



Learning Disabilities Mortality Review (LeDeR) Programme: Fact Sheet 28

Nutrition and diet

Key considerations for reviewers

- Was the person underweight or overweight/obese? If so, what measures had been taken in recognition of this? Was the person screened and assessed for nutritional and dietary needs? Where appropriate, was the person referred to a specialist? Who was this? What accessible support was given by this specialist?
- Did the person have a record of their 'baseline' weight, any weight management plan, the name of the responsible clinician monitoring this and review dates in their records or in their Health Action Plan?
- Did the person have an accurate Malnutrition Universal Screening Tool assessment?
- Were records kept of the person's diet, fluid intake, weight and bowel movements if there had been any concerns?
- Were reasonable adjustments made to ensure a positive and person-centred eating experience?
- Were family carers or paid staff adequately trained and supported to provide good care relating to the person's diet and nutritional status?
- Were any of the person's health conditions significantly influenced by their diet/weight? Did nutritional assessments take place, was accessible information/advice provided to the person and/or their carers?

Introduction

People with learning disabilities are more likely to have poor diet, and are more likely to be underweight or obese than people in the general population. Being underweight, overweight or malnourished raises the risk of serious health problems, and can affect quality of life. In hospitals, malnourished patients have a higher mortality rate and stay in hospital longer. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD, 2013) highlighted concerns about the completeness of nutrition monitoring records, particularly of diet and fluid intake, weight and bowel movements, in people who were known to be at risk of inadequate nutrition or weight loss. It also reported a lack of facilities such as wheelchair scales for weighing people with physical impairments in the community. Inadequate knowledge about nutrition by care staff led to a lack of the recognition of malnutrition in some people whose deaths were reviewed by CIPOLD.

Key Principles

Nutritional problems are common in people with learning disabilities, with underweight and overweight more frequently found than in the general population. Nutritional disorders can be complex, and their management requires a multiagency approach.

In some cases, learning disabilities are associated with other conditions that make being overweight more likely, such as Down's syndrome, or Prader-Willi syndrome (which causes an insatiable appetite). Some people, particularly those



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with autism may have sensory differences and routinized behaviours that result in very limited diets and malnutrition. These factors can make weight management and maintaining good nutrition particularly challenging.

People with profound and multiple learning disabilities are often underweight because of poor feeding and swallowing, while other people with learning disabilities may be under or overweight and/or malnourished because they aren't getting the support they need to make healthy diet and lifestyle choices and provide and prepare healthy food.

The frequency with which a person should be weighed depends on each person's individual circumstances. A record should be kept in the person's Health Action Plan of their weight, which can be used as a 'baseline' or reference point. A measure that is commonly used to classify a person's weight is body mass index, calculated by dividing weight in kilograms by height in metres squared.

Indications that a person may need to be weighed more frequently include someone's clothes becoming too tight or too loose, or a change in appetite. Changes in weight can be an indicator of unrecognised chronic illness and should be reported to a doctor. If a person's weight has changed more than or less than 10% of their 'baseline' weight, or if there are concerns about their nutritional intake, they should also be referred to a dietician.

Underweight

A person with a BMI of less than 18.5 is considered to be underweight. Being underweight is a manifestation of short-term or long-term under-nutrition. In people with learning disabilities, chronic long-term underweight may be mistakenly ascribed to the person's learning disabilities and accepted as part of their condition. Although it is common for people with severe learning disabilities to be under-weight, it is not normal and warrants intervention as it has serious implications for the person's health. The consequences of being underweight include:

- Compromised immunity with increased susceptibility to infections.
- Reduced respiratory function.
- Decreased energy levels leading to reduced participation in daily activities.
- Reduced overall quality of life.

Assessment and management of underweight people with learning disabilities requires a multi-disciplinary approach with regular review of the management plan.

Overweight and obesity

A person with a BMI of more than 25 is classed as overweight; obesity is defined as having a BMI of 30 or more. The prevalence of overweight and obesity in people with learning disabilities is generally acknowledged to be more than in the general population, particularly for women, those living in community settings, and those with mild or moderate learning disabilities. However, being overweight or obese is not usually inevitable for people with learning disabilities, and is usually the result of lifestyle factors. The consequences of being overweight or obese include:

- Coronary artery disease and strokes.
- Type 2 diabetes.
- Hypertension.
- Obstructive sleep apnoea, particularly in people with Down's Syndrome who may have narrowed upper airways.
- Osteoarthritis.
- Increased risk of some cancers, including breast, endometrial and colon.



