails to work, touching food against the person’s lips gives a non-verbal cue to open the lips. If someone cannot initiate voluntary movement, it is better to give indirect encouragement to eat, for example saying ‘This meal looks tasty.’ Some guidelines for helping a person to eat are given below. It is also essential for staff to be trained in helping people to eat and to do this in a sensitive and efficient way. The training might include experiencing what it is like to be helped to eat.

Other practical suggestions include ensuring that people have an empty bladder before they start eating, and that their glasses or dentures are accessible and well-fitting. Suggestions for dealing with particular problems and behaviour associated with eating are given on page 108.

Guidelines for helping a person to eat

- The same carer should stay with the person throughout the meal.
- If the person uses glasses, dentures and/or a hearing aid, make sure these are in place.
- Make sure the person is sitting in an upright position.
- The carer should sit at eye level, and either immediately in front of or slightly to one side of the person who needs help.
- Give small mouthfuls but enough for the person to feel the food in his or her mouth.
- Give adequate time for the person to swallow each mouthful before continuing.
- Assist but never force.
- Maintain eye contact with the person who needs help. Do not talk to someone else while offering food.
- Use verbal prompts: talk clearly about the food you are offering (especially if it is puréed), and use a gentle but firm tone.
- Discourage the person from distractions (such as talking or laughing with food in their mouth) because of the risk of choking.

Adapted from: Layne 1990⁴; and Holzapfel et al 1996⁵

Positioning when people need help with eating and drinking

The importance of good positioning for eating and drinking cannot be over-emphasised for many people with learning disabilities. Family carers may be experienced in achieving the best position. The normal position for eating is in the upright position. No two people are the same and so the position best suited to an individual will vary, but it is useful for everyone to be aware of some of the basic principles when preparing to help someone to eat well.

It is difficult to balance and eat and drink at the same time, so whatever positions are used for mealtimes, the advice of a physiotherapist or occupational therapist can be very helpful to ensure that the best and safest positions can be found for each person. The general suggestions given below are designed to open up discussion and make all those who help with eating and drinking reflect on their current practice and pool ideas for discussion. Eating and drinking can be hazardous and it is important that any changes in position or support are reviewed in the light of how someone can be helped if they cough or choke.

- Aim for symmetry and alignment of the body when someone is sitting or standing ready to eat – with the head upright, the back of the neck elongated and the chin tucked slightly in.
- Usually, both the person eating and the person helping them should be sitting at the same height so that they can have face-to-face contact to help communication during meals. In some cases people with a visual impairment might prefer someone to sit next to them and maintain contact side-by-side, but eye contact is generally preferred.
- An extended head, neck and body position makes eating and drinking uncomfortable and potentially dangerous, as the person may be more likely to cough and choke. So avoid sitting so that the person has to look up.
- For some people, eating standing up may be preferable. Standing with the help of a frame or prone stander may help with stability. Standing can also ease the descent of fluid and food to the stomach and may help to prevent gastro-oesophageal reflux.
- Ensure that people are well supported so that they don’t push against tables or hyperextend their limbs to make themselves feel safer.
- Headrests and neck supports can be very important for ensuring the head stays upright and the neck stays elongated.
- Regular review of the position that best suits each person at mealtimes is essential.

- How a person is positioned after the meal can also impact on whether they manage wind or reflux problems. Some people may find it easier to stand up or remain standing for a short time after the meal. For some people, a period of 30 minutes sitting after a meal may be recommended.
- If someone needs help with eating, it is also important that the physical needs of the helper are taken into consideration so that they are comfortable and can focus all their attention on the job in hand. Support staff may also need cushions to ensure that they are in a comfortable position and do not get neck or back pain when helping someone to eat.

Strategies to deal with eating and drinking difficulties

This section makes some suggestions about how to handle eating and drinking difficulties for people with learning disabilities. However, it is important to remember that everyone is an individual and all those who support a person with learning disabilities should work together to find strategies that best suit each person.

Extreme faddy or selective eating

Some people with learning disabilities may be selective eaters or have phases of only being willing to choose from a small selection of foods and drinks. This is often associated with autistic spectrum disorders (ASD). ASD children may display strong preferences for foods of a particular colour, smell, texture, taste or temperature. They may also accept only processed foods with familiar packaging. They may find it difficult to try new foods and may be distressed in some mealtime environments, resulting in food refusal. They may also accept only foods presented on a plate in a particular sequence.⁶

Food refusal

People may refuse food for a number of reasons, and managing food refusal can be difficult and distressing for those who support them. There can be a number of reasons why people might refuse food and it is important that all avenues are investigated to find out why this might be the case and that the person is given every opportunity to communicate their feelings and choices around food and drink.

- There may be a physical problem such as a sore mouth, painful teeth or gums, or thrush which may require investigation and treatment.

Strategies which may help with selective eating

- Make mealtimes predictable by having a structured eating routine.
- At the start of each week, prepare 'visual timetables' using picture symbols, photos or words as appropriate, detailing when and where people will eat, what they will eat and the behaviour expected at mealtimes.
- Ensure there are no underlying health problems that might make eating some foods uncomfortable. For example, mouth ulcers may put people off fruit and fruit juice, or swallowing difficulties might make people fearful of food which they previously found difficult to chew or swallow.
- Try to identify the specific anxieties for each person and devise a step-by-step programme for overcoming them, including creating a calm, comfortable eating environment.
- Use games and stories to talk about new foods, and keep a visual list of foods liked and foods they might try.

Adapted from *Diet and autistic spectrum disorder: Food Fact Sheet* from the British Dietetic Association ⁶

- Food may be refused because there is an underlying swallowing difficulty (see page 28).
- Medication may make a person feel nauseous. See the next page for strategies to handle nausea.
- Medication may have other side effects which impact on eating and drinking. A drugs review may therefore be useful.
- Constipation may make a person feel nauseous.
- Food may be refused because it isn't liked. Make sure that people's food preferences are recorded and considered, and that where possible a whole variety of foods of different tastes, textures and temperatures are offered.
- People who refuse food may take it from a specific family member, friend or member of the support staff they know well.
- Paranoia can mean people are fearful of food and may think, for example, that it has been poisoned. Paranoia can also be treated with talking therapy if communication allows, or with medication.

- Depression can cause loss of appetite. Depression can be treated with medication or with talking therapies if communication allows.
- A person at the end stage of life may refuse to open their mouth and accept any food and drink, but it is still important to offer food and drink regularly regardless of the outcome at previous eating occasions. Decisions on how to manage food and drink at the end stage of life should involve doctors, family, friends, support staff and any advocates, including Independent Mental Capacity Advocates.
- Holding hands with a person, giving reassuring touches and singing softly have been found to help overcome resistance to eating among older people with dementia.⁷

People who are losing weight and refusing food may benefit from nutrition support for a period of time while the reasons for food refusal are examined and treated (see page 62).

Nausea and vomiting

If someone is feeling nauseous or vomiting, it is important to investigate the cause of this. In some cases nausea may be a response to essential medication and some simple strategies may help to alleviate this. Support staff may find some of the suggestions below helpful, but should ensure that the needs of each individual are carefully considered.

- Fresh air before a meal, and a well ventilated room, may help.
- Make sure people are sitting upright for meals and rest after eating.
- Aim for five or more smaller meals a day so that people are not ‘overfaced’ with large portions. Small portions of attractive food may be more tempting.
- Avoid foods with a strong odour and keep cooking smells to a minimum if these cause nausea.
- Dry, savoury foods – such as toast, crackers, rice cakes, bread sticks or plain popcorn – may be tolerated. Some people find dry biscuits or toast helpful to relieve nausea on waking.
- Cold foods may be easier to tolerate than hot ones: for example, thick and creamy yoghurt, jelly, ice cream or egg custard.
- Cold drinks drunk through a straw may cause less nausea.
- Ginger is well known to alleviate nausea: ginger cordials, ginger ale or ginger beer, ginger biscuits or stem/crystallised ginger might be helpful. Peppermint tea may also alleviate symptoms.

Mouth sensitivity

Hypersensitive oral reactions are exaggerated responses to touch in the mouth or around the face.⁸ An individual may be hypersensitive for several reasons. Neurological impairment may cause an individual to over-respond to sensory information, limited motor capabilities which inhibit someone from touching their own face may mean the area remains sensitive to touch, and being fed via a gastrostomy tube may limit someone’s exposure to oral stimulation. There is also some evidence that a lack of feeding experiences during critical periods of weaning in the first year of life can lead to oral hypersensitivity.⁹

Children or adults with hypersensitive oral reactions may not let you into their mouth for feeding or toothbrushing. Or they may have problems moving from one food texture to the next, spitting out or gagging on any food but purée. They may gag when a spoon touches the tip of their tongue and may gag on a tiny lump of food instead of swallowing it.

Some people become so sensitive and emotional that their reactions become aversion reactions. They may cry, fuss, pull away, push food away, or refuse even to let you near their mouths. Gagging may turn into vomiting in an aversive reaction. Fears can develop around feeding or any touch around the mouth and people may try to control all aspects of a meal in an effort to protect themselves from uncomfortable situations. For example, they may want only certain food textures, certain spoons, certain plates or certain cups. An excessive reaction to stimulation may trigger a bite reflex, clamping down in the biting position.

What can help?

It is important that you work with a speech and language therapist and occupational therapist to handle mouth sensitivity.

- Ensure the person is sitting in a stable, upright position. (For more on positioning, see page 107.)
- Ensure mealtimes are calm and relaxed, play calming music and reduce other sensory information.
- Eating involves many different types of touch: the spoon, fork, and cup touch the lips as they bring food to the mouth. Try gradually keeping the spoon or cup at the lips longer each time you help someone to eat, using favourite foods for this activity.
- Providing cues that the spoon is coming may help. Ringing a bell attached to the spoon, stating verbally “Here comes the food”, or placing the food on a brightly coloured spoon may provide a cue that the mouth is about to be touched and reduce unwanted reflexes.
- Food temperature can often cause overreactions.

Remember that room-temperature foods tend to be easier to handle. Make temperature changes very slowly and with foods that are liked.

- Plastic-coated spoons may be needed if people bite or are hypersensitive to temperature.
- If people over-react by gagging when you try to switch from strained foods to thicker, more textured or lumpy foods, you probably need to make the transition more slowly.
- Toothbrushing with a regular or electric toothbrush can help, but should only be done with guidance from a speech and language therapist or occupational therapist.
- Wipe the face regularly with warm cloths or soft sponges, using deep pressure. This can be calming.

Drooling or dribbling

The ability to swallow saliva is normally learnt automatically and most adults swallow the 1 to 1.5 litres of saliva produced a day on 1,000 to 2,000 swallows.¹⁰ Saliva control depends largely on trunk stability and head control, being aware of the need to swallow, and factors such as positioning, fatigue and drugs taken. Dribbling can be a common problem among people with learning disabilities and can lead to sore mouth, dry mouth, eating difficulty, gum or dental problems and dehydration, as well as being embarrassing. Drooling or dribbling can also be linked to swallowing difficulties (see page 28). Individuals who drool may need higher fluid intakes.

What can help?

- Good positioning – being well supported and upright with an elongated back of the neck – will help with jaw stability.
- Gently dry the mouth with a small piece of absorbent cloth, explaining what is happening and using small dabs so as not to over-stimulate the mouth.
- Special clothing or the creative use of scarves which can be frequently replaced may help with embarrassment.
- Behaviour modification or the development of oral control may be possible among some people.¹⁰
- Some drugs can be used but these may have side effects such as drying the eyes as well as the saliva, and increasing thirst.
- Travel bands designed to alleviate nausea associated with travel sickness have been anecdotally suggested as useful for some people with mild dribbling.

Bruxism (teeth grinding)

Teeth grinding might be related to oral pain or discomfort, or to anxiety, medication or communication difficulties, and dentists should work with family, friends and support staff to look at potential causes of bruxism. Bite guards may be helpful but should only be used after careful discussion with dentists.

Other problem behaviours around food and drink

Some people with learning disabilities may exhibit a number of other eating behaviours which support staff may find very distressing to deal with. It is frequently reported anecdotally that people with learning disabilities may use behaviour around food to communicate their distress – for example, if they have changed carer or place of residence, or if habits and patterns they are used to are disrupted. It is essential that routines around food and drink and mealtimes are respected, that as much information as possible is gathered from family carers about preferences and habits, and that care is taken to interpret signs and signals from the individual about their choices around food. Taking the time and trouble to understand the causes of people's behaviour and address any underlying issues may prevent considerable distress.

The observed behaviours on the next two pages, and the suggestions for dealing with them, may be useful in dealing with problem behaviour around food for people with learning disabilities including those with dementia. With more extreme eating difficulties, help should be sought from a GP to exclude any underlying physical ill health, or from psychologists and other team professionals within learning disability services as well as psychiatrists.

Observed behaviour

Suggestions for dealing with the behaviour

Style of eating and pattern of intake

Incorrectly uses spoon, fork or knife	Try verbal cues and show correct use. The person may benefit from additional aids or devices. Consult with occupational therapist.
Incorrectly uses cup or glass	Try verbal cues and show correct use. Offer a cup with handles, or a straw.
Unable to cut meat	Provide cut meats, soft meats or finger food.
Difficulty getting food onto utensils	A plate guard or lipped plate may help. Finger foods may take the pressure off cutlery use.
Plate wanders on the table	Use a no-skid placemat or suction plate.
Eats desserts or sweets first	Serve meal components one at a time and keep desserts or sweets out of sight until the main course is finished.
Eats too fast	Offer food in small portions. Provide verbal cues to slow down, and model slower eating. Reassure the person that there is plenty of food available and it will not run out.
Slow eating and prolonged mealtimes	Serve small portions at a time so the food stays warm, and offer second helpings.
Eats other people's food	Sit between the client and other people or keep other people's food out of reach. Serve small amounts of food at a time.
Eats non-food items	Take non-food items away and replace with food or drink or another distraction. Remove commonly eaten non-food items from reach and use simple picture cues to remind people what is not edible. Make sure the diet includes good sources of iron and zinc every day.
Mixes food together	Ignore as long as the food is eaten.
Drinks excessively	Ensure that a variety of drinks are offered regularly by the glass, cup or mug. Encourage individuals to sit and drink with friends and support staff. Distract people from drinking, with other activities that they enjoy. Offer small, regular drinks or ice lollies during the day. Store drinks in individual sized bottles or drinks containers.

