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BDA The Association of UK Dietitians

The Nutritional Care of Adults with a Learning Disability in Care Settings

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Executive Summary

The importance of nutritional care for People with Learning Disabilities (PWLD) should not be underestimated. As a group, they are more at risk from obesity, problems with eating, drinking and swallowing and certain types of cancer, but at the same time, can be some of the most vulnerable members of society. They are often dependent on others to choose which foods they eat, when they eat and how much they eat. Understanding the impact of diet on health and wellbeing is paramount for those caring for or supporting PWLD.

The Professional Consensus Statement set out standards of nutritional care which care providers are expected to achieve. They give clear, concise criteria for staff to follow to be able to meet these standards and some tools to help them achieve this e.g. a weight monitoring chart and guidance on how to complete.

Training and education for carers will be paramount in attempting to achieve these standards. Senior staff should attend relevant courses, such as the REHIS Elementary Food and Health Course for Carers of Adults with a Learning Disability and have nutrition, hydration and healthy eating high on their agenda of training topics.

The Professional Consensus statement is a step towards addressing some of the health inequalities which our client group experience.

Introduction

People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. However life expectancy is increasing, in particular for people with Down's syndrome 2016.[3]

In 2015 there were 4.3 adults (16- 64) with a learning disability per 1000 of the general population in England known to local authorities.[1] The figure in Scotland was higher at 6.1 adults with learning disability per 1,000 adults.[2]

The median age of death for people with learning disabilities is 65 years for men and 63 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population.[4]

Difficulties with eating, drinking and swallowing have implications for health, safety and wellbeing. Among adults with learning disabilities, 40% of people with dysphagia experience recurrent respiratory tract infections. Other negative health consequences of dysphagia include asphyxia, dehydration, poor nutritional status and urinary tract infections.[4]

The most frequent cause of death in people with learning disabilities is respiratory infection often linked with difficulties with eating, drinking and swallowing.

Underweight, overweight and obesity are more prevalent than the general population.[5]

	General population (percentage)		LD population (percentage)	
Underweight	2		17	
Overweight	30 men	25 women	41 men	31 women
Obese	24 men	27 women	31 men	45 women

"With the move towards health and social care integration, services will be jointly responsible for the health and care needs of patients, to ensure that those who use services get the right care and support whatever their needs, at any point in their care journey" (Scottish Government) 2014)[6]

The National Health and Social Care standards aim to ensure that people who receive care and support get the high quality service they are entitled to. Recommendations are included about eating and drinking (National Health and Social Care Standards 2017)[7]

It is recognised that less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient intake of fruit and vegetables. Carers generally have poor nutritional knowledge about public health recommendations on dietary intake.[3]

There is a need to support carers in the provision of good nutritional care. This is an update of the original professional consensus statement produced in 2008 and updated in 2012. This document has been based on the framework of the HIS Food Fluid and Nutritional Care Standards Oct 2014.[8]

Aim: To review and update the 2012 Professional Consensus Statement, The Nutritional Care of Adults with a Learning Disability in Care Settings.

Objective: To review current publications in relation to learning disabilities and nutritional care. We have undertaken a systematic review of published work to develop clear and concise best practice guidelines in this field.

There are 6 standards:

Standard 1 - Consensus Statement
Standard 2 - Assessment, screening and care planning
Standard 3 - Menu design, food preparation and presentation
Standard 4 - Facilities available for eating and drinking
Standard 5 - Communication and empowerment
Standard 6 - Education and training

In developing these standards consultation has been sought from the Scottish Dietetic Learning Disability Dietetic Clinical Network, Mental Health Specialist Group of the British Dietetic Association and learning disability care providers.

Standard 1 - Consensus Statement

Standard Statement

Each organisation will implement the 'Professional Consensus Statement. The Nutritional Care of Adults with Learning Disability in Care Settings' to ensure that all clients receive safe, effective and person-centered nutritional care.

