

Protecting and improving the nation's health

# Health inequalities: Dysphagia

## Introduction

Dysphagia (difficulty in eating, drinking or swallowing) is associated with serious health complications and psychosocial consequences. Aspiration pneumonia is of particular concern due to its link with subsequent morbidity and mortality<sup>1 2 3</sup>.

## Prevalence and risk factors

For the general population, literature reviews have reported dysphagia prevalence rates ranging from 2.3 to 16%<sup>4</sup> and 1.7 to 11.3%<sup>5</sup>, with prevalence being higher in older people.

For people with learning disabilities, estimates vary from 1% of adults without cerebral palsy, to 99% of children with severe generalised cerebral palsy and learning disability<sup>6</sup>. Estimates from population-based samples of people with learning disability from areas of England give rates of 8.1%<sup>7</sup> and 11.5%<sup>8</sup> of adults known to formal learning disability services. However as both estimates are reliant on dysphagia initially being recognised by caregivers or professionals, who may under-recognise dysphagia, actual prevalence may be higher<sup>6</sup>.

A large-scale population-based study in Greater Glasgow incorporating health assessments found a prevalence of 14.4%, with higher prevalence in those with more severe learning disabilities (for example profound learning disability OR 10.50, 95% CI 6.13-17.98)<sup>9</sup>. For England, data from 47% of GP practices in England for 2017/18 indicate that 5.0% of patients with a learning disability also had a diagnosis of dysphagia, with the highest prevalence recorded in patients aged 75 and over (11.7%)<sup>10</sup>. Dysphagia is more common in people with more severe learning disabilities, in people with learning disabilities who have cerebral palsy, and is also associated with motor impairment<sup>6</sup>. Specific syndromes associated with learning disabilities can result in both anatomical and neurological precursors for dysphagia, including Down syndrome<sup>11</sup>, Rubinstein Taybi syndrome<sup>12</sup>, and Rett syndrome<sup>13</sup>. People with learning disabilities have also been shown to be at a higher risk of choking<sup>14 15</sup>.

## Impact on people with learning disabilities

Aspiration (breathing food or liquid into the lungs) is common in people with learning disabilities and dysphagia<sup>16</sup>. Many of those who aspirate do so silently (aspiration without a cough or other sign), which may go unnoticed and have chronic health implications<sup>16</sup>. Respiratory infections and choking are common in people with learning disabilities and dysphagia.

Respiratory disease, particularly bronchopneumonia, is a leading cause of death in people with learning disabilities, in particular in those with profound and multiple disabilities, accounting for significantly more deaths than in the local general population<sup>1 17</sup>.

Preventable lung inflammation caused by solids or liquids, or foreign bodies, has also been associated with mortality in people with learning disabilities<sup>14</sup>. The issue of dysphagia in people with learning disabilities may be complicated by co-occurring physical health issues, psychiatric, communicative, cognitive and behavioural issues. For example, there is a link between the side-effects of neuroleptic medications and dysphagia<sup>18</sup> and people with learning disabilities are more likely than others to be prescribed these types of anti-psychotic medication<sup>19</sup>.

Behavioural factors which may be an issue for people with learning disabilities (such as pica, cramming food and eating and drinking quickly) may also exacerbate dysphagia symptoms<sup>20 21</sup>. Learning disability may also impact on the ability to learn compensatory strategies and retain skills<sup>22</sup>.

Finally, some people with learning disabilities may be unable to communicate verbally their dysphagia related experiences.

## Healthcare and treatment

There is very little research evidence available on current practice in relation to supporting people with learning disabilities and dysphagia<sup>16</sup>. Individualised interventions include altering positioning, modification of food and drink consistency, giving advice on equipment, and working on the physical environment through carer training<sup>23</sup>. Noncompliance with dysphagia management advice in people without learning disabilities has been associated with adverse outcomes, including chest infection, aspiration pneumonia, and death<sup>24</sup>. Numerous barriers to compliance with eating and drinking recommendations have been identified<sup>25</sup>. Education to increase knowledge of dysphagia and its associated risks amongst caregivers can increase adherence to dysphagia management guidelines<sup>16</sup>. There is an urgent need for research on improving the management of dysphagia in people with learning disabilities including positioning, dietary modification and long-term postural care

which may prevent changes in body shape that can cause problems with swallowing<sup>26 27</sup>.

The quality of caregiver support provided to people with learning disabilities and dysphagia can have an influence on health and ultimate risk of death<sup>20</sup>. Despite dysphagia being identified as a key risk area for people with learning disabilities<sup>28</sup>, less than 20% of inpatients with learning disabilities were found to have received a swallowing assessment<sup>29</sup>.

# Social determinants

The problems associated with dysphagia may be compounded by social determinants of health such as the quality of social care support received and access to appropriate healthcare, although research investigating these issues in lacking.