Observed behaviour

Suggestions for dealing with the behaviour

Resistive or disruptive behaviour

Hoard, hides or throws food	Remove items. Keep the number of items on the table to a minimum. Serve small portions.
Interrupts food service or wants to help	Give the person a role in the meal service – such as setting the table, or pouring water.
Plays with food	Remove the items. Serve smaller portions.
Distracted from eating	Make sure the room is calm and quiet, that the person has everything needed for the meal (eg. has been to the toilet, has their glasses, dentures or hearing aid if needed, and is sitting comfortably). Other people modelling eating may help.
Stares at food without eating	Use verbal or manual cues to eat: place food or utensils into the person's hands. Model eating and offer encouragement.
Demonstrates impatient behaviour during or before a meal	Make sure that people are not alerted to meals too early, that they are offered something to eat if they have to wait for a meal to arrive, or that meals are served in small courses to minimise waiting times.
States 'I can't afford to eat' or 'I can't pay for this meal'	Make sure that the person is not depressed. Provide meal tickets or vouchers.
Wanders during mealtimes and is restless	Make sure that mealtimes are calm and try and encourage people to eat together. If wandering persists and food intake is compromised, encourage the person to use finger food while wandering. If there is a time of day when the person will sit for longer periods (for example, first thing in the morning), ensure a good variety of foods is on offer.

Oral behaviour

Consult with a speech and language therapist about these problems. For more detailed information on handling swallowing difficulties, see page 74.

Difficulty chewing	Provide foods that are easier to chew. Check dental health.
Prolonged chewing without swallowing	Liaise with speech and language therapist. Use verbal cues to chew and swallow.
Does not chew food before swallowing	Use verbal cues to chew. Purée and thicken food if choking is a hazard.
Holds food in the mouth	Use a verbal cue to chew. Massage the cheek gently. Offer small amounts of different foods and flavours.
Bites on spoon	Use a plastic-coated spoon.
Spits out food	Check that the food is liked, that the temperature is appropriate, and that the food is of an appropriate texture.
Doesn't open mouth	Use a verbal cue to open the mouth. Touch the lips with a spoon. Use straws for drinks.

Identifying distress among people with moderate to severe communication difficulties

Difficulties with eating and drinking can cause distress – either because of the eating and drinking difficulty itself, or because of the effects of lack of nutrition or hydration. People with a learning disability who have difficulty communicating can find it hard to make clear the cause of their distress, or may not even be able to make it clear that they are distressed. This is a major barrier to identifying the problem and convincing healthcare professionals that a problem exists. For those who have communication difficulties, pain and discomfort may be expressed by a range of changes¹¹ such as:

- eating less
- sleeping less or more
- whimpering, crying or screaming
- appearing irritable, unhappy or withdrawn, or seeking comfort
- grimacing, cringing, frowning, clenching or grinding teeth, or thrusting the tongue
- being less active or more agitated
- having floppy or tense limbs, gesturing to or protecting the part of the body that hurts
- shivering, changing colour or sweating.

In the late 1990s a combined learning disability and palliative care team at Northgate Hospital in Northumberland began to explore the issue of identifying distress in people with severe communication difficulties. They made three observations:

- Family, friends and support staff were skilful at identifying distress, but had little confidence in that skill.
- This lack of certainty in what support staff were observing made it difficult for them to advocate for the person with the communication difficulty when faced with a challenge to their observation.
- A number of pain score tools existed for people with cognitive impairment, even though there was no research evidence that pain produced any specific signs or behaviours.

This resulted in the development of DisDAT (Disability Distress Assessment Tool).^{12, 13} DisDAT is intended to help identify distress cues in people who have severely limited communication because of cognitive impairment or physical illness. It documents the ‘cues’ people give when they are contented and compares these with the person’s distress cues, thus enabling distress cues to be identified more clearly. It includes a checklist to help identify the cause of the distress. The DisDAT tool is not a scoring tool;

it simply documents what many staff have done instinctively for many years, providing a record against which subtle changes can be compared. The tool can be used by family, friends and support staff and increases their confidence in the observational skills they already have. It provides a clearer picture of a person’s ‘language’ of distress, but is still only one step in the process of identifying the distress. The DisDAT tool is available free online, from www.DisDAT.co.uk.^{14, 15}

KEY MESSAGES

Monitoring nutritional status

- All support staff should be able to make simple nutritional assessments that might alert them to changes in the nutritional status of those they care for.

Maintaining independence in eating, and helping people to eat

- Those who are able to eat independently, even if this is by hand only, should be encouraged to do so to maximise independence and dignity. If independent eating skills are not encouraged, there may be a rapid decline to dependence.
- Where people need help with eating, it is essential for staff to be trained in helping them to eat and to do this in a sensitive and efficient way.

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- 15 Mencap website:
<http://www.mencap.org.uk/html/campaigns/deathbyindifference/goodpractice.asp> (scroll down to DisDAT – assessment tool)



Chapter 10 **Nutrient-based standards and food-based guidance**

This chapter provides nutrient-based standards for children, young people and adults with learning disabilities, as well as food-based guidance, for those who provide food and drink for groups of children, young people or adults with learning disabilities.

Nutrient-based standards specify the amounts of nutrients that should be provided to a group of people over a period of time to ensure that the nutritional needs of the majority of people in that group are met. They are based on the *Dietary Reference Values for Food Energy and Nutrients for the UK*¹ and guidance from the Scientific Advisory Committee on Nutrition (SACN) on salt intakes.² Nutrient-based standards provide a numerical but flexible framework around which caterers can plan their menus.

The food-based guidance on pages 120-125 makes suggestions about the sorts of foods that people are advised to choose to ensure that nutritional needs are met. Nutrient-based standards take this a step further by asking people to account more closely for the nutritional quality of foods served and the ingredients in recipes, to ensure that food of the right quality

and quantity is available. Adopting nutrient-based standards sends a clear message that policy makers take the promotion of good nutrition seriously and are willing to invest in supporting people to eat better.

Nutrient-based standards

The nutrient-based standards for food and drink for children, young people and adults shown on the next page should become minimum standards for all residential, day care and other settings where children, young people or adults with learning disabilities are provided with food and drink.

Government departments should make reference to the nutrient-based standards and practical guidelines in this report in all guidance and legislation affecting residential, day care and domiciliary support for children, young people and adults with learning disabilities.

All those responsible for legislative change to national minimum care standards for residential, day care and domiciliary care should include standards which will ensure children, young people and adults are supported in all settings by staff and managers who are competent in enabling service users to eat well.

The information and advice in this chapter is particularly aimed at those catering for groups of people in care settings since nutrient-based standards relate to groups of people rather than individuals. However, in chapter 11 we give some examples of eating plans that would meet the nutrient-based standards. These will be useful for all those who support people with learning disabilities to make food choices (those who provide food either for groups or for individuals), as they give an idea of the types and amounts of foods that can provide all the nutrients needed.

The nutrient-based standards in Table 2 on the next page give figures for the recommended nutrient content – of fibre, protein and some important vitamins and minerals – of an average day's food and drink that should be provided over a period of a week or more. The amounts of energy, fat and carbohydrate for each age group have not been specified here since there are likely to be significant differences among individuals with learning disabilities in the amount of energy (and therefore fat and carbohydrate) they need each day, as explained on page 118.

The nutrient-based standards given in Table 2 show the amounts of nutrients that are recommended for groups of people to ensure that the majority of members of the group have sufficient for their needs. The figures give an

average for a whole day – but typically we calculate average daily intakes over a period of at least a week rather than on a daily basis, as some foods which might be very nutrient-dense may not be eaten every day.

Main meals

Adults

For adults aged 19 and above, nutrient-based standards are given both for 'all day' and 'main meal'. Where main meals are served, it is suggested that this main meal should provide 35% of the minimum nutrient-based standards. Meals are likely to provide a greater proportion of micronutrients than snacks and for this reason it would seem prudent to ensure that main meals provide a slightly higher proportion of micronutrients than they might provide of energy (on the assumption that most meals provide about 30% of daily energy intakes). The exception to this is for sodium and salt where meals should provide no more than about 30% of the total daily intake.

Children and young people

Information on nutrient-based standards at mealtimes for children aged under 5 can be found in the CWT report *Eating Well for Under-5s in Child Care*. Children of school age who eat a main meal at school are covered by the relevant school meal guidance in their area (see page 89).

Iron

For adults, an average iron intake of 12mg a day has been suggested as the nutrient-based standard. This is likely to meet the needs of all men, all women over the age of 50 years or who do not menstruate, and more than half of women aged 19-50 years. The average iron intake of women in the UK is about 10mg a day from food sources (or 11.6mg a day if supplements are included).³ Approximately 8% of women are found to have low haemoglobin levels (indicating anaemia) and about 11% have low serum ferritin values (indicating that they may be at risk of iron deficiency).⁴ There is little information available on the iron status of women with learning disabilities, but for all women lower intakes and lower iron status are more frequently reported among younger women. For those women who have higher iron needs (either because they have heavy menstrual losses or because they have been found to have low haemoglobin or serum ferritin levels), good sources of iron should be included in the diet regularly (see page 44) and, if iron status is found to be low, iron supplementation should be considered after consultation with a medical practitioner.

Zinc

Men have a higher requirement for zinc than women, but zinc is an important nutrient that is frequently low in the diets of adults in the UK. Recent data suggests that 43% of men and 45% of women fail to achieve the reference nutrient intake (RNI) for zinc.¹ (An explanation of RNI is given on the right.) It is therefore likely that many adults with learning disabilities may also have zinc intakes below the RNI. Zinc is important for a wide range of enzymes involved in body processes and is particularly important for the immune system and for wound healing. It is therefore very important that menus provide adequate amounts of zinc to meet the needs of those with the greatest needs in the group. For this reason the RNI for zinc for men (9.5mg per day) is suggested as the nutrient-based standard for groups of people with a learning disability.

Dietary reference values (DRVs)

Dietary reference values are quantified nutritional guidelines for energy and nutrients. They apply to groups of people; they are not intended for assessing individual diets.

Reference nutrient intake (RNI)

The reference nutrient intake is the amount of a nutrient that is likely to meet the requirements of nearly everybody in a group. Reference nutrient intakes have been set for protein and for most vitamins and minerals.

Estimated average requirement (EAR)

The amount which satisfies 50% of people in a group.

Table 2 Nutrient-based standards for children, young people and adults with learning disabilities

The table below provides figures for the recommended nutrient content of an average day's food and drink over a period of one week or more for fibre, protein and selected vitamins and minerals. Standards for an average main meal for adults aged 19+ are also provided. A discussion about intakes of energy, carbohydrate and fat can be found on page 118. Some examples of how these standards can be achieved are shown on pages 129-131.

Nutrient		DRV		Children	Children	Young	Adults 19+ years	
				1-4 years	5-10 years	people 11-18 years	All day	Main meal
				All day	All day	All day	All day	
Fibre	g	DRV	MIN	-	14	18	18	6.3
Protein	g	RNI	MIN	15.8	25.4	45.9	50	17.5
Vitamin A	µg	RNI	MIN	425	500	600	650	230
Vitamin C	mg	RNI	MIN	30	30	37.5	40	14
Folate	µg	RNI	MIN	60	130	200	200	70
Calcium	mg	RNI	MIN	375	520	900	700	245
Iron	mg	RNI	MIN	6.7	7.8	13.1	12	4.2
Zinc	mg	RNI	MIN	5.4	7.0	9	9.5	3.3
Sodium	mg	SACN	MAX	900	1,800	2,400	2,400	720
Salt	g	SACN	MAX	2.3	4.5	6	6	1.8

- All children aged 1-4 years should receive a daily vitamin supplement containing vitamins A, C and D (see www.healthystart.nhs.uk).
- For information on vitamin D supplements, see page 47.
- For information on folic acid supplements for women who are planning a pregnancy or who are pregnant, and on vitamin D supplements for pregnant women, see www.healthystart.nhs.uk and page 54.

DRV = Dietary reference value
 RNI = Reference nutrient intake
 SACN = Scientific Advisory Committee on Nutrition²
 See above for an explanation of DRV and RNI.

Sodium (salt)

The nutrient-based standards for salt given in Table 2 are based on current recommendations that the adult population should have no more than 6g of salt per day. This may be difficult to achieve for those with higher energy needs, since foods such as bread which might be eaten in higher quantities are often high in salt. For the population as a whole, salt reduction will be aided by the gradual reduction of the sodium content of manufactured foods and everyone should be encouraged to choose lower-salt foods where possible and to adapt recipes to reduce the amount of salt used. While 6g has been set as the nutrient-based standard, some flexibility might be required in menu planning, and caterers should look holistically at the foods served and the ingredients used rather than making artificial or unpalatable changes solely to achieve a 'standard'.

Energy (calories)

People require a different amount of energy (calories) depending on their levels of activity as well as their gender and basic bodily needs (basal metabolic rate, or BMR, which is based primarily on age and body weight). Adults who are physically small, and those who are very inactive, will have lower energy needs. (Inactivity is common among people with learning disabilities and this may be due to immobility of adults with specific physical challenges or due to lack of support for, or disinclination to, exercise.⁵) Adults who are larger, and those who walk, pace or shake constantly are likely to have greater energy needs.

The range of energy needs for people with learning disabilities will therefore vary widely and it is important that everyone is aware of the types of foods and amounts of foods that are needed by people who are more or less active or have greater or lesser needs. Even when energy intakes are lower, the amounts of most micronutrients (vitamins and minerals) required remain the same, and so it is important that caterers are aware that low-energy diets need to be nutrient-dense (that is, they need to be high in vitamins and minerals).

Table 3 Examples of energy intakes which may be appropriate for population groups with differing energy needs

These figures are examples only, to demonstrate the ranges of energy intake that may exist, and are not intended as recommendations or standards. See *Energy* above for an explanation of how these figures have been calculated.