Rationale

- People with learning disabilities have greater health needs compared to the general population.[3,4,5,9]

- Malnutrition is an important public health problem. People with learning disabilities have a high risk of being nutritionally compromised. Whether this is due to obesity, underweight or eating and drinking difficulties.[5]

Criteria

- Each care provider has an implementation plan to improve the provision of food, fluid and nutritional care.[8]

Standard 2 – Assessment, Screening and Care Planning

Standard Statement

It is recommended that the nutritional status of every client be assessed by the care provider both on moving to a new care home and on an ongoing basis.

Rationale

Malnutrition is an important public health problem. People with learning disabilities have a high risk of being nutritionally compromised.[5]

Clients' energy intake below their nutritional needs may put them at risk of under nutrition.[4,9,10]

Clients' energy intake above their nutritional needs will put them at risk of obesity and associated health risks.[12]

The screening and assessment process help to identify under nutrition and factors that may prevent clients from eating and drinking adequately.[9,10,11]

Criteria

2.1 The nutritional care assessment should accurately identify and record:

(a) Measured height and weight, with the date and time that these measurements were taken (if estimates are used, this should be stated and a rationale provided)
(b) Food allergies or intolerances
(c) Eating and drinking likes and dislikes
(d) Therapeutic or texture-modified diets requirements
(e) Cultural, ethnic or religious dietary requirements
(f) Social and environmental mealtime requirements
(g) Physical difficulties with eating and drinking, including swallowing difficulties
(h) The need for help and support with eating and drinking, for example prompting and encouragement, equipment or community meals, and
(i) Oral health status [22]

2.2 The nutritional care assessment includes accurate screening for the risk of malnutrition using a validated tool that is appropriate for the patient population and includes criteria and scores that indicate actions to be taken, such as the Malnutrition Universal Screening Tool (MUST) for adults.[10]

2.3 Routine nutritional screening should take place at 6 monthly intervals.

2.4 Weigh on accurate and appropriate scales.

2.5 Weigh monthly and record on annual weight monitoring chart (Appendix 1 and 2).

2.6 Information about the client's eating, drinking and nutritional care requirements is effectively communicated and accurately documented.

2.7 Should nutritional screening or assessment highlight concerns - follow local management guidance.

2.8 The assessment process identifies the need for referral to specialist services, for example dental and oral health, dietetic, occupational therapy, physiotherapy and speech and language therapy.[4,9]

Standard 3 - Menu Design, Food Preparation and Presentation

Standard Statement

Meals should be varied and nutritious, reflecting special dietary requirements and texture modification, food preferences, seasonal variation, cultural, religious considerations and any special dietary needs. They should be prepared safely and attractively presented.[7, 12]

Rationale

Client's food and fluid intake, eating and drinking pattern, specific likes and dislikes are recognised and accounted for.

Provision of suitable, nutritious food will ensure that client's nutritional requirements are met, and will help minimise food and fluid waste.

Food that is freshly prepared from raw ingredients and presented attractively is more likely to be eaten, thus optimising nutrition.

Criteria

3.1 All care staff have a responsibility to ensure optimal nutritional care for their clients.

3.2 A system is in place to ensure menus are routinely planned with client participation where possible.

3.3 Menus are based on the Eat Well Guide unless advised otherwise by a medical professional.[14]

3.4 Menus need to reflect any therapeutic dietary requirements e.g. texture modified diets, weight management diets along with clients likes and dislikes.[13,15]

Standard 4 - Facilities Available for Eating and Drinking

Standard statement

The eating environment in which the client eats must be conducive to the client's needs. Clients should never feel rushed or uncomfortable whilst eating or drinking.[7,12]

Rationale

The environment in which the clients eat is as important as the food provided, as it can have a major impact on nutritional intake.

Criteria

4.1 Assistance should be available for eating and drinking if required.

4.2 Dining areas should be available with appropriate furniture.

4.3 Dining areas must be as homely as possible to provide a relaxed environment also encouraging the social aspects of eating and drinking.