# Resources

Public Health England (2016) Dysphagia and people with learning disabilities

# References

<sup>2</sup> Martino R and others. Dysphagia After Stroke: Incidence, Diagnosis, and Pulmonary Complications. Stroke, 2005. 36(12): p. 2756-2763

<sup>4</sup> Kertscher B and others. Prevalence of Oropharyngeal Dysphagia in the Netherlands: A Telephone Survey. Dysphagia, 2015. 30: p. 114-120

<sup>&</sup>lt;sup>1</sup> Hollins S and others. Mortality in people with learning disability: risks, causes, and death certification findings in London. Developmental Medicine & Child Neurology, 1998. 40(1): p. 50-6

<sup>&</sup>lt;sup>3</sup> Heslop P and others. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. Lancet, 2014. 383: p. 889-895

<sup>&</sup>lt;sup>5</sup> Roden DF and Altman KW. Causes of dysphagia among different age groups: a systematic review of the literature. Otolaryngologic Clinics Of North America, 2013. 46(6): p. 965-987

<sup>&</sup>lt;sup>6</sup> Robertson J and others. Prevalence of dysphagia in people with intellectual disability: a systematic review. Intellectual & Developmental Disabilities, 2017. 55(6): p. 377-391

<sup>&</sup>lt;sup>7</sup> Chadwick DD and Jolliffe J. A descriptive investigation of dysphagia in adults with intellectual disabilities. Journal of Intellectual Disability Research, 2009. 53: p. 29-43

<sup>8</sup> Ball S and others. The extent and nature of need for mealtime support among adults with intellectual disabilities. Journal of Intellectual Disability Research, 2012.
56(4): p. 382-401

<sup>9</sup> Kinnear D and others. Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross-sectional study. BMJ Open, 2018. 8(2)

<sup>10</sup> NHS Digital (2019) <u>Health and Care of People with Learning Disabilities:</u> <u>Experimental Statistics: 2016 to 2017</u>

<sup>11</sup> O'Neill AC and Richter GT. Pharyngeal Dysphagia in children with down syndrome. Otolaryngology-Head & Neck Surgery, 2013. 149(1): p. 146-150

<sup>12</sup> Shashi V and Fryburg JS. Vascular ring leading to tracheoesophageal compression in a patient with Rubinstein-Taybi syndrome. Clinical Genetics, 1995.
48(6): p. 324-327

 <sup>13</sup> Abraham SS, Taragin B and Djukic A. Co-occurrence of Dystonic and Dyskinetic Tongue Movements with Oral Apraxia in Post-regression Dysphagia in Classical Rett Syndrome Years of Life 1 Through 5. Dysphagia, 2015. 30(2): p. 128-138
 <sup>14</sup> Glover G and Ayub M. How People with Learning Disabilities Die 2010: Improving

Health & Lives: Learning Disabilities Observatory

<sup>15</sup> Thacker AA. Indicators of choking risk in adults with learning disabilities: A questionnaire survey and interview study. Disability and Rehabilitation, 2007. 30(15): p. 11312-1138

<sup>16</sup> Robertson J and others. People with intellectual disabilities and dysphagia. Disability and Rehabilitation, 2018. 40(11): p. 1345-1360

<sup>17</sup> Patja K, Mölsä P and livanainen M. Cause-specific mortality of people with intellectual disability in a population-based, 35 year follow-up study. Journal of Intellectual Disability Research, 2001. 45(1): p. 30-40

<sup>18</sup> Dziewas R.and others. Neuroleptic-Induced Dysphagia: Case Report and Literature Review. Dysphagia, 2007. 22(1): p. 63-67

<sup>19</sup> Glover G and others. <u>Prescribing of psychotropic drugs to people with learning</u> <u>disabilities and/or autism by general practitioners in England</u>. 2015, Public Health England London

<sup>20</sup> Ball SL and others. The extent and nature of need for mealtime support among adults with intellectual disabilities. Journal of Intellectual Disability Research, 2012. 56(4): p. 382-401

<sup>21</sup> Samuels R and Chadwick DD. Predictors of asphyxiation risk in adults with intellectual disabilities and dysphagia. Journal of Intellectual Disability Research, 2006. 50(Part 5): p. 362-370

<sup>22</sup> Sheppard J. Developmental disability and swallowing disorders in adults, in
Dysphagia: Foundations, Theory and Practice, J. Cichero and B. Murdoch, Editors.
2006, Wiley & Sons: Chichester

<sup>23</sup> Chadwick DD. Dysphagia management for people with intellectual disabilities: Practitioner identified processes, barriers, and solutions. Journal of Policy and Practice in Intellectual Disabilities, 2017. 14(4): p. 319-331 <sup>24</sup> Low J and others. The Effect of Compliance on Clinical Outcomes for Patients with Dysphagia on Videofluoroscopy. An International Multidisciplinary Journal Devoted to Swallowing and Its Disorders, 2001. 16(2): p. 123-127

 <sup>25</sup> Chadwick DD and others. Barriers to Caregiver Compliance with Eating and Drinking Recommendations for Adults with Intellectual Disabilities and Dysphagia. Journal of Applied Research in Intellectual Disabilities, 2006. 19(2): p. 153-162
 <sup>26</sup> Cobb J and Giraud-Saunders A. Commentary: Biomechanics and prevention of body shape distortion. Tizard Learning Disability Review, 2010. 15(2): p. 30-32
 <sup>27</sup> Hill S and Goldsmith J. Biomechanics and prevention of body shape distortion. Tizard Learning Disability Review, 2010. 15(2): p. 15-29

<sup>28</sup> Public Health England (2016) <u>Dysphagia and people with learning disabilities</u>
 <sup>29</sup> Sheehan R and others. An audit of the quality of inpatient care for adults with
 learning disability in the UK. BMJ Open, 2016. 6 doi: 10.1136/bmjopen-2015-010480