		Dietary reference value (DRV)		Inactive and low body weight *		Weight-reducing	Moderately active	Very active	
				M	F			M	F
Energy	kcal MJ	EAR		1,780 7.45	1,360 5.69	1,440 6.02	2,240 9.37	3,200 13.39	2,450 10.25
Fat	g	No more than 35% of energy	MAX	69.2	52.8	56.0	87.1	124.4	95.3
Saturated fat	g	No more than 11% of energy	MAX	21.8	16.6	17.6	27.4	39.1	29.9
Total carbohydrate	g	At least 50% of energy	MIN	237.3	181.3	192.0	298.7	426.7	326.7
Non-milk extrinsic sugars	g	No more than 11% of energy	MAX	52.2	39.9	42.2	65.7	93.9	71.9

* Some people who are inactive and have very small appetites may need to have a diet which provides a greater proportion of energy from fat and sugar in order to prevent weight loss. These figures are for those who do not have special dietary needs.

DRV = Dietary reference value

EAR = Estimated average requirement

See page 117 for an explanation of DRV and EAR.

Estimated energy requirements for adult populations have been suggested⁶ and a range of figures can be estimated for those who are inactive, those who are moderately active and those who have greater energy needs, for example because they are very active. These differences are based on variations in the physical activity levels (PAL) for different population groups. The PAL is multiplied by the estimated BMR to give a daily calorie intake but will vary depending on a person's weight, age and gender. To give some idea of the energy requirements that might be estimated for different population groups, some examples have been outlined in Table 3 based on the following:

- For groups of **inactive** people of **low body weight** (for example, someone who is chairbound and of small stature), PAL has been taken as 1.1 and average body weight as 50kg.
- For groups of people who are **moderately active** for at least 30 minutes a day and need to maintain their weight, PAL has been taken as 1.4.
- Those who need to **reduce their body weight** are likely to require approximately 800kcal less than the average energy requirement (based on an average 1.4 PAL) to reduce body weight by about 1kg per week.
- For **very active** groups of people who have higher energy needs (for example, people who are very active, or who pace or shake constantly), PAL has been taken as 1.8.

It is important to remember that individuals may have energy needs that are significantly lower or higher than these and anyone who is underweight or overweight or who has eating difficulties needs individual dietary advice. **The figures in Table 3 are examples only, to demonstrate the ranges of energy intake that may exist, and are not intended as recommendations or standards.**

The figures in Table 3 are based on a population where 50% of people are aged 19-29 years and 50% are aged 30-59 years, but these figures are applicable to adults of all ages unless they have special dietary needs. For those who may have very low or very high energy needs, differences are shown by gender, but for populations of moderately active people and those who may need to reduce weight, average values have been given for mixed gender populations.

Food-based guidance

This section, including the tables on pages 121-125, contains some information about the five food groups and how to choose foods which will contribute to a healthy balanced diet.

It is also useful to look at the nutrition information labels and ingredients lists on foods, and to choose those that are lower in salt, sugar and fat.

The Food Standards Agency provides information on what is 'a lot' of and 'a little' salt, sugar and fat in foods. This is outlined below.

Foods high in fat have more than 20g of fat per 100g of food	Foods low in fat have 3g of fat or less per 100g of food
Foods high in saturated fat have more than 5g of saturated fat per 100g of food	Foods low in saturated fat have 1.5g of saturated fat or less per 100g of food
Foods high in sugar have more than 15g of sugars per 100g of food	Foods low in sugar have 5g of sugars or less per 100g of food
Foods high in salt have more than 1.5g of salt per 100g of food or more than 0.6g (600mg) of sodium per 100g of food	Foods low in salt have 0.3g of salt or less per 100g of food or 0.1g (100mg) of sodium or less per 100g of food

Source: [www.eatwell.gov/healthy diet](http://www.eatwell.gov/healthy-diet)⁷

For more information about nutritional information on food labels see www.eatwell.gov.uk

Table 4 Food-based guidance for food served to adults with learning disabilities, aged 19-74 years

Food group	Guidance	Rationale	What's included
<p>Bread, other cereals and potatoes</p>	<p>Starchy foods should make up a third of the daily diet.</p> <p>A variety of breads should be available daily at every meal.</p> <p>Different starchy foods should be offered in main meals throughout the week so that a variety of starchy foods are included. Aim to include pasta and rice on the menu once a week.</p> <p>Wholegrain and wholemeal cereal foods are a good source of fibre and other nutrients.</p>	<p>Starchy foods are a good source of energy and the main source of a range of nutrients in the diet. As well as starch, these foods supply fibre, calcium, iron, and B vitamins.</p>	<p>All varieties of bread including wholemeal, granary, seeded, chapattis, bagels, roti, tortillas and pitta bread</p> <p>Potatoes, yam, sweet potato, plantain, cocoyam, dasheen, breadfruit and cassava</p> <p>Breakfast cereals</p> <p>Rice, couscous, bulgar wheat, maize (polenta) and cornmeal</p> <p>Noodles, spaghetti and other pastas</p>

Tips

- Serve more pasta and rice and use less sauce. Opt for tomato-based sauces instead of cheese-based sauces.
- When serving rice and pasta, try to use wholemeal, wholegrain, brown or high-fibre versions.
- Some breakfast cereals are nutrient-fortified (that is, with added iron, folic acid and other vitamins and minerals). Choose wholegrain cereals or mix some in with other cereals.
- Offer a variety of breads, such as seeded, wholegrain and granary, and use thicker slices with low-fat options for fillings.
- If you are making chips or fried potatoes, use large pieces of potato and thick or straight-cut chips as these absorb less fat.
- Baked potatoes do not need to have butter or margarine added when served with moist fillings or sauces.
- For people who avoid gluten in wheat, oats, barley and rye, good alternatives to offer are foods made from maize (eg. polenta), rice, rice flour, potatoes, potato flour, buckwheat, sago, tapioca, soya and soya flour.
- Cereal foods which are good sources of iron and zinc include fortified cereals, wholegrain cereals, wholemeal bread and flour, couscous and wholemeal pasta.

Food group	Guidance	Rationale	What's included
Fruit and vegetables	<p>Fruit and vegetables should make up about a third of the daily diet.</p> <p>It is important to offer a variety. 5 a day is an achievable target.</p> <p>Aim for 1 or 2 portions with each meal and offer fruit and vegetables as snacks.</p> <p>One portion is about 80g of fresh fruit or vegetables.</p> <p>A glass of 100% fruit juice can count as 1 portion of fruit each day.</p>	<p>Fruit and vegetables are good sources of many vitamins and minerals.</p> <p>There is evidence that consuming 400g a day or more of fruit and vegetables reduces the risk of developing chronic diseases such as coronary heart disease and some cancers.</p> <p>Including fruits and vegetables in the diet will help to increase the intake of fibre and can help to reduce the total amount of calories consumed among those who may wish to lose weight.</p>	<p>All types of fresh, frozen and tinned vegetables, eg. broccoli, Brussels sprouts, cabbage, carrots, frozen peas, peppers, swede and sweetcorn</p> <p>Beans and pulses, including baked beans, chick peas and kidney beans</p> <p>All types of salad vegetables including lettuce, cucumber, tomato, raw carrots, peppers and beetroot</p> <p>All types of fresh fruit, eg. apples, bananas, kiwi fruit, oranges, pears, mango and plums</p> <p>All types of tinned fruit in fruit juice, eg. pineapple, peaches and mandarin oranges</p> <p>Stewed fruit</p> <p>Dried fruit</p> <p>Fruit juice (100% juice)</p>
<p>Tips</p> <ul style="list-style-type: none"> • Steaming or cooking vegetables with minimum amounts of water and serving as soon as possible will help retain vitamins. • Use fresh fruit and vegetables as soon as possible, rather than storing, to avoid vitamin loss. • Incorporate fruit and vegetables in snack options. Offer a variety of healthy snack alternatives. • Add vegetables and pulses to curries, casseroles or stir-fry dishes and serve at least two types of vegetables with fish, chicken or meat. • Baked beans (as a vegetable) should be served a maximum of twice a week. • Encourage a daily glass of fruit juice (100% juice, unsweetened) with meals. • Add a handful of dried fruit to cereal options and porridge. • Offer traditional salads as well as raw vegetables, to increase colour, taste and texture at mealtimes. • Add extra vegetables to savoury dishes. • Vegetable soups are a useful way of increasing vegetable intake. • Avoid dried fruit that has added sugar or vegetable oil. • Fruit and vegetables which are useful sources of iron include spinach, broccoli, spring greens, dried apricots, raisins, baked beans, broad beans and blackcurrants. • Fruit and vegetables which are useful sources of folate include spinach, broccoli, peas, oranges, melon, green leafy salads and tomatoes. • Fruit and vegetables which are useful non-dairy sources of calcium include green leafy vegetables, dried fruit and oranges. 			

Food group	Guidance	Rationale	What's included
Milk and dairy products	<p>Offer dairy foods such as milk, yoghurt and cheese as part of meals and snacks.</p> <p>Offer low-fat options such as semi-skimmed milk, low-fat yoghurt and skimmed milk cheeses.</p> <p>Do not rely on cheese as the main protein item for vegetarians.</p>	<p>Milk and dairy products are good sources of calcium, protein and vitamin A. Calcium helps to contribute to good bone health.</p> <p>The fat content of different dairy products varies and much of this is saturated fat.</p>	<p>Skimmed, semi-skimmed, whole milk</p> <p>Dried milk, goat's and sheep's milk</p> <p>All types of cheeses eg. Cheddar cheese, cottage cheese, cheese spreads, Brie, feta, Edam, goat's cheese, stilton and parmesan</p> <p>Yoghurt Fromage frais</p>

Tips

- Choose reduced-fat hard cheeses, cottage cheese and skimmed-milk soft cheese.
- Some dairy products can contain high levels of salt. Look for lower-salt cheeses and use smaller amounts of stronger cheese.
- Offer semi-skimmed or skimmed milk and low-fat yoghurts and fromage frais.
- Use plain yoghurt and fromage frais instead of cream, soured cream or crème fraîche in recipes.
- Try serving frozen yoghurts as an alternative to ice cream.
- For those on dairy-free diets, serve soya drinks fortified with calcium as an alternative.
- Restrict sweetened milk drinks to mealtimes as the sugars in these drinks can damage teeth.

Food group	Guidance	Rationale	What's included
Meat, fish and meat alternatives	Offer a variety of meat and meat alternatives at main meals.	Meat and meat alternatives are a good source of protein, vitamins and minerals such as iron and zinc.	Meat includes all cuts of beef, pork, lamb, poultry, offal* and meat products such as bacon, sausages, beef burgers, pies and cold meats.
	Use lean meat.	Some meat and meat products can have a high fat and saturated fat content.	
	Fish should be offered at least twice a week.	White fish is low in fat.	Fish includes fresh, frozen and tinned fish, such as tuna and sardines. Fish products such as fish cakes and fish fingers may have a low fish content.
	It is strongly recommended that oily fish – such as salmon, trout, mackerel, herring, pilchards or sardines – should be served once a week.	Oil-rich fish provides a good source of omega-3 fats, which may help to protect against heart disease. Oil-rich fish are also a source of vitamins A and D.	
	Eggs can be served at breakfast and as part of main meals.	Eggs are a good source of protein, vitamin A, vitamin D and some minerals.	Boiled, poached or scrambled eggs, or omelettes
Ensure meat alternatives for vegetarians are varied.	Beans, pulses, eggs, meat alternatives and nuts all provide good sources of nutrients.	Beans and pulses such as chick peas, lentils, kidney beans, butter beans, textured vegetable protein, nuts, Quorn, and soya products such as tofu	

Tips

- Always choose the leanest cuts of meat and remove visible fat and poultry skin.
- Roast meat on a rack in order to let the fat run off.
- Grill, poach or bake meat rather than frying. If you do fry, use clean oil and at the correct temperature to minimise absorption. Note that larger pieces of fish and meat absorb less fat.
- Do not add extra fat or oil when cooking meat.
- Use more vegetables, pulses and starchy food to extend dishes further, and to add more texture and flavour. Less meat is also required, reducing the fat content and the cost of the meal.
- Buy good-quality meat and use smaller amounts.
- Offer unsalted nuts and seeds as snacks.
- Reduce the amount of processed meat products served, such as meat pies and pasties, sausages, burgers and coated chicken products.
- Reduce the amount of processed fish products on offer, particularly those that are fried or coated such as fish fingers or fish cakes.

* Liver and liver pâté are very rich in vitamin A and it is recommended that these foods are consumed no more than once a week. For more information see Review of Dietary Advice on Vitamin A.⁸

Food group	Guidance	Rationale	What's included
<p>Foods containing fat, and foods and drinks containing sugar</p>	<p>These foods can add palatability to the diet but should be eaten in small amounts each day.</p> <p>Reduce the amount of foods containing fat – for example, margarine and butter, cooking oils and mayonnaise.</p> <p>Other foods containing fat – such as cakes and biscuits – should be eaten only occasionally.</p>	<p>Foods containing fat and foods containing sugar often provide a lot of calories and a lower proportion of other nutrients.</p> <p>Some foods in this group are also high in sodium/salt.</p> <p>Foods and drinks containing sugar often contain few other nutrients and frequent consumption between meals can contribute to tooth decay.</p>	<p>Foods containing fat include:</p> <p>butter, margarine, other spreading fats and low-fat spreads, cooking oils, oil-based salad dressings, mayonnaise, cream, chocolate, crisps, biscuits, pastries, cakes, puddings, ice cream, rich sauces, and gravies.</p> <p>Foods and drinks containing sugar include: soft drinks, sweets, chocolate, jams, sugar, cakes, puddings, biscuits, pastries and ice cream.</p>

Tips

- Use fat spreads rich in monounsaturated or polyunsaturated fats.
- Use cooking oils high in monounsaturates such as soya, rapeseed or olive oils.
- Avoid serving pastry dishes frequently.
- Measure oil for cooking carefully and reduce the amount of oil used in the preparation of soups, stews and casseroles. Vegetables can often be dry-fried, steamed or stewed to form the basis of sauces and other dishes.
- Use low-fat yoghurt or non-dairy ice cream to complement puddings or pies.
- Produce puddings lower in fat and sugar and incorporate fresh fruit, tinned fruit in juice or dried fruit.
- Offer water, unsweetened fruit juices and chilled milk drinks.
- Serve wholegrain or plain cereals rather than sugar-coated cereals.
- When preparing sandwiches, try and avoid using butter or spreads if the filling is already moist.