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The assessment and management of people with learning disabilities who are overweight or obese should follow the same guidelines as for the rest of the population with regards to assessing the cause of the imbalance, the motivation to change and providing advice and support about diet and exercise. However, in people with learning disabilities who rely on others for their dietary intake or access to engagement in physical activity, a range of additional issues need to be considered, including:

- The knowledge and attitudes of family or paid carers.
- The potential uses of food as a reward or diversion.
- The cost and quality of any support package commissioned for the person.
- The cognitive limitations of a person that may limit their understanding and make behavioural changes more difficult to implement.
- The person's state of mental wellbeing, including engagement in meaningful daytime activity.
- The physical health status of the person, including their dental health.
- The consistency of approaches between different paid carers.
- The level of physical exercise that the person is able to do.

In addition, some psychotropic and antiepileptic medications can induce weight gain.

Dehydration

Dehydration occurs when the fluid intake is less than the body requires. We can live for only a few days without fluid, and to maintain hydration, most adults require approximately 1.5 – 2 litres of fluid a day (approximately 8-10 glasses). In hot weather, when exercising, or when we have diarrhoea, our fluid requirement is more than this. Signs of dehydration include:

- Headaches.
- Passing dark coloured urine or passing little or no urine.
- Confusion.
- Tiredness.

Signs of dehydration should be treated with fluids or medical attention.

Constipation

Constipation is when a person passes hard, infrequent stools. It can be particularly problematic in people with reduced gut motility. Chronic constipation can lead to:

- Impaired appetite.
- Abdominal pain.
- Increased seizures.
- Incontinence.
- Diarrhoea.
- Vomiting.
- Changes in behaviour.

Good dietary and lifestyle practices can be beneficial in reducing the risk of constipation, including plenty of fluids, a diet high in fruit and vegetables, and keeping as active as possible.



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Assessment and screening

People with learning disabilities should be routinely screened, including when they are admitted to a hospital or residential setting, and when they are transferred between settings. In addition, those who are nutritionally at risk must have a full assessment by a specialist dietician. Assessment should include scrutiny of medical and nutritional history, behavioural history related to food and fluids, dental and oral function, sensory function, any dietary needs and preferences, and any assistance the person may require with feeding. Where necessary, the person should be referred for specialist input for example a speech and language therapist for those with dysphagia or a physiotherapist where the person has problems with vomiting and regurgitation.

Supporting a healthy diet and lifestyle

People with learning disabilities may find it more difficult to understand nutritional concepts and advice, and should be supported to lead a healthy lifestyle, for example through accessible information and easy read recipes. The individual's preferences should be taken into account to ensure a positive eating experience and balanced diet, by providing social or private eating environments, making food look appetising, giving the person time to eat, providing assistance discreetly to those who need it, providing explanations about the food to people with sensory impairments, and ensuring religious and personal value preferences are taken into account. Adequate time and resource should be prioritised to ensure the person has the time, help and encouragement they need at meal times.

Supported nutrition

Oral dietary supplements may be needed for people with poor dietary intakes at risk of malnutrition. These are usually in the form of energy and nutrient dense drinks and are available on prescription. When a person is unable to orally take in enough nutrition to satisfy their energy requirements, nutrition may be given via a feeding tube, either via the mouth (orogastric) or nose (nasogastric) as a short term measure, or via the stomach (gastrostomy) or jejunum (jejunostomy) as a longer term measure. The technique for creating a gastrostomy is called PEG (percutaneous endoscopic gastrostomy), such tubes are often referred to as PEGs. Similarly, the technique to create a jejunostomy is called a PEJ and such tubes are known as PEJs.

Summary of key points

Good nutrition is vital to the health and wellbeing of people with learning disabilities, but they are more likely than the general population to be underweight or overweight/obese, in most cases due to lifestyle factors and not to causes inherent to their learning disabilities. As in the general population, both underweight and overweight are associated with increased risk of other health problems, which are largely preventable. Nutritional disorders in people with learning disabilities can be complex, and their management is likely to require a multiagency approach.

Additional sources of information

The Francis report www.england.nhs.uk/wp-content/uploads/2015/10/nut-hyd-guid.pdf?dm_i=6N7,3PMDD,KWHTQV,DF91H,1

Nursing times article www.nursingtimes.net/nutrition-and-learning-disabilities/200644.fullarticle



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SCIE guide www.scie.org.uk/publications/guides/guide15/files/guide15-nutrition.pdf?res=true

Eating well - children and adults with learning disabilities <https://www.cwt.org.uk/wp-content/uploads/2015/02/EWLDGuidelines.pdf>

Malnutrition Universal Screening Tool assessment MUST https://www.bapen.org.uk/pdfs/must/must_full.pdf