4.4 Clients are provided with the equipment and utensils for eating and drinking that meet their individual needs.

4.5 Try to ensure a quiet environment free from distractions.

Standard 5 - Communication and Empowerment

Standard Statement

Staff should communicate regularly with clients about nutritional care, food and fluid provision, using pictorial information where necessary, in order to support informed choice.[13]

Rationale

Clients have the right to the information and support they need to make informed choices.

Good communication between staff and clients around food fluid and nutritional care will result in clients nutritional needs been met.

Criteria

5.1 Information and communication about food, fluid and nutritional care are delivered in a format suitable to the client's identified communication needs.

5.2 Menu plans are based on the Eatwell Guide. [14] They are designed taking into account, not only therapeutic requirements, but also informed food choices, ethnic, cultural, religious or other preferences clients may have.

Standard 6 – Education and Training

Standard Statement

Staff have the knowledge and skills required to meet client's food, fluid and nutritional care needs.[7,13]

Rationale

Staff require information and training to ensure that the nutritional needs of clients are met.

It is important that all staff involved in the provision of food, fluid and nutritional care recognise the critical nature of this task, and receive training in nutritional care.[16]

Criteria

6.1 All staff should have a working knowledge of the principals of healthy eating e.g. Eatwell Guide

6.2 All senior staff should be trained in the specific nutritional needs of adults with learning disabilities e.g. REHIS Elementary Food and Health Course for Carers of Adults with a Learning Disability.[16]

6.3 Staff should use evidence based resources when educating their clients about healthy eating e.g. Healthy Eating Healthy Living Resource, pictorial cookbooks – My Own Cookbook, Cook Your Own Takeaway, Cyrenians Good Food [18.19,20,21]

6.4 A programme of nutritional care education is regularly reviewed and updated by a senior member of staff to include

(a) The correct use of nutritional screening tools and related measurements.
(b) Risk factors for dehydration, over nutrition and under nutrition.
(c) Recognising physical difficulties with eating drinking and swallowing.
(d) Providing assistance with eating drinking and swallowing difficulties.

Appendix 1

Weight Monitoring Chart

WEIGHT MONITORING CHART

Name:	Height (m):	**Measuring information:** (e.g. which scales have been used? Is there a wheelchair weight? Has height been measured using an alternative method?)
DoB:		

MONTHLY MEASUREMENTS (Please plot weight on the vertical line)

Weight Scale (kg)

Start weight

Date																														
Weight (in kg)																														

Appendix 2

Guidelines for Using Weight Monitoring.

The weight monitoring chart has been developed to allow care staff to monitors the client's weight on a monthly basis.

To complete the chart:

1. Details the client's name and date of birth
2. Details of height in metres
3. Details of measuring information: (e.g. which scales have been used? Is there a wheelchair weight? Has height been measured using an alternative method?)
4. Record date of weight and actual weight in kg on a monthly basis
5. Complete left hand side of graph by filling in appropriate scale for weight in kg
6. Each month fill in date and mark weight with a cross on the graph, join up subsequent recordings with a line to give a pictorial representation

Appendix 3

Authors Curriculum Vitae

Janie Faulkner

Qualified in 1979 with a Post Graduate Diploma in Dietetics from Queens College Glasgow and subsequently registered with the Health and Care Professions Council. Have worked in Learning Disabilities since 1992 and involved in the production of resources and training materials for this group. MSc Certificate achieved 2011. Currently Team Lead for Learning Disability Nutrition and Dietetic service within NHS Forth Valley.

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Kirsty Hamilton

Qualified in 1983 with a BSc Nutrition and Dietetics at Queen Margaret College in Edinburgh and subsequently registered with the Health and Care Professional Council. Has been working in the field of Adults with Learning Disabilities since 1993 and involved in establishing a specialist community service across Tayside. Currently Team Lead for Learning Disability Nutrition and Dietetic service within NHS Tayside.

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Elspeth Ryan

Qualified in 1995 with a BSC Nutrition and Dietetics at Caledonian University Glasgow. subsequently registered with the Health and Care Professional Council. Has been working in the field of Adults with a learning Disability since 2000. In addition acted as NHS Fife Nutrition champion and was actively involved in the implementation of the Food Fluid and Nutritional Care Standards across NHS Fife.