To increase the amount of dietary vitamin D in menus

- Use margarine fortified with vitamin D for baking and as a fat spread.
- Include an oily fish that is rich in vitamin D in the menu at least once a week – for example, herring, mackerel, pilchards, salmon, sardines, trout or roe. These fish contain between 5 and 14 micrograms of vitamin D per 100g.
- Canned tuna fish can also make a significant contribution to vitamin D intake as it contains about 3.6 micrograms of vitamin D per 100g.
- Egg yolks are rich in vitamin D, and eggs contain about 2.0 micrograms of vitamin D per 100g.
- Meat and poultry contribute small but significant amounts of vitamin D.

References

- 1 Department of Health (1991) *Dietary Reference Values for Food Energy and Nutrients for the United Kingdom. Report on Health and Social Subjects No 41*. London: HMSO
- 2 Scientific Advisory Committee on Nutrition (2003) *Salt and Health*. London: TSO
- 3 Henderson L, Irving K, Gregory J et al (2003) *The National Diet and Nutrition Survey: Adults Aged 19-64 Years. Volume 3 Vitamin and Mineral Intakes and Urinary Analytes*. London: TSO
- 4 Ruston D, Hoare J, Henderson L et al (2003) *The National Diet and Nutrition Survey: Adults Aged 19-64 Years. Volume 4 Nutritional Status (Anthropometry, Blood Analytes), Blood Pressure and Physical Activity*. London: TSO
- 5 Prasher VP and Janicki MP (eds) (2002) *Physical Health of Adults with Intellectual Disabilities*. Oxford: Blackwell Publishing
- 6 Shetty P (2005) Energy requirements of adults. *Public Health Nutrition*; 8: 994-1009
- 7 www.eatwell.gov.uk/healthydiet.
- 8 Scientific Advisory Committee on Nutrition (2005) *Review of Dietary Advice on Vitamin A*. London: TSO



Chapter 11 **Menu planning and special diets**

This chapter contains some example eating plans which give an idea of the types and amounts of foods which meet the nutrient-based standards given in chapter 10. It also includes information on finger foods, special diets such as textured and puréed diets, and on fortified foods and food supplements.

The nutrient-based standards shown in chapter 10 provide a framework around which caterers and support staff can plan suitable menus for groups of children, young people and adults with learning disabilities. It is also useful to have examples of eating plans for those people with learning disabilities who live independently, to show the types of foods and amounts of foods that people typically need over a week.

Meeting the nutrient-based standards

To use nutrient-based standards effectively in group settings requires either the support of a registered dietitian or simple tools for use by those who plan menus or provide food for others. The Caroline Walker Trust pioneered the development of computerised menu planning tools which allowed caterers and others to easily and quickly put together menus which

meet nutrient-based standards for groups of the population from a detailed database of foods and drinks for which nutrient analysis had already been calculated. Suitable computer menu planning tools are available for use in a number of settings and it would be helpful if a tool were designed specifically to provide guidance for those who cater for groups of adults in residential care settings. Menu planning software can be purchased from www.nutmeg-uk.com.

Menu planners should ensure that any menu analysis software they do use is based on nutrient values for cooked foods and recipes, and that recipe analysis is provided by a registered dietitian or registered public health nutritionist.

The cost of a good diet

There is no evidence that providing the raw materials for a healthy diet costs any more than for a less healthy diet, but the amount of time and resources spent cooking may well be greater. There is little clear information on the cost of food for people with learning disabilities in residential care, or on how much people may typically spend on their food if they live independently. The average amount spent per person per week on food and drink throughout the UK to be consumed at home in 2005 was £23.56 (from the Expenditure and Food Survey¹) but costs obviously vary depending on the number of people per household. The example eating plans on pages 129-131 have been costed based on current (2007) supermarket prices and it is estimated that a food budget of £27-£30 is likely to be needed for an individual to achieve the minimum nutrient-based standards shown on page 117 and to follow the food-based guidance on pages 120-125.

Sustainability

Concerns about the environmental impact of food travelling long distances, intensive farming and dwindling stocks of some fish have prompted Government and many local authorities to encourage more sustainable procurement policies for the buying of food. Responsibility for food purchasing will vary in different settings, but those who are responsible for buying food or helping others to shop are encouraged to buy food that is grown locally and that is in season. Where possible, people should consider buying fish with the Marine Stewardship Council logo, which ensures it is from a sustainable source.

Food waste is another important issue as this wastes the resources used to grow and transport the food, and food

placed in landfill sites will emit methane gas. If significant amounts of food are regularly wasted in a care setting then an audit of what is wasted, and when, might be useful.

Reducing the amount of food purchased pre-packed, recycling and composting food packaging and other waste and growing your own fruit and vegetables where possible can all help to reduce global greenhouse gas emissions.

Example eating plans

The eating plans for adults shown on pages 129-131 act as examples of the sorts of foods and amounts of foods that will meet the nutrient-based standards. For simplicity and clarity these are presented as guides to how foods and drinks might be consumed throughout the day rather than as formal menu plans. In many circumstances a choice of foods at mealtimes is required and caterers need to ensure that any menus they design meet minimum care standards that are applicable in their setting. These eating plans may not be suitable for all individuals and many people will require individual advice or support on what a suitable diet may be for them.

We hope people will find the eating plans useful as a guide. Example menus and eating suggestions for children under 5 years and for children and young adults can be found in the CWT reports *Eating Well for Under-5s in Child Care*, *Eating Well for Looked After Children and Young People* and *Eating Well at School*.

Example eating plans

These eating plans are just examples of the sorts of foods and amounts of foods that would meet the nutrient-based standards for adults on page 117, and are presented here just to give an idea of some healthy daily menus. Weights in grams have been added to indicate portion sizes, as these may be used when planning menus with computer software. In many circumstances a choice of foods at mealtimes is required. These eating plans may not be suitable or liked by all individuals and many people will require individual advice or support on what a suitable diet may be for them.

Breakfast

Grapefruit segments 120g
Shredded wheat 22g with semi-skimmed milk 100g
2 slices wholemeal toast 31g with polyunsaturated margarine 10g and reduced-sugar jam 15g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water and fresh fruit juice available

Mid-morning snack

Slice of malt loaf 35g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Lunch

Roast sliced turkey with gravy 145g
Sage and onion stuffing 30g
Roast potatoes 180g
Carrots 80g and broccoli 80g
Lemon meringue pie 100g
Drinking water and fresh fruit juice available

Mid-afternoon snack

Fresh apple slices 80g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Evening meal

Green pea soup 200g
Wholemeal or white bread sandwich with tuna and sweetcorn filling 70g
Low-fat fruit yoghurt 125g
Drinking water and fresh fruit juice available

Late evening snack and drink

Hot chocolate drink 218g
Digestive biscuit 13g
Drinking water available

Breakfast

Scrambled egg 110g
2 slices wholemeal toast 31g, with polyunsaturated margarine 10g and marmalade 15g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water and fresh fruit juice available

Mid-morning

Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Lunch

Houmous 100g
2 slices of wholemeal or white toast
Mixed green salad 70g and sliced tomato 85g
Canned pears in juice 140g with fromage frais 60g
Drinking water and fresh fruit juice available

Mid-afternoon snack

Slice of banana bread 70g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Evening meal

Pasta Roma 320g
Roasted vegetables 150g
Chocolate mousse 80g with gingernut biscuit 15g
Drinking water and fresh fruit juice available

Late evening drink

Ovaltine drink 218g
Drinking water available

Breakfast

Apricots, canned in juice 140g
Puffed wheat 40g and semi-skimmed milk 100g
2 slices wholemeal toast 31g, with polyunsaturated margarine 10g and reduced-sugar jam 15g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water and fresh fruit juice available

Mid-morning snack

Hot chocolate drink 218g
Shrewsbury biscuit 13g
Drinking water available

Lunch

Coconut fish curry 300g
Flat bread 50g
Rice and peas 200g
Spiced banana crumble 170g
Custard 150g
Drinking water and fresh fruit juice available

Mid-afternoon snack

Date bars 75g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Evening meal

Greek salad 180g
French stick 50g
Fresh pear slices 80g
Drinking water and fresh fruit juice available

Late evening snack

Fresh satsuma segments 80g
Drinking water available

Breakfast

Branflakes 50g and semi-skimmed milk 100g
2 slices wholemeal toast 31g, with polyunsaturated margarine 10g and marmalade 15g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water and fresh fruit juice available

Mid-morning snack

Chocolate yoghurt cake 70g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Lunch

Lamb curry 300g
Okra 80g
Rice 200g
Fresh fruit salad 120g
Drinking water and fresh fruit juice available

Mid-afternoon snack

Grapes 80g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Evening meal

Welsh rarebit 85g
Tomato quarters 85g
Fresh apple wedges 80g and shortcake biscuit 15g
Drinking water and fresh fruit juice available

Late evening drink

Horlicks drink 218g
Drinking water available

Breakfast

Muesli 70g and semi-skimmed milk 100g
2 slices wholemeal toast 31g, with polyunsaturated margarine 10g and reduced-sugar jam 15g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water and fresh fruit juice available

Mid-morning snack

Fresh orange slices 80g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Lunch

Quiche Lorraine 120g
Mixed bean salad 100g
Boiled new potatoes 180g
Fresh banana slices 80g
Drinking water and fresh fruit juice available

Mid-afternoon snack

Slice of carrot cake 75g
Cup of tea or coffee, with semi-skimmed milk 30g
Drinking water available

Evening meal

Cottage pie 300g
Peas 80g and cauliflower 80g
Gravy 70g
Jelly whip 200g
Drinking water and fresh fruit juice available

Late evening snack and drink

Horlicks drink 218g
Oat biscuit 15g
Drinking water available



Breakfast

Weetabix 40g and semi-skimmed milk 100g
2 slices wholemeal toast 31g, with polyunsaturated margarine 10g
and reduced-sugar jam 15g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water and fresh fruit juice available

Mid-morning snack

Fresh banana slices 80g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Lunch

Carrot and coriander soup 200g
Wholemeal or white bread sandwich with cheddar cheese 35g and
salad 35g filling
Fresh orange segments 80g
Drinking water and fresh fruit juice available

Mid-afternoon snack

Bran tea loaf 70g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Evening meal

Mackerel fish cakes 150g
Spiced potato wedges 150g
Diced mixed vegetables 80g
French stick 50g
Apple fool 110g
Drinking water and fresh fruit juice available

Late evening snack and drink

Horlicks drink 218g
Oat biscuit 15g
Drinking water available



Breakfast

Prunes, canned in juice 140g
2 slices wholemeal toast 31g with polyunsaturated margarine 10g
and marmalade 15g
Cup of tea or coffee with semi-skimmed milk 30g
Drinking water and fresh fruit juice available

Mid-morning snack

Cup of tea or coffee with semi-skimmed milk 30g
Fresh grapes 80g
Drinking water available

Lunch

Spinach curry 150g
Chick pea curry 150g
Rice 200g
Lemon sorbet 80g
Drinking water and fresh fruit juice available

Mid-afternoon

Cup of tea or coffee with semi-skimmed milk 30g
Drinking water available

Evening meal

Wholemeal or white bread sandwich
Egg and cress filling 60g
Sliced raw carrots, peppers and tomatoes 80g
Fruit squares 75g
Drinking water and fresh fruit juice available

Late evening snack and drink

Ovaltine drink 218g
Digestive biscuit 13g
Drinking water available

Finger foods

The use of finger foods – foods which are presented to the person in a form that can be eaten easily by hand – has been suggested as a way of preserving eating skills and promoting independence for those who have difficulty using utensils or who do not recognise the purpose of cutlery.^{2,3} Finger foods have the advantage of allowing food to be served at room temperature so that people can eat at their own pace. Since spills are minimised, they make it easier to make an accurate assessment of the amount of food eaten by an individual. It is also suggested that the use of finger foods triggers people's attention and increases their physical involvement and interaction with their meal, which may encourage them to eat more.⁴ One possible solution for people who are unable to sit still during meals is to provide them with a 'brown bag' meal – suitable finger foods in a waist pouch or bag – which they can carry with them.⁵ Or, more practically, make sure that snacks are always available. Some examples of finger foods are given in the box on the right. Finger foods should be easy to hold while eating. Some foods such as breaded chicken or meat may be too dry for some people to swallow; small, moist finger foods may be most appropriate. Avoid sugary finger foods unless they are part of a finger food meal.

Particular care needs to be taken when planning finger food diets to ensure that all nutrients are included, and advice should be taken if someone has special dietary needs. Finger foods are unlikely to be suitable for most people who have swallowing difficulties. For more information about finger foods and other special diets, see the National Association of Care Catering (NACC) publication *Menu Planning and Special Diets in Care Homes* (details in *Resources* on page 156).

Finger foods

The following are examples of foods which are appropriate as finger foods.

