

Grŵp Trawsbleidiol ar Glefydau Seliag a Dermatitis Herpetiformis Cross Party Group on Coeliac Disease & Dermatitis Herpetiformis

Date & time: Nos Fawrth 11 Mehefin 2019, 18.00-19.30
Tuesday 11 June 2019, 18.00-19.30

Venue: Ystafell Gynadleda C & D, Tŷ Hywel.
Conference Room C & D, Ty Hywel.

Dr Dai Lloyd AM –Chair (DL), Tristan Humphreys – Secretary/Colieac UK (TH)

Attendees: Marcia Spooner, Claire Constantinou, Ian Severn, Dr Jill Swift.

No.	Item
1	<p>Apologies for absence:</p> <p>Graham Philips, Rhun ap Iorwerth AM, Dr Geraint Preest, Henry Wilkins, Sian Evans.</p>
2	<p>Minutes of last meeting</p> <p>a. Amendments and approval of the Minutes</p> <p>The minutes were approved without amendments.</p> <p>b. Matters arising</p> <p>Matters arising were incorporated into the agenda for this meeting.</p>
3	<p>Hywel dda prescribing pilot</p> <p>a. Oral update</p> <ul style="list-style-type: none"> • Hywel dda will be continuing to provide subsidy cards to participants on the pilot scheme. • They are liaising with the local Community Health Council (CHC) to work in collaboration for potential further roll out across the health board this year. • A steering group has been established and is developing an implementation plan though timelines are to be confirmed. • Representatives from Hywel Dda dietetic support team will be meeting with Juvela and Coeliac UK on 21st June in Cardiff. <p>b. Questions and discussion</p> <p>TH is still awaiting the full report on evaluation of the pilot though hopes to have this in the coming weeks. There are still some concerns, particularly regarding subsidy level and the shift from an opt out rather than opt in approach. These concerns will to be raised at the meeting on the 21st and a further discussion will be added to the agenda at the next meeting of the CPG.</p> <p>ACTION: TH to write to Chief Pharmacist, Andrew Evans ACTION: TH to meet with Juvela and Hywel Dda University Health Board.</p>
4	<p>Supporting learners with healthcare needs</p>

a. Oral update (TH)

Following the publication of the draft 'Additional Learning Needs and Education Tribunal (Wales) Act 2018' Code, the Care in Schools Alliance (CISA) has shifted its focus back to engaging with the 'Supporting Learners with Healthcare Needs (2017)' guidance (SLHCN). The Welsh Government plans to update this guidance in light of the overhaul of the Additional Learning Needs (ALN)/Special Educational Needs (SEN) system, though this is likely to be mainly cosmetic and there are no plans for public consultation. Further there appears to be limited willingness or interest to engage with CISA over any substantial issues with the guidance. There may however be further opportunity to engage at Local Authority level in addition.

Analysis of Local Authority policies shows many do not currently have policies and, where they do, they can be hard find and largely transposed directly from SLHCN guidance. They do not tend to be regularly updated. With this in mind, CISA is looking to engage with Local Authority Education teams to seek opportunity to influence and improve local authority level policies in addition to our further engagement at national level.

b. Wales Local Government Association (WLGA) catering for special diets working group

Over the past 12 month the WLGA has been hosting regular regional working groups with Local Authority (LA) caterers, educators, thirds sector organisations and health care professionals to look at developing best practice guidance for catering for special diets in schools.

- Guidance documents and resources are being finalised including roles and responsibilities for schools, LAs & caterers.
- An Interim report is being finalised bringing together learning from all the sessions.
- The secondary and primary school split will be crucial, particularly for children with coeliac disease, and the guidance will need to take account of this. Most issues tend to arise in secondary school, in part due to the more chaotic mealtime environment and the challenge of young people having to take more responsibility for managing their diet amidst social and time pressures.
- There has been clear will from LA caterers but this is not always getting through to the front line, particularly in secondary schools.
- The increasing demand and diversity of dietary needs is a challenge for caterers who are absorbing the cost (E.g in some schools, it has been necessary to invest in c. £1000 blenders for provision of texture modified diets).
- A National special dietitian is to be recruited to continue support the WLGA's work on special diets, support caterers with resources and coordinate the working groups.

	<ul style="list-style-type: none"> • Issues remain around engagement with schools and by extension LA education teams. E.g – too often there is a failure to recognised responsibility for ‘whole school day’. This should be addressed by SLHCN work. <p>c. Discussion</p> <p>Jill Swift asked as to the best advice to give parents and carers looking to arrange support in school. TH recommended looking at Coeliac UK’s school packs and advised that all children with coeliac disease are entitled to an Individual Health Plan, a plan laying out how the school will support the child to take part in school activities. This should involve a meeting with parent/carer, headteacher and all relevant school personnel including a representative of the catering team.</p>
5	<p>Gluten free provision in hospitals</p> <p>a. Background (TH)</p> <p>As of April 2013, ‘All Wales Nutrition and Catering Standards for Food and Fluid Provision for Hospital Inpatients’ 2011 became mandatory in hospital settings. The standards require all hospitals and Local Health Boards (LHB) to ensure an appropriate meal is provided for patients on a therapeutic diet.</p> <p>Rachel Flint submitted a petition with 40 signatures on the issue of hospital catering standards and particular catering for therapeutic diets to the Welsh Assembly petitions committee, resulting in responses from LHBs, the then Minister for Health & Social Care, the Auditor General and the Public Accounts Committee Chair.</p> <p>In May 2015, the Cross Party Group (CPG) wrote to all LHBs concerning there adherence to these regulations and specifically asking;</p> <ul style="list-style-type: none"> • Are therapeutic dietary needs, including gluten free assesd on admission? • Are gluten free meals available to patients with coeliac disease in all hospitals within your health board? • What controls are in place to ensure gluten free food is prepared safely within the hospital environment? <p>The responses were broadly positive/reassuring, however anecdotal evidence suggest this picture is not being reflected on the ground. TH has personally heard of 4 different cases in the last year (Swansea Bay University Hospital, University Hospital of Wales) where patients did not receive a proper dietary assessment and were unable to secure an appropriate gluten free meal.</p> <p>TH has spoken with contact in Cardiff & Vale CHC and been given details for lead in the health board.</p> <p>TH asked the group how we can get a better idea of the reality on the ground.</p>

	<p style="text-align: center;">b. Discussion</p> <p>Claire Constantinou (CC) noted that on paper there is lots available and that in theory patients shouldn't struggle. However in reality the challenge of getting patients admitted, communicating information and getting the right meal doesn't always work as well smoothly. Patients often don't want to complain and although caterers should be able to manage and menus are available, confidence and training is often lacking on the frontline. There was a recognition from the groups that some time has passed since the last correspondence with health boards and groups agreed it may be worth following this up.</p> <p>CC noted a potential review of the 'All Wales Menu Framework' with a view to whether the existing standards are still appropriate. This could be an opportunity to engage. The focus needs to shift towards looking at the patient pathway or journey in order to better understand changes required. Dr Jill Swift (JS) added from feedback from patients she spoke with, the issue seemed to mainly lie with unexpected admissions where there was less time to play for dietary requirements.</p> <p>There was further discussion of how the reality of patient experience might be better captured. One challenge is the unwillingness of patients to complain after a bad experience. Many quite understandably have other