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We are all active members of the Scottish Dietetic Learning Disability Dietetic Clinical Network, which to date have completed the following pieces of work:

- NDR Pictorial Diet Sheets- on ‘Are You Constipated?’, Do you want to stay fat? Healthy eating and gentle exercise.

- Group members have contributed to The Caroline Walker Trust ‘Eating Well: children and adults with learning disabilities.

- The group has been involved in the development and delivery of 2 resources:
  (a) REHIS Elementary Food and Health Course for Cares of Adults with a Learning Disability.[16]
  (b) Healthy Eating Healthy Living Pack.[17]

References

1. Public Health England People with Learning Disabilities in England 2015. Available from https://www.gov.uk/government/statistics/learning-disabilities
2. Scottish Commission for Learning Disability (2016). Learning Disability Statistics Scotland, 2015. Available from https://www.scld.org.uk/
3. Learning Disabilities Observatory 2010 Health Inequalities & People with Learning Disabilities in the UK: Available from https://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf
4. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) 2013. Available from http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf
5. Public Health England (2016) Making reasonable adjustments to obesity and weight management services for people with learning disabilities. Available from http://www.improvinghealthandlives.org.uk/securefiles/170306_1031//Obesity%20RA%20report%20final.pdf
6. Scottish government 2016 available from http://www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration
7. Scottish Government 2017 National Health and Social Care Standards: my support, my life. Available from http://www.gov.scot/Publications/2017/06/1327
8. Healthcare Improvement Scotland. Food, fluid and nutritional care standards. October 2014. Available from http://www.healthcareimprovementscotland.org/programmes/patient_safety/programme_resources/nutritional_care_standards.aspxm
9. NHS Health Scotland. (2004) Health's Needs Assessment Report: People with Learning Disabilities in Scotland. Available from http://www.healthscotland.com/documents/1040.aspx
10. BAPEN British Association for Parenteral and Enteral Nutrition (2003) Malnutrition Universal Screening Tool Available from http://www.bapen.org.uk/screening-and-must/must/introducing-must
11. BAPEN British Association for Parenteral and Enteral Nutrition (2012) available from http://www.bapen.org.uk/resources-and-education/publications-and-reports/other-reports/combating-malnutrition-recommendations-for-action
12. SIGN (2010) Guideline 115 Management of Obesity. http://www.sign.ac.uk/guidelines/fulltext/115/index.html
13. Caroline Walker Trust: EatingWell : Children and Adults with Learning Disabilites (2007) Available from http://www.cwt.org.uk/publications/
14. EatWell Guide 2016 available from https://www.gov.uk/government/publications/the-eatwell-guide
15.Dysphagia Diet Food Texture Descriptors (2011) National Patient Safety Agency,Royal college of Speech and language Therapists, British Dietetic Association,National Nurses Nutrition Group, Hospital Caterers Association Available from. http://www.thenacc.co.uk/assets/downloads/170/Food%20Descriptors%20for%20Industry%20Final%20-%20USE.pdf
16. Scottish Government (2013) The keys to life - Improving Quality of Life for People with Learning Disabilities. Available from. http://www.gov.scot/Publications/2013/06/1123
17. REHIS Elementary Food and Health Course for cares of adults with a learning Disability. (2017) Available from. http://www.rehis.com/community-training/courses/course/elementary-food-and-health-course-carers-adults-learning-disability
18. Healthy Eating Healthy Living Pack (2012) Available from https://www.scld.org.uk/healthy-eating-healthy-living-pack/
19. My Own Cookbook NHS Fife.
20. Cook Your Own Takeaway NHS Fife
21. Cyrenians Good Food A pictorial recipe book. www.ctreniansgoodfood.org.uk
22. NHS Health Scotland. Oral Health and Nutrition Guidance for Professionals 2012 [updated 2012; cited 2014 September 11]; Available from: http://www.healthscotland.com/uploads/documents/19664-OralHealthAndNutritionGuidance.pdf.

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