Breads and cereals

toast fingers
rolls
sandwiches
muffins
crumpet fingers
crackers
biscuits
fruit buns
French toast
fruit loaf
fruit cake
teabread
gingerbread
waffles
drop scones
breakfast cereals
cereal bars
chapattis
small pittas
won-tons
prawn crackers

Meat, fish, cheese and other protein alternatives

sliced meat, cut up into pieces
chicken fingers from moist breast
sausages and frankfurters
hamburgers
meatballs
meatloaf
pizza
slices of pork pie
quiche
fish fingers or fishcakes
fish sticks or crab sticks
smoked mackerel slices
vegetable/soya sausages
vegetable burgers/fingers
quarter hard-boiled eggs
cheese on toast
cheese cubes
fried bean curd cubes
Jamaican patties
kebabs

Vegetables

carrot sticks or coins, cooked
broccoli spears, cooked
Brussels sprouts, cooked
green beans, cooked
chips
potato waffles
new potatoes
sweet potato coins
fried battered onion rings
fried plantain
fried, crumbed whole mushrooms
sliced cucumber
quartered tomato
celery sticks
bhajias

Fruit

banana
melon
sliced apple or pear
strawberries
grapes
mandarin orange segments

Snacks

dried apricots and prunes (stones removed)
jelly cubes
ice cream in cones
peanut butter sandwiches
muesli bars
marmite on toast
pâté on toast
savoury snacks

Adapted from Ford, 1996²

Changing food and drink textures

The type and consistency of foods served are very important to ensure food is both acceptable and safe. There are some nationally recognised descriptors for texture modification of food for adults⁶ which are designed for use by dietitians and speech and language therapists. When texture modification is required, specialist advice should always be sought to ensure that the person's nutrient needs are met and the food is of the correct texture, but some general information is included here on how menus can be adapted.

Fluid texture modification

Some people will find it difficult to manage fluids and may require that fluids are thickened. Thin fluids are those such as water, tea or coffee or squash. There are some naturally thick fluids such as milkshakes and drinks such as Complan or Build-up. Where people with swallowing difficulties require a thickened fluid, these are prepared with a commercial thickener (see box on the right) to one of three consistencies:

Stage 1 Can be drunk through a straw or from a cup; leaves a thin coat on the back of a spoon.

Stage 2 Cannot be drunk through a straw; can be drunk from a cup; leaves a thick coat on the back of a spoon.

Stage 3 Cannot be taken through a straw or from a cup; needs to be given on a spoon.

Food texture modification

The way food is texture-modified will vary depending on the swallowing difficulty. Descriptors have been designed to categorise food into five types of texture modification.

Texture A A smooth, pouring, uniform consistency, the equivalent of tinned tomato soup or thin custard.

Texture B A puréed or sieved food that drops rather than pours from a spoon, such as soft whipped cream or thick custard.

Texture C A smooth puréed food that can be eaten with a fork or spoon, such as mousse or smooth fromage frais.

Texture D Moist food, mashed with a fork, served with a thick sauce, that requires little chewing, such as flaked fish in thick sauce or stewed apple and custard.

Texture E Soft moist food that can be broken into pieces with a fork, but avoids foods that could be a choking hazard.

High-risk foods to avoid if a texture-modified diet is required

Stringy, fibrous textures such as pineapple, runner beans, celery or lettuce

Vegetable and fruit skins including beans, grapes, peas, sweetcorn, flakes and seeds in breads

Mixed consistency foods such as minestrone soup, or cereals in milk

Crunchy foods such as toast, dry biscuits or crisps

Crumbly items: such as pie crusts, cakes or dry biscuits

Hard foods: such as boiled sweets, toffees, nuts or seeds

The requirements of individuals with swallowing difficulties will be highly varied and specialist advice should always be sought when a texture-modified diet is required. More information on menu planning for special diets can be found in the NACC publication *Menu Planning and Special Diets in Care Homes* (see page 156).

Thickeners and soaking solutions

Before puréed diets are considered, advice should be sought from a dietitian and speech and language therapist to ensure that the appropriate foods and products are used.

A number of commercial products are available which can thicken food and drink and alter the texture. Examples of thickeners currently available include Thick & easy (Fresenius), Vitaquick (Vitaflo), Thixo-D (Sutherland) and Nutilis thickener (Nutricia). Information on these products can be found on page 157. Many of these companies will provide advice and demonstrations on how to use thickeners, use food moulds (which they often provide), and prepare soaking solutions. Soaking solutions can be made from any non-lumpy liquid with thickener added, and can be used on foods such as some plain bread, sandwiches, biscuits and cakes to provide a puréed texture item while maintaining the integrity of the food – for example, so that it still looks like a slice of cake.

Puréed diets

Puréed diets may be required when food of a uniform smooth consistency is required. Puréed foods require no chewing and can be easily managed in the mouth, therefore reducing the risk of choking. Puréed diets are likely to be lower in energy and nutrients and less palatable than soft diets and the decision to move to puréed foods should not be made lightly. To ensure that nutrient needs are met and food is of the correct texture takes skill, and anyone who prepares a puréed diet should seek advice from a speech and language therapist on how to do this most appropriately.

Adding liquids to puréed foods dilutes their nutrient content and should be done with care. Most puréed diets will require the addition of high-energy and protein ingredients (for example, extra full-fat milk, cream, cheese, butter, oil, mayonnaise or full-fat yoghurt or crème fraîche) but it is important to seek advice for each person about what is appropriate. Fruits and vegetables do not need to be, and should not be, overcooked before puréeing as this will reduce the amount of some vitamins present.

It is also important that the puréed food looks attractive. The use of food moulds and food soaking solutions to prepare purées in appropriate shapes can be useful (see page 157). It is important to purée each food separately and as far as possible maintain its original colour and taste.

Particular care needs to be taken that puréed foods do not become contaminated during preparation (see the *Food hygiene and safety hints* on page 92).

More detailed information on menu planning for special diets can be found in the NACC publication *Menu Planning and Special Diets in Care Homes* (see page 156).

Fortified foods

The fortification of commonly eaten foods is another way of increasing nutrient intake and can be valuable if used to enhance foods which people enjoy. Adapting common recipes to increase their energy and protein content can be particularly useful when appetites are reduced but people can eat and drink normally. Advice should be sought on suitable fortification to meet an individual's needs.

Examples of how to fortify foods to increase calorie content

- Add dried milk powder to whole milk and use in drinks ('fortified milk').
- Add dried milk powder or cream to custard.
- Make soups with fortified milk, and add cream and/or cheese.
- Add cream and fortified milk to porridge and serve with honey or maple syrup.
- Add butter and cream to mashed potato.
- Add melted butter to vegetables or serve with cheese sauce.
- Serve ice cream with chocolate or fudge sauce or additional cream topping.
- Make milk puddings with extra milk powder and/or cream, and serve with jam or syrup.

Food supplements

A wide range of commercially produced high-energy (and vitamin- and mineral-enriched) food supplement products are available and may be prescribed by a hospital doctor or medical practitioner. These supplements should not be seen as long-term food substitutes, but can be useful for short-term emergencies after illness or operations, or where there has been sudden unexpected weight loss.

How to use food supplement products safely

- Check the use-by date on products before you use them.
- Do not use damaged or distorted packets.
- Follow the prescriber's instructions for use and manufacturer's instructions for storage.
- Remember good hygiene practice.

Ask for regular review of the prescription to ensure that these supplements are needed.

Adapted from NAGE, 1994 ⁷

KEY MESSAGES

- Where people need help with eating, it is essential for staff to be trained in helping them to eat and to do this in a sensitive and efficient way.
- The use of finger foods – foods which are presented in a form that can be eaten easily by hand without the need for cutlery – should be used as a way of preserving eating skills and promoting independence for those who have difficulty using utensils or who do not recognise the purpose of cutlery.
- Some people with swallowing difficulties may need to have their food or fluid modified. Specialist advice should always be sought when texture modification is required, to ensure that the person's nutrient needs are met and the food is of the correct texture.

References

- 1 <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=361>
- 2 Archibald C, Carver A, Keene J and Watson R (1994) *Food and Nutrition in the Care of People with Dementia*. Stirling: University of Stirling
- 3 Ford G (1996) Putting feeding back into the hands of the patient. *Journal of Psychosocial Nursing and Mental Health Services*; 34: 35-39
- 4 Soltesz KS and Dayton JH (1993) Finger foods help those with Alzheimer's maintain weight. *Journal of the American Dietetic Association*; 93: 1106-1108
- 5 Hall GR (1994) Chronic dementia: challenges in feeding the patient. *Journal of Gerontological Nursing*; 35: 31-38
- 6 The British Dietetic Association and The Royal College of Speech and Language Therapists (2002) National descriptors for texture modification in adults. <http://www.bda.uk.com/Downloads/dysphagia.pdf> (Currently under review)
- 7 Nutrition Advisory Group for Elderly People (NAGE) (1994) *Taking Steps to Tackle Eating Problems*. Leeds: NAGE

Appendix 1

National minimum standards: care home regulations and home care (domiciliary) services

Standards for care homes

England, Wales and Northern Ireland

In England the Department of Health provides guidance on the National Minimum Standards for *Care Homes for Adults (18-65) and Supplementary Standards for Care Homes Accommodating Young People Aged 16 and 17 Years*¹ which were last updated in 2003. Similar standards are used:

- in Wales (see www.csiw.wales.gov.uk/docs/Adult_Placement_Schemes_e.pdf), and
- in Northern Ireland (see <http://www.opsi.gov.uk/Sr/sr2005/20050161.htm>).

The standards relating to Meals and Mealtimes (Standard 17) from the standards for England are given below. These standards are likely to change in 2008 but many of the principles in these standards will remain intact so they are provided here as background information.

Meals and mealtimes

Outcome

Service users are offered a healthy diet and enjoy their meal and mealtimes.

Standard 17

- 17.1 The registered person promotes service users' health and wellbeing by ensuring the supply of nutritious, varied, balanced and attractively presented meals in a congenial setting and at flexible times.
- 17.2 Service users are offered a choice of suitable menus, which meet their dietary and cultural needs, and which respect their individual preferences.

17.3 Meals are offered three times daily including at least one hot cooked meal; and a range of drinks and snacks to meet individual needs are available at all times.

17.4 Service users are actively supported to help plan, prepare and serve meals.

17.5 Service users can choose where and when to eat, and whether to eat alone or with others including staff.

17.6 The preparation and serving of food respects service users' cultural and religious requirements.

17.7 Mealtimes are relaxed, unrushed, and flexible to suit service users' activities and schedules.

17.8 Service users' nutritional needs are assessed and regularly reviewed including risk factors associated with low weight, obesity and eating and drinking disorders.

17.9 Service users who need help to eat or are fed artificially are assisted appropriately while maintaining choice of when, where and what they eat; and assisted to choose appropriate eating aids.

An additional standard relates to those aged 16-17 years:

17.10 The home seeks medical advice if a service user consistently refuses to eat, and for those who over-eat or have any other eating disorders.

Scotland

National Care Standards for care homes for people with learning disabilities in Scotland were amended in 2005 (see www.scotland.gov.uk/Resource/Doc/77843/0018375.pdf) and are outlined below.² These are written from the perspective of the service user.

Eating Well Standard 13

Your meals are varied and nutritious. They reflect your food preferences and any special dietary needs. They are well prepared and cooked, and attractively presented.

- 1 Catering and other staff get to know your food choices and any ethnic, cultural, faith or other preferences you have. Any special diet (for example, vegetarian, low-fat or high-protein) is recorded in your personal plan.
- 2 You are offered a daily menu that reflects your preferences. The menu varies regularly according to your comments, and will always include fresh fruits and vegetables.
- 3 You have a choice of cooked breakfast and choices in

courses at the midday and evening meals.

- 4 Meals are nutritionally balanced for your dietary needs, for example, if you have diabetes or poor kidney function or need a liquidised or textured soft diet.
- 5 You can have snacks and hot and cold drinks whenever you like.
- 6 If you are unable to check if you are getting enough of the right things to eat or drink, staff will keep an eye on this for you. If, for any reason, you are not taking enough, staff will explain this to you or your representative. With your agreement, staff will take any action needed, including seeking advice from a dentist, dietitian, speech and language therapist or your GP.
- 7 If there is anything that may affect your ability to eat or drink, for example problems with your teeth or with swallowing, you are confident that this will be assessed and regularly reviewed. Staff will provide appropriate help, for example, adapted cutlery or crockery, a liquidised diet, or someone to assist you with eating and drinking in a discreet manner, in a way that suits you and respects your dignity.
- 8 If you are unable to take food or drink by mouth, you get these by other means, for example PEG or parenteral feeding, in a way that best suits you and respects your privacy and dignity.
- 9 You enjoy meals that are well presented. All food handling follows good food-hygiene practices.
- 10 You are free to eat your meals wherever you like, for example, in your own room or in the dining room. You can take them in your own time.

For more information

Additional information on catering standards in residential settings can be found in the following NACC publications:

- The National Minimum Standards for Care Catering (Care Homes for Older People)
- A Recommended Standard for Community Meals
- The National Minimum Standard for Care Catering (Care Homes for Adults Aged 18-65 Years)

For further details see www.thenacc.co.uk.

Standards for domiciliary care

There are standards for those who organise or work in home care, supporting service users by giving care to people in their own homes.

England and Wales

The Domiciliary Care National Minimum Standards for England can be found at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4083671.pdf. Those relevant to food and drink are summarised below.

Similar standards are available in Wales. See: www.csiw.wales.gov.uk/legislation/wales/wsi_20063251_mi.pdf.

Regulations relating to food and drink in domiciliary care in England

Standard 2.3

For individuals who are self-funding a care needs assessment is undertaken (appropriate to the level of support requested) in the individual's own home, by a manager competent and trained for the task, covering the delivery of the services agreed. Issues that may arise include:

Dietary requirements and preferences (if appropriate)

Standard 8.1

Personal care and support is provided in a way which maintains and respects the privacy, dignity and lifestyle of the person receiving care at all times with particular regard to assisting with:

Eating and meals

Standard 11

The registered person ensures that the agency has systems and procedures in place to comply with the requirements of the Health and Safety legislation including:

Food Safety Act 1990

In addition it is expected that among the health and safety issues covered in the induction programme will be information on food preparation, storage and hygiene.

Northern Ireland

In Northern Ireland, domiciliary care is about to be regulated. For more information see www.rqia.org.uk

Scotland

The National Care Standards: Care at Home (2005) are available at:
www.scotland.gov.uk/Resource/Doc/924/0013253.pdf

In Scotland the national care standards are more explicit about the role of home care staff in helping people in their own homes to eat well.

Standard 6

If shopping for food or preparing meals is part of the service, you know that the food will be handled safely and meals will reflect your choices and special dietary needs (if any).

