

P 43

Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal
Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Coeliac UK

Response from: Coeliac UK

Priorities for the Health, Social Care and Sports Committee:

Coeliac UK response (31st August 2016)

1. About Coeliac UK

1.1. Coeliac UK is the national charity for people with coeliac disease and dermatitis herpetiformis (DH), the skin manifestation of coeliac disease, giving support on health care and the gluten-free diet. We campaign, research and offer support and advice to people with these conditions and those supporting them. We have over 65,000 members across the UK and more than 3,000 in Wales.

2. Coeliac disease:

2.1. Coeliac disease is a lifelong auto-immune disease, affecting around 1 in 100 people (c.30,000 in Wales). It is a genetic condition that is triggered by gluten (found in wheat, barley and rye) and that is characterised by an abnormal immune response when gluten is eaten. Coeliac disease is associated with a range of symptoms including bloating, diarrhoea, nausea, wind, constipation, anaemia, severe mouth ulcers and even hair loss. It is not an allergy or simple food intolerance.

2.2. In Wales only 22% of those with the condition have a diagnosis. This means tens of thousands of people across Wales could be affected by coeliac disease and not know why they are feeling unwell. The long term health complications associated with undiagnosed and untreated coeliac disease are osteoporosis, infertility, and in very rare cases, small bowel cancer. Currently, the only medical treatment for coeliac disease is strict adherence to a gluten-free diet for life.

3. Suggested priorities for the committee:

3.1. **Waiting times**

- 3.1.1. We ask the committee to examine what action the Welsh Government is undertaking to improve waiting times, particularly with regard to endoscopy services.
- 3.1.2. In order to attain a diagnosis for coeliac disease there are two steps, blood test in primary care and endoscopy in secondary care. The process requires the patient to maintain a gluten containing diet in order for the testing to be effective. Withdrawing gluten from the diet at this stage could lead to inaccurate results and a missed diagnosis. Lengthy waiting times between the blood test and endoscopy can not only result in prolonged period of illness for the individual but also risk them withdrawing gluten from their diet or deciding against having endoscopy to confirm diagnosis of coeliac disease, altogether.
- 3.1.3. Yet endoscopy waits over 8 weeks (NHS Wales' operational standard) have risen from 8% in October 2009 to 39% in March 2014¹.
- 3.1.4. Endoscopy services are under mounting pressure in Wales and its clear there are a number of challenges to overcome. The Welsh Government has committed to all 19 endoscopy units attaining JAG (Joint Advisory Group) accreditation (an independent assessment of endoscopy unit standards) yet to date only 4 have achieved this standard. Two key barriers have been highlighted in our discussions with health care professionals; outdated clinical environments and waiting times.
- 3.1.5. Whilst clinical environments can be upgraded at unit level, there is a far more systemic challenge posed by long waiting times and we would ask that the committee examines what action the Welsh Government is undertaking to address drivers such as limited capacity, an ageing

¹ NHS Waiting Times for Elective Care in Wales Technical Report, Auditor General for Wales, January 2015, p.28

http://www.wao.gov.uk/system/files/publications/nhs_waiting_times_technical_report_english.pdf

population and reluctance of some patients to travel.

3.2. Supporting children with medical needs in School

- 3.2.1. There is a need for a change in legislation in Wales to introduce a statutory duty of care for children with medical needs in schools. This could be included within the newly proposed Additional Learning Needs (ALN) Framework.
- 3.2.2. The Welsh Government's proposed ALN Framework documentation states that children with medical needs will not be covered by the ALN Bill (see page 30 of the draft ALN Code of Practice). This is of concern to us and we ask the Committee to look at this again.
- 3.2.3. The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England.
- 3.2.4. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must make additional arrangements for supporting pupils at schools with medical conditions. This includes the creation of an individual health care plan for all children with medical needs which in the case of coeliac disease includes measures to limit the chances of a child with coeliac disease becoming ill at school or that they are excluded from school activities due to their condition. It also provides a framework that enables parents to respond where they feel this duty is not being met.
- 3.2.5. The legislation does not apply to schools in Wales. The current system in Wales therefore puts children with medical conditions, including those with coeliac disease, at an academic disadvantage in comparison to their peers in England and does not protect them to the same degree whilst they

are at school. This is an inequity with which we feel the committee should be concerned.

3.2.6. It is for this reason we are particularly concerned that there is little to no reference in current guidance to the importance of food management as a crucial facet of support for many children with medical needs both in the context of emergency and non-emergency chronic conditions. This applies not just in terms of ensuring inclusive and safe meal times but also in other contexts such as cookery lessons or schools trips. A child should not be prevented from accessing a safe hot meal with their peers or taking part fully in school activities because of any perceived inconvenience caused by their requirement for gluten-free food.

3.2.7. We regularly receive enquiries from families of children whose attendance, attainment and overall educational experiences are compromised because of their condition and the lack of guaranteed support from the current framework. It is vital that children are kept safe and healthy whilst they are learning to enable them to achieve their full potential.

3.2.8. Providing such support to children and young people with medical conditions to enable them to participate in all aspects of school life requires a co-ordinated effort. A framework of support for children with medical conditions, agreed between the school and parents to enable children to participate fully in the school day is vital to ensure effective care and learning in the school environment.

3.2.9. We ask the Committee to consider the current situation and question whether there is a need to bring the rights, support and protection provided to children and young people living with coeliac disease in Wales in line with those in England. There is currently a unique and rare opportunity to do this during this Government's legislative programme.

3.3. **Prescriptions for gluten-free staple food**

3.3.1. We welcome the recent statement² from the Minister for Health and Social Care, in support of the continued provision of Gluten-free staples on prescription. A strict gluten-free diet is the complete medical treatment for coeliac disease yet gluten-free products can cost 3-4 times as much as gluten-containing equivalents in the shops and can be particularly difficult to access for those rural, more isolated Welsh communities.

3.3.2. The cost of such provision represents just 0.34%³ of prescription spending in Wales, making it one of the most cost effective treatments for a long term condition in the NHS. We ask the committee to ensure such vital provision is maintained at a time of increased pressure on NHS budgets.

3.4. **Consistent standards of care**

3.4.1. We would like to draw the committee's attention to the upcoming publication of NICE's updated Quality Standard on Coeliac Disease. We anticipate this will provide welcome and substantive direction on the process for effective diagnosis and treatment of the condition. In particular we welcome a proposed new standard with regards endoscopy waiting times and the importance of health equality challenges associated with accessing gluten-free products for those on low incomes.

² [Questions to the Cabinet Secretary for Health, Wellbeing and Sport - OAQ\(5\)0025\(HWS\)](#)

³ Prescription cost analysis: Data totals, 2014 (published 18 March 2015) available at <http://gov.wales/statistics-and-research/prescriptions-dispensed-community/?lang=en> [last accessed 01.09.2015]