- 1 Your home care worker gets to know your food choices and any ethnic, cultural, faith or other preferences you have. Any special diet (for example vegetarian, low-fat or high-protein) is recorded in your personal plan
- 2 Unless you ask for it to be otherwise, the food that is bought and prepared for you will reflect your known choices and preferences and any special dietary needs
- 3 All food handling follows good hygiene practice. Your meals are well prepared and well presented
- 4 You must be able to eat and enjoy your food. If you need any help to do so, for example, adapted cutlery or crockery or a liquidised diet, your home care worker will arrange this for you
- 5 You can expect your home care worker to notice anything that affects your ability to eat or drink, such as dental health or loss of appetite. If so, she or he will discuss these with you and help you to get professional help if you want.

References

- 1 Department of Health (2003) *Care Homes for Adults (18-65) and Supplementary Standards for Care Homes Accommodating Young People Aged 16 and 17 Years. National Minimum Standards. Care Home Regulations*. London: TSO.
- 2 Scottish Executive (2005) *National Care Standards. Care Homes for People with Learning Disabilities*. Edinburgh: Scottish Executive

Appendix 2

Good sources of nutrients

This Appendix shows a number of foods and drinks which are important sources of certain vitamins and minerals. These are based on average servings.

	EXCELLENT	GOOD	USEFUL
VITAMIN A	liver* liver sausage/pâté* carrots spinach sweet potatoes red peppers mango canteloupe melon dried apricots	nectarine peach blackcurrants fresh or canned apricots watercress tomatoes cabbage (dark) broccoli Brussels sprouts runner beans, broad beans margarine butter cheese kidney	canned salmon herrings egg honeydew melon prunes orange sweetcorn peas whole milk
VITAMIN D	fortified breakfast cereals herrings mackerel, pilchards roe sardines trout tuna salmon egg	liver* (other than chicken liver) liver sausage/pâté* margarine	chicken liver malted-style drinks
B VITAMINS Thiamin	liver and liver pâté* pork, bacon and ham fortified breakfast cereals malted drinks	wholemeal bread yeast extract oatcakes currant buns nuts potatoes	lean meat chicken and other poultry eggs white or brown bread semi-sweet biscuits

* Liver and liver pâté are very rich in vitamin A and these foods should be consumed no more than once a week. For more information see *Review of Dietary Advice on Vitamin A*.¹

	EXCELLENT	GOOD	USEFUL
Riboflavin	liver* kidney	milk malted drinks fortified breakfast cereals almonds	lean meat or poultry bacon mackerel, tuna, salmon sardines, pilchards cheese yoghurt eggs
Niacin	fortified breakfast cereals salmon tuna pilchards chicken	lean meat sausages kidneys herrings sardines	wholemeal bread peanut butter yeast extract bacon liver sausage*
VITAMIN B₆	bran flakes red meat poultry liver* oily fish	potatoes bananas nuts peanut butter dried fruit white fish	baked beans lentils and other pulses green vegetables tomatoes wholemeal bread cheese
VITAMIN B₁₂	liver* kidney oily fish	beef lamb pork turkey fish eggs	chicken milk cheese yoghurt marmite ribena bran flakes
FOLATE	most fortified breakfast cereals, eg. cornflakes, bran flakes, crisped rice liver* spinach	yeast extract cabbage Brussels sprouts broccoli peas orange melon kidney	wholemeal bread/flour wheat bisks cauliflower beef runner beans tomatoes parsnip potatoes green leafy salads ackee peanuts

* Liver and liver pâté are very rich in vitamin A and these foods should be consumed no more than once a week. For more information see *Review of Dietary Advice on Vitamin A*.¹

Continued on next page

	EXCELLENT	GOOD	USEFUL
VITAMIN C	blackcurrants orange (and orange juice) strawberries canned guava spring greens green and red peppers	broccoli cabbage cauliflower spinach tomato Brussels sprouts watercress kiwi fruit mango grapefruit	potatoes green beans peas satsumas eating apples nectarines peaches raspberries blackberries
IRON	fortified breakfast cereals liver* kidney liver sausage/pâté*	wholemeal bread or flour wheat bisks beef beefburger corned beef lamb sardines pilchards soya beans chick peas lentils spinach broccoli spring greens dried apricots raisins	white bread baked beans broad beans black-eyed peas blackcurrants salmon tuna herrings sausage chicken and other poultry egg tofu
CALCIUM	green leafy vegetables sardines cheese tofu	pilchards yoghurt milk (all types) soya drink fortified with calcium cheese spread sesame seeds	canned salmon muesli white bread/flour peas, beans and lentils dried fruit orange egg yolk
ZINC	liver* kidney lean meat corned beef	bacon ham poultry canned sardines shrimps and prawns tofu wholegrain breakfast cereals, eg. puffed wheat, bran flakes, wheat bisks nuts	sausages cold cooked meats canned tuna or pilchards eggs milk cheese beans and lentils brown or wholemeal bread plain popcorn sesame seeds

* Liver and liver pâté are very rich in vitamin A and these foods should be consumed no more than once a week. For more information see *Review of Dietary Advice on Vitamin A*.¹

	EXCELLENT	GOOD	USEFUL
FIBRE	wholegrain or wholewheat breakfast cereals such as bran flakes, wheat bisks, shreddies, shredded wheat, sultana bran wholemeal bread baked beans, chick peas, kidney beans (and most beans) lentils dried apricots, dried figs prunes	muesli wholemeal pasta brown bread white bread with added fibre baked potato with skin sweet potato broad beans fresh or frozen peas sweetcorn broccoli Brussels sprouts Quorn blackberries dried dates almonds hazelnuts	puffed wheat cereal brown rice white pitta bread pizza potatoes yam houmous canned peas cabbage carrots plantain banana mango raisins sunflower seeds potato crisps

Reference

- 1 Scientific Advisory Committee on Nutrition (2005) *Review of Dietary Advice on Vitamin A*. London: TSO

Appendix 3

Weight monitoring chart and nutrition checklist

This Appendix contains:

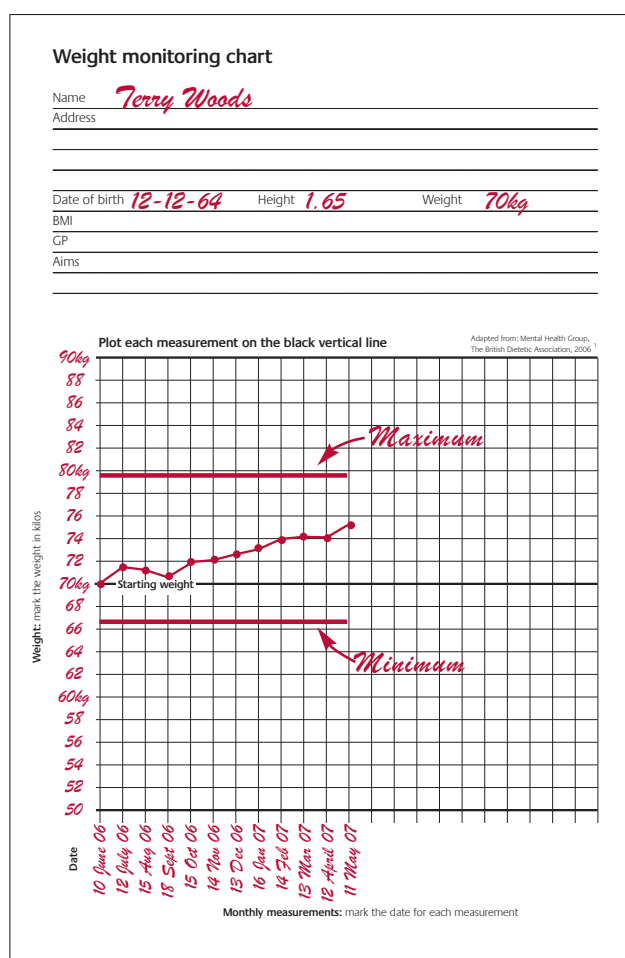
- A sample *Weight monitoring chart*.¹ See page 60 for more details.
- A sample *Nutrition checklist*.² See page 106 for more details.

How to use the weight monitoring chart

The aim of the *Weight monitoring chart* shown on the next page is to provide a simple visual record of weight change over a two-year period. The chart allows each person's starting weight to be recorded as the central point. The boxes above and below this starting point can be annotated at 1kg intervals. Monthly weight measurements can then be plotted and recorded on each vertical line as shown in the example on the right.

Any significant upward or downward trend in a person's weight should alert staff to potential weight difficulties. The chart works best if a health professional can also add lines to the chart which suggest a minimum and maximum weight where intervention should be considered. (See the red lines in the example on the right.) These should be calculated very carefully, as everyone is an individual and their particular circumstances must be taken into consideration. However, for someone who wants to maintain their weight, we suggest that the 'maximum' line is drawn at the equivalent to a BMI of 30 and the 'minimum' line at -5% of the starting body weight. For those who are trying to lose or gain weight, these lines need to be adapted accordingly.

To be most effective, we suggest that the lines should be drawn for one-year periods at a time and then reconsidered for the next period to reflect any weight changes that have occurred. Anyone concerned about any unexplained weight loss for an individual should always seek advice from the person's medical practitioner. For more information on managing weight, see chapter 5.



References

- 1 Adapted from: Mental Health Group, The British Dietetic Association. 2006. *Professional Consensus Statement. The Nutritional Care of Adults with a Learning Disability in Care Settings*. London: BDA
- 2 Adapted from: Bryan F, Jones JM and Russell L (1998) Reliability and validity of a nutrition screening tool to be used with clients with learning difficulties. *Journal of Human Nutrition and Dietetics*; 11: 41-50

Weight monitoring chart

Name _____

Address _____

Date of birth _____ Height _____ Weight _____

BMI _____

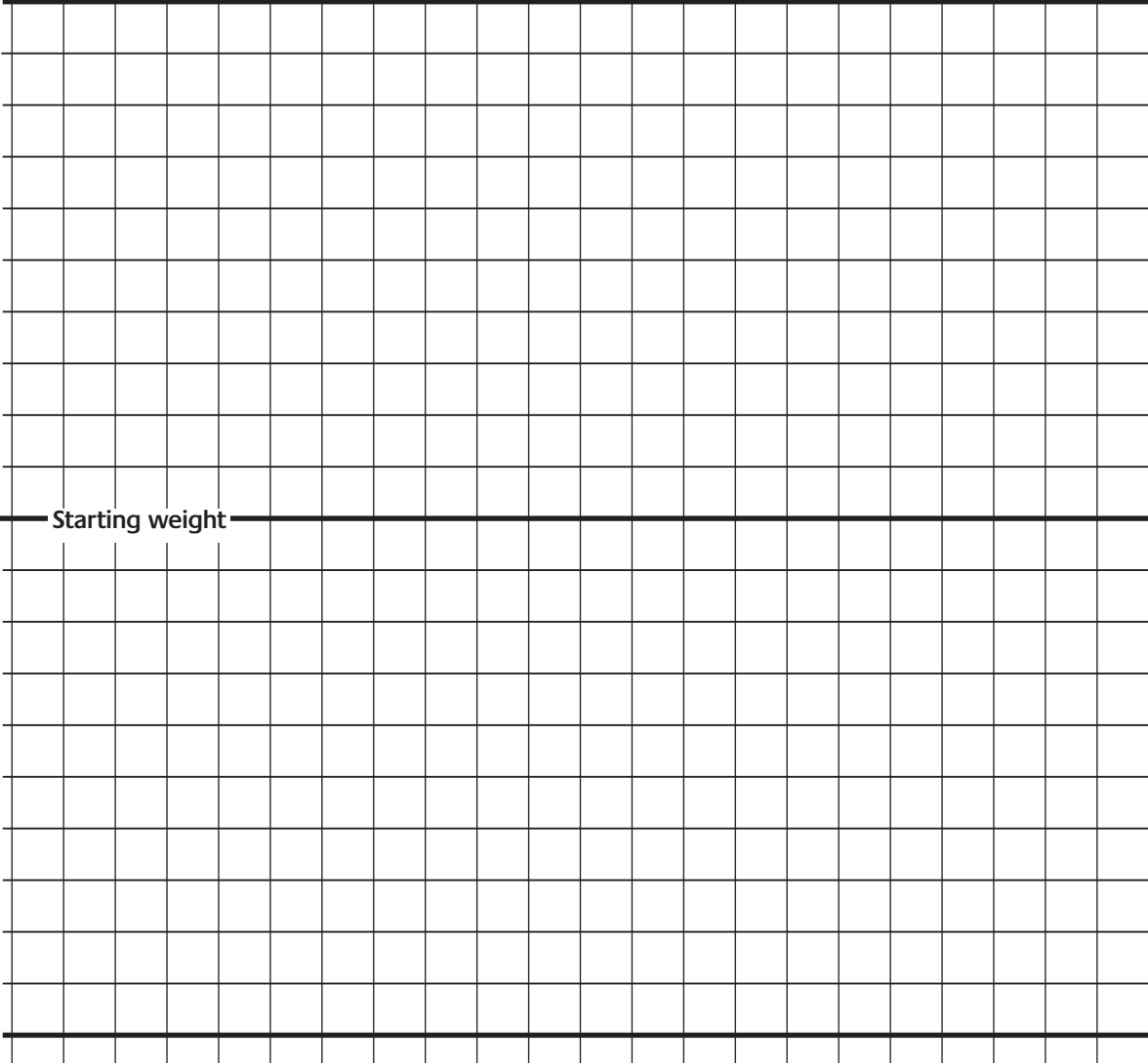
GP _____

Aims _____

Plot each measurement on the black vertical line

Adapted from: Mental Health Group,
The British Dietetic Association, 2006 ¹

Weight: mark the weight in kilos



Date

Monthly measurements: mark the date for each measurement

Check with a health professional annually or more frequently if there are weight concerns.

Nutrition checklist

Name

Address

Date of birth

Name and position of person completing form

Date form completed

Please answer each question on the form by ticking the appropriate box or by writing your answer in the space provided.

1 Food groups

Does the person eat the following types of food every day?

- | | | | |
|---|-----------------------------|------------------------------|-------------------------------------|
| a) Bread, cereals, potatoes, rice or pasta (at every meal) | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Don't know |
| b) Fruit or vegetables (at least 3-5 portions a day) | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Don't know |
| c) Milk or yoghurt (1/2 – 1 pint milk equivalent) | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Don't know |
| d) Meat, fish, eggs or other meat alternatives (2 servings daily) | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Don't know |
| e) Fluids (at least 6 glasses a day) | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Don't know |
| f) Does he or she nearly always finish a meal? | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Don't know |

If any of the answers are **No** or **Don't know**, please tick the **At risk** box on the right and go to section 2.

If all your answers are **Yes**, go to section 2.

At risk

2 Weight

Please refer to weight charts over the past year to help you complete this section.

a) What is the person's height?

b) What is his or her present weight?

c) What was his or her weight one year ago?

d) Has there been any unintentional weight gain during the last year? (More than 2kg.) No Yes Don't know

e) Has there been any unintentional weight loss in the last year? (More than 2kg.) No Yes Don't know

f) Is the person underweight? No Yes Don't know

(Look at subcutaneous fat, prominence of bones such as ribs, muscle-wasting, frame size, fit and size of clothes.)

g) Is the person overweight? No Yes Don't know

(Look at subcutaneous fat, frame size, fit and size of clothes.)

If any of the answers are **Yes** or **Don't know**, please tick the **At risk** box on the right and go to section 3.

If all your answers are **No**, go to section 3.

At risk

3 Nutrition-related problems

Please tick the boxes below to indicate if any of the following problems are putting the client nutritionally at risk.

- | | |
|--|--------------------------|
| a) Problems with swallowing, eg. choking | <input type="checkbox"/> |
| b) Problems chewing food | <input type="checkbox"/> |
| c) Small or poor appetite | <input type="checkbox"/> |
| d) Gastrointestinal symptoms, eg. loose stools, constipation, vomiting, regurgitation | <input type="checkbox"/> |
| e) Unable to feed himself or herself | <input type="checkbox"/> |
| f) Psychological reasons – eg. paranoia, depression or mania – leading to an altered food intake | <input type="checkbox"/> |
| g) Disease state influencing nutritional requirements – for example, cancer, stroke, pressure sores or multiple injuries | <input type="checkbox"/> |
| h) Other nutrition-related problem(s)
(Please specify.) | <input type="checkbox"/> |
| | |
| | |
| | |
| | |

If any of the boxes in a) to h) have been ticked, please tick the **At risk** box on the right. **At risk**

If any of the **At risk** boxes have been ticked, advice should be sought from a medical practitioner or a dietitian.

Adapted from: Bryan F, Jones JM and Russell L (1998) Reliability and validity of a nutrition screening tool to be used with clients with learning difficulties. *Journal of Human Nutrition and Dietetics*; 11: 41-50

Appendix 4

Resources

Organisations

There are many organisations which offer help and support related to specific learning disabilities and we are unable to list them all here. General information and advice on all learning disability issues, on specific learning disabilities and on local organisations can be obtained from Mencap (see contact details on page 149).

Allergy UK

3 White Oak Square
London Road
Swanley
Kent BR8 7AG
T: 01322 619898
E: info@allergyuk.org
www.allergyuk.org

Association for Real Change (ARC)

ARC House
Marsden Street
Chesterfield
Derbyshire S40 1JY
T: 01246 555043
E: contact.us@arcuk.org.uk
www.arcuk.org.uk

ARC Northern Ireland

43 Marsden Gardens
Cavehill
Belfast BT15 5AL
T: 028 9022 9020
E: arcni@arcuk.org.uk

ARC Scotland

Unit 13
Hardengreen Business Centre
Eskbank
Dalkeith
Midlothian EH22 3NX
T: 0131 663 4444
E: arc.scotland.arcuk.org.uk

ARC Cymru

Unit 3A
Mentec
Deiniol Road
Bangor LL57 2UP
T: 01248 361990
E: arc.cymru@arcuk.org.uk

Asthma UK

Summit House
70 Wilson Street
London EC2A 2DB
T: 020 7786 4900
Helpline: 0845 701 0203
www.asthma.org.uk

Contact details for Asthma UK Scotland, Asthma UK Cymru and Asthma UK Northern Ireland can also be found on this website.

British Dietetic Association

5th Floor
Charles House
148-9 Great Charles Street
Queensway
Birmingham B3 3HT
T: 0121 200 8080
E: info@bda.uk.com
www.bda.uk.com

British Institute for Learning Disability (BILD)

Campion House
Green Street
Kidderminster
Worcestershire DY10 1JL
T: 01562 723 010
E: enquiries@bild.org.uk
www.bild.org.uk

British Society for Disability and Oral Health

www.bsdh.org.uk

Carers UK

20/25 Glasshouse Yard
London EC1A 4JT
T: 020 7490 8818
www.carersuk.org

Change

Units 19/20
Unity Business Centre
26 Roundhay Road
Leeds LS7 1AB
T: 0133 2430202
www.changepeople.co.uk

Chartered Institute of Environmental Health

Chadwick Court
15 Hatfields
London SE1 8DJ
T: 020 7928 6006
E: info@cieh.org
www.cieh.org

The Coeliac Society

Suites A-D
Octagon Court
High Wycombe
Bucks HP11 2HP
T: 01494 437 278
www.coeliac.co.uk

College of Occupational Therapists

106-114 Borough High Street
London SE11 1LB
T: 020 7357 6480
www.cot.org.uk

Commission for Social Care Inspection (CSCI)

www.csci.org.uk
T: 0845 015 0120
or 0191 233 3323

Community Practitioners' and Health Visitors' Association (CPHVA)

33-37 Moreland Street
London EC1V 8HA
T: 020 7780 4089
E: infocphva@amicustheunion.org
www.amicus-cphva.org

Daycare Trust

21 St George's Road
London SE1 6ES
T: 020 7840 3350
E: info@daycaretrust.org.uk
www.daycaretrust.org.uk

Department of Health

PO Box 777
London SE1 6XH
T: 0800 555 777
www.dh.gov.uk

Diabetes UK

Macleod House
10 Parkway
London NW1 7AA
T: 020 7424 1000
E: info@diabetes.org.uk
www.diabetes.org.uk

**Disability Rights Commission
DRC Helpline**

Freeport MID02164
Stratford upon Avon CV37 9BR
T: 08457 622 633
Textphone: 08457 622 644
England: www.drc-gb.org
Scotland: www.drc-gb.org/about_us/drc_scotland.aspx
Wales: www.drc-gb.org/wales

Down's Syndrome Association

Langdon Down Centre
2a Langdon Park
Teddington TW11 9PS
T: 0845 230 0372
E: info@downs-syndrome.org.uk
www.downs-syndrome.org.uk

Down's Syndrome Scotland

158/160 Balgreen Road
Edinburgh EH11 3AU
T: 0131 313 4225
E: info@dsscotland.org.uk
www.dsscotland.org.uk

The Elfrida Society

34 Islington Park Street
London N1 1PX
T: 020 7359 7443
E: elfrida@elfrida.com
www.elfrida.com

Enable

6th Floor
7 Buchanan Street
Glasgow G1 3HL
T: 0141 226 4541
E: enable@enable.org.uk

**FAIR (Family Advice and Information
Resource)**

95 Causewayside
Edinburgh EH9 1QG
T: 0131 622 1962
E: fair@fairadvice.org.uk
www.fairadvice.org.uk

Foetal Alcohol Syndrome Aware UK

T: 01942 223 780
www.fasaware.co.uk

The Food Commission

94 White Lion Street
London N1 9PF
T: 020 7837 2250
E: enquiries@foodcomm.org.uk
www.foodcomm.org.uk

Food Standards Agency

www.food.gov.uk
www.eatwell.gov.uk

**Foundation for People with
Learning Disabilities**

London office
9th Floor
Sea Containers House
20 Upper Ground
London SE1 9QB
T: 020 7803 1100
www.learningdisabilities.org.uk

Headway

4 King Edward Court Service
King Edward Street
Nottingham NG1 1EW
Helpline: 0808 800 2244
www.headway.org.uk

Health Challenge Wales

c/o Welsh Assembly Government
Cathays Park
Cardiff CF10 3NQ
T: 02920 825793
<http://new.wales.gov.uk/subsite/healthchallenge/?lang=en>

Healthcare Commission

Finsbury Tower
103-105 Bunhill Row
London EC1Y 8TG
T: 020 7448 9200
E: feedback@healthcarecommission.org.uk
www.healthcarecommission.org.uk

**Health Promotion Agency
Northern Ireland**

18 Ormeau Avenue
Belfast BT2 8HS
T: 028 9031 1611
E: info@hpani.org.uk
www.healthpromotionagency.org.uk

Hospital Caterers Association

www.hospitalcaterers.org

Look Up

SeeAbility House
Hook Road
Epsom
Surrey KT19 8SQ
T: 0800 121 8900
E: info@lookupinfo.org
www.lookupinfo.org

Mencap

123 Golden Lane
London EC1Y 0RT
T: 020 7454 0454
E: information@mencap.org.uk
www.mencap.org.uk
Mencap Northern Ireland and Mencap Wales can be contacted via this website.

Mental Health Foundation

London office
9th Floor
Sea Containers House
20 Upper Ground
London SE1 9QB
T: 020 7803 1101
E: mhf@mhf.org.uk
www.mentalhealth.org.uk

Mental Health Foundation (Scotland)

Merchant House
30 George Square
Glasgow G2 1EG
T: 0141 572 0125
E: scotland@mhf.org.uk

MIND

13-15 Broadway
London E15 4BQ
T: 020 8519 2122
Mind info line: 0845 766 0163
E: contact@mind.org.uk
www.mind.org.uk

National Association of Care Catering

Meadow Court
Faygate Lane
Faygate
West Sussex RH12 4SJ
T: 08707 480 180
E: info@thenacc.co.uk
www.thenacc.co.uk

National Autistic Society

393 City Road
London EC1V 1NG
T: 020 783 2299
E: nas@nas.org.uk
www.nas.org.uk

Contact details for NAS Scotland, NAS Cymru and NAS Northern Ireland are available from this website.

National Family Carer Network

Merchants House
Wapping Road
Bristol BS1 4RW
T: 0117 930 2600
www.familycarers.org.uk

National Heart Forum

Tavistock House South
Tavistock Square
London WC1H 9LG
T: 020 7383 7638
www.heartforum.org.uk

National Institute for Health and Clinical Excellence (NICE)

MidCity Place
71 High Holborn
London WC1V 6NA
T: 020 7067 5800
www.publichealth.nice.org.uk

The National Society for Epilepsy

Chesham Lane
Chalfont St Peter
Bucks SL9 0RJ
T: 01494 601 300
Helpline: 01481 601 400
www.epilepsynse.org.uk

NHS Direct

T: 0845 4647
www.nhsdirect.nhs.uk

NHS Health Scotland

Woodburn House
Canaan Lane
Edinburgh EH10 4SG
T: 0131 536 5500
www.healthscotland.com

Nutrition Society

10 Cambridge Court
210 Shepherd's Bush Road
London W6 7NJ
T: 020 7602 0228
E: office@nutsoc.org.uk
www.nutritionssociety.org

PAMIS

Springfield House
15/16 Springfield
University of Dundee
Dundee DD1 4JE
T: 01382 385 154
E: pamis@dundee.ac.uk
www.dundee.ac.uk/pamis

The Relatives and Residents Association

24 The Ivories
6-18 Northampton Street
London N1 2HY
Helpline: 020 7359 8136
www.relres.org

ResCare

Steven Jackson House
31 Buxton Road
Heaviley
Stockport SK2 6LS
T: 0161 474 7323
Helpline: 0800 032 7330
www.rescare.org.uk

Royal College of Nursing (RCN)

20 Cavendish Square
London W1G 0RN
T: 020 7409 3333
www.rcn.org.uk

Royal College of Paediatrics and Child Health

50 Hallam Street
London W1W 6DE
T: 020 7307 5600
www.rcpch.ac.uk

Royal College of Psychiatrists

17 Belgrave Square
London SW1X 8PG
T: 020 7235 2351
www.rcpsych.ac.uk

Royal College of Speech and Language Therapists

2 White Hart Yard
London SE1 1NX
T: 020 7378 1200
E: info@rcslt.org
www.rcslt.org

The Royal Institute of Public Health

28 Portland Place
London W1B 1DE
T: 020 7580 2731
www.riph.org.uk

SCOPE

6 Market Road
London N7 9PW
T: 020 7619 7100
Helpline: 0808 800 3333
E: webmaster@scope.org.uk
www.scope.org.uk

Scottish Consortium for Learning Disability

Room 16
The Adelphi Centre
12 Commercial Road
Glasgow G5 0PQ
T: 0141 418 5420
E: administrator@sclcd.co.uk
www.sclcd.org.uk

SENSE

11-13 Clifton Terrace
London N4 3SR
T: 0845 127 0060
Text: 0845 127 0062
E: info@sense.org.uk
www.sense.org.uk

Thrive

The Geoffrey Udall Centre
Beech Hill
Reading RG7 2AT
T: 0118 988 5688
www.thrive.org.uk

Turning Point

Standon House
21 Mansell Street
London E1 8AA
T: 020 7481 7600
www.turning-point.co.uk

United Response

113-123 Upper Richmond Road
London SW15 2TL
T: 020 8246 5200
www.unitedresponse.org.uk

Valuing People Support Team website

www.valuingpeople.gov.uk

Vegan Society

Donald Watson House
21 Hylton Street
Hockley
Birmingham B18 6HJ
T: 0121 523 1730
www.vegansociety.com

Vegetarian Society

Parkdale
Dunham Road
Altrincham
Cheshire WA14 4QG
T: 0161 928 0793
www.vegsoc.org

Publications and resources

Many organisations provide publications and resources related to food and health, and details are available on the websites listed in this Appendix. Contact details for ordering publications are given on pages 148-151, unless otherwise stated. This section contains a selection of publications and resources on the following topics:

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Where to get advice about eating well

For individual advice on eating well, special diets, altering the texture of foods, monitoring nutritional status or any other area relating to diet and health, contact a **dietitian** through your GP or medical practitioner. (See also the British Dietetic Association website www.bda.uk.com.) Nutrition advice for groups of people should be sought from either a **dietitian** or a **registered public health nutritionist** (RPHNutr). Registered public health nutritionists can be accessed via the Nutrition Society at www.nutrition society.org.

Eating well: resources for people with learning disabilities

Check your local health promotion department or primary care trust website as they may produce easy-read or accessible versions of leaflets for use in your area. A selection of other useful publications is given below.

Books Beyond Words

Food ... Fun, Healthy and Safe (2003)

S Hollins and M Flynn
ISBN 1-901242-95-1

Looking after My Heart (2005)

S Hollins, F Cappuccio and P Adeline
ISBN 1-904671-24-1

Both published by the Royal College of Psychiatrists and St George's, University of London: www.rcpsych.ac.uk

British Institute for Learning Disability (BILD)

BILD publications can be accessed from www.bild.org.uk, or phone BookSource on 08702 402 182. All books priced at £8.

Eating and Drinking

ISBN 1 873791 933.

Exercise

ISBN 1 873791 283

Alcohol and Smoking

ISBN 1 873791 240

Look Cook Book

A cook book designed to promote healthy eating for people with learning disabilities. Produced by Groundwork, Oldham and Rochdale.

Available for downloading from:

www.bild.org.uk/pdfs/01news/look_cook.pdf

Department of Health

5 a Day Easy Read booklet

http://www.5aday.nhs.uk/original/locally/documents/5_A_DAY_Easy_Read_booklet.pdf

Down's Syndrome Association

Eating and Drinking

An illustrated booklet to inform people with a learning disability about health issues and how to get help and advice.

Health – Looking after Yourself Part 1

Accessible health information for adults with Down's syndrome, including a photocopyable personal health record.

Healthy Eating and Exercise

A booklet giving an overview of why healthy eating and exercise are important for young people and adults with Down's syndrome.

Down's Syndrome Scotland

Diet, Weight and Exercise

A workbook to help people to eat healthily, lose weight and be more active.

Available to download from:

www.dsscotland.org.uk/publications/learning-disability/

The Elfrida Society

Food

ISBN 1-901863-00-X. £4.

Available from: www.elfrida.com/publications.htm

FAIR (Family Advice and Information Resource)

Keep Yourself Healthy – A Guide to Having a Healthy Heart

A booklet for people with a learning disability which explains the importance of having a healthy heart.

Manchester Health Promotion Resources Library

A Practical Guide to Weight Management, Healthy Living, Keeping Fit and Health Education

A guide for people with learning disabilities. Available from:

Manchester Health Promotion Resources Library

Withington Hospital Site

Nell Lane

Manchester M20 2LR

T: 0161 611 3642

E: pia.felg@manchester.nwest.nhs.uk

The Plymouth Projects (2005)

A series of very simple leaflets for people with learning disabilities was developed by Plymouth Learning Disability Services, funded by the Big Lottery. It includes leaflets on:

Healthy Eating

Weight

Smoking and Alcohol

These and a range of other accessible leaflets on health-related issues can be accessed at:

[www.salford-](http://www.salford-pct.nhs.uk/LDAccessibleHealthLeaflets.asp?id=27)

pct.nhs.uk/LDAccessibleHealthLeaflets.asp?id=27

Eating well: resources for helping people with learning disabilities make choices

Food, Fitness, Fun: A Training Pack in Weight Management for People with Learning Disabilities

P McIntosh and JM O'Neill (1999)

Available priced £75 from Pavilion Publishing. T: 01273 623222. www.pavpub.com

Menu Planning Pack

Surrey and Borders Partnership NHS Trust.

This pack includes a bound, laminated menu book, sheets of laminated food photos, and notes and guidance on how to introduce the pack to service users. Available priced £45 from: Community Learning Disability Service, 11 Church Road, Frimley GU16 7AD. T: 01483 782940.

Talking Mats

Talking Mats and Learning Disability Package

J Murphy and L Cameron

ISBN 1 857 69 215 2. £69.95.

Talking Mats and Alternative Methods of Eating and Drinking

S Boa, L Cameron and J Murphy

ISBN 1 85769 217 9. £69.95.

Both available from www.talkingmats.com

Games and activities

A number of games and activities which encourage healthy eating are available. These may be available through your local health promotion office or primary care trust.

Healthy eating games are also available from educational resource suppliers such as:

TTS Group Ltd

Park Lane Business Park

Kirkby-in-Ashfield

Nottinghamshire NG17 9LE

T: 0800 318 686

E: sales@tts-groups.co.uk

www.tts-group.co.uk

Eating well: resources for family, friends, support staff and health professionals

British Institute for Learning Disability (BILD)

BILD publications can be accessed from www.bild.org.uk, or phone BookSource on 08702 402 182.

Down's Syndrome and Health Care

A book providing practical information for staff, families and carers.

Down's Syndrome Association

Diabetes and Down's Syndrome – Notes for Parents and Carers

A booklet discussing the relationship between diabetes and Down's syndrome.

Health – Looking after Yourself Part 2

A set of notes on medical issues, to be used by the carers of adults with Down's syndrome.

Food Standards Agency (FSA)

FSA publications are available from:

PO Box 369

Hayes

Middlesex UB3 1UT

T: 0845 606 0667

F: 020 8867 3225

Minicom (for people with hearing disabilities): 0845 606 0678

E: foodstandards@eclogistics.co.uk

www.food.gov.uk/aboutus/publications/nutritionpublications

The Balance of Good Health FSA 0008

Feeding your Growing Child FSA/0456/0602

Healthy Diets for Infants and Young Children FSA0249

The Little Book of Salt FSA1133

Mencap

Supporting Healthy Eating: What You Need to Know

Available priced at £10 from www.mencap.org.uk.

North East Essex Primary Care Trust

Nutrition by Design: A Reference Manual Offering Nutritional Advice to Carers of People with Learning Disabilities

K Hurst, L Child and SR Feldman (1993)

ISBN 0952602504

Food, Fluid and Fibre: A Guide on Constipation Offering Nutritional Advice to Carers of People with Learning Disabilities

K Leech and J MacDonell (1999)
ISBN 0952602512

Both available priced at £12 including postage and packing from: North East Essex Primary Care Trust, Heath House, Grange Way, Colchester CO2 8GU. T: 01206 747741.

Scope

Eating and Mealtimes (Factsheet)

Available from: www.scope.org.uk/information/factsheets

Scottish Nutrition and Diet Resources Initiative

The following resource is for dietitians to use with people with learning disabilities.

Are You Constipated? (2005)

Two resources, for health professionals to use with people with learning disabilities, are also available:

Healthy Eating and Gentle Exercise

Do You Want to Stay Fat?

Details from www.caledonian.ac.uk/sndri

Oral health

British Institute for Learning Disability (BILD)

BILD publications can be accessed from www.bild.org.uk, or phone BookSource on 08702 402 182.

Looking After Your Teeth

ISBN 1 873791 372

Faculty of Dental Surgery and the British Society for Disability and Oral Health

For guidelines on oral health care for people with learning disabilities from these organisations, see <http://www.bsodh.org.uk/guidelines.html>

Special diets and conditions

Can't Eat, Won't Eat – Dietary Difficulties and Autistic Spectrum Disorders

B Legge (2002)

Published by Jessica Kingsley. ISBN 978 18533029745.

Diabetes and Down's Syndrome – Notes for Parents and Carers

Published by Down's Syndrome Association.

A booklet discussing the relationship between diabetes and Down's syndrome.

Eating Well for Older People with Dementia

Published by VOICES (1998).

Out of print but available as a free pdf from www.cwt.org.uk

Food, Drink and Dementia. How to Help People with Dementia Eat and Drink Well

H Crawley (2002)

Published by Dementia Services Development Centre, University of Stirling. Available from: www.stir.ac.uk/dsdc

The Fun with Food Programme: Therapeutic Intervention for Children with Aversion to Oral Feeding

Arlene McCurtin

Speedmark Publishing Ltd.

ISBN 13 978 0 86388 5662. £39.99

Down's Syndrome Association Scotland

About Dementia: For People with Learning Disabilities

K Dodd, V Turk and M Christmas (2005)

ISBN 1 904082 90 4. £8.

Food for Thought

A4 poster about nutrition for people with dementia.

Available from:

www.dsscotland.org.uk/publications/professionals-students/food-for-thought.pdf

Nutrition support

Norah Fry Research Centre

Food for Thought? Effective Support for Families Caring for a Child Who is Tube Fed

R Townsley and C Robinson (2000)

ISBN 1 874291 76 4

Nutritional screening

MUST tool

The MUST tool is widely used in community settings by health professionals to determine nutritional status. This tool is explained and can be viewed and accessed at: www.bapen.org.uk

For local screening tools, talk to your hospital or community dietitian who will be able to advise you on suitable tools to use.

Pregnancy and breastfeeding

Department of Health

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4084370

Breastfeeding

Leaflet available in 12 languages

Leaflets are also available on *Bottle Feeding* and *Weaning*.

Foetal Alcohol Syndrome Aware UK

For information on alcohol consumption during pregnancy and preconception see:

<http://www.fasaware.co.uk/flashfiles/ads/FASleafletA4.pdf>

Food Standards Agency

See page 153 for ordering details. Also available from:

<http://www.food.gov.uk/aboutus/publications/nutritionpublications>

Thinking of Having a Baby	FSA0452
Eating While You Are Pregnant	FSA0451
Eating for Breastfeeding	FSA0453
Feeding Your Baby	FSA0454

Resources for parents with learning disabilities

You and Your Baby 0 - 1 Year Book

Available as a book (£36) or as a tape (£7) from Change.

<http://www.changepeople.co.uk/sendform.aspx?page=11393>

Health visitors can get this book free from their local health promotion unit.

British Institute for Learning Disability (BILD)

BILD publications can be accessed from www.bild.org.uk, or phone BookSource on 08702 402 182.

Children Need Healthy Food

ISBN 1 873791 41 0. £11.

Medication

Handbook on Medication for Carers of People with Learning Disabilities

M Wilcher (2005)

Published by South Birmingham Primary Care Trust.

Health action planning

Health Action Planning in a Person Centred Way

Compiled by the Foundation for People with Learning Disabilities.

Available from:

<http://valuingpeople.gov.uk/dynamic/valuingpeople143.jsp>

My Health Action Plan

Published by Mencap.

Available priced at £5 from www.mencap.org.uk.

Diet and mental health

MIND

The following publications are available from:

www.mind.org.uk/Information/Factsheets/

MIND Guide to Food and Mood

Understanding Eating Distress

MIND Guide to Physical Activity

The Mental Capacity Act

The Department for Constitutional Affairs/Ministry of Justice

A range of simple leaflets has been produced by the Department for Constitutional Affairs, with the Public Guardianship Office, the Department of Health and the Welsh Assembly Government, which explain the Mental Capacity Act (2005), including those listed below. For details: T: 023 80 878038/878036.

E: reorder@inprintlitho.com

They are also available online at: www.dca.gov.uk/legal-policy/mental-capacity/publications.htm or from www.justice.gov.uk

Making Decisions About Your Health, Welfare or Finance. Who Decides When You Can't?

Making Decisions. A Guide for Family, Friends and Other Unpaid Carers

Making Decisions. An Easy Read Guide

Therapeutic horticulture

Thrive

The Geoffrey Udall Centre
Beech Hill
Reading RG7 2AT
T: 0118 988 5688
www.thrive.org.uk

Thrive offers courses, information, resources and support to those who may find therapeutic horticulture beneficial for themselves or for those they support.

Catering and menu planning

Catering for Health

Produced by the Food Standards Agency and Department of Health. Available free from: PO Box 369, Hayes, Middlesex UB3 1UT. T: 0845 6060667

National Association of Care Catering

The following resources provide practical guidance on catering in residential care, catering for special diets and catering for community meals. Further details from: www.thenacc.co.uk. T: 0870 748 0180.

The Catering Checklist

Menu Planning and Special Diets in Care Homes

The National Minimum Standard for Care Catering (Care Homes for Adults Aged 18-65 Years)

The National Minimum Standards for Care Catering (Care Homes for Older People)

Quality Standard Indicators for Catering

A Recommended Standard for Community Meals

Nutmeg UK

www.nutmeg-uk.com
Provides menu planning software.

Suppliers of specialist eating and drinking equipment and thickeners for puréed food

Disabled Living Foundation

The Disabled Living Foundation can advise on disability equipment.
www.dlf.org.uk
T: 0845 1309177

Suppliers of specialist equipment

Specialist equipment is available from a number of suppliers including:

Ableworld

Ableworld (UK) Limited
39 Beam Street
Nantwich
Cheshire CW5 5NF
T: 01270 627185
www.ableworld.co.uk

Disabled Accessories

The Tanyard
Leigh Road
Street
Somerset BA16 0HR
T: 01458 449028
E: info@disabledaccessories.com
www.disabledaccessories.com

Nottingham Rehab Supplies (NRS)

Findel House
Excelsior Road
Ashby de la Zouch
Leicestershire LE65 1NG
T: 0845 120 4522
E: customerservice@nrs-uk.co.uk
www.nrs-uk.co.uk

Suppliers of thickeners, food moulds and soaking solutions for puréed diets

Nutilis: Nutricia Clinical Care

Nutricia Ltd

White Horse Business Park

Newmarket Avenue

Trowbridge BA14 0XQ

T: 01225 711677

Clinical Nutrition Direct Helpline: 01225 751098

E: cndirect@nutricia.co.uk

www.nutricia-clinical-care.co.uk

Thick & Easy: Fresenius Kabi Ltd

Melbury Park

Clayton Road

Birchwood

Warrington WA3 6FF

T: 01925 898040

www.fresenius-kabi.co.uk

Thixo-D: Sutherland Health Ltd

Unit 1

Rivermead

Pipers Way

Thatcham

Berkshire RG13 4EP

T: 01635 874488

Vitaquick: Vitaflo International Ltd

11 Century Building

Brunswick Business Park

Liverpool L3 4BL

T: 0151 709 9020

E: vitaflo@vitaflo.co.uk

www.vitaflo.co.uk

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Caroline Walker Trust at www.cwt.org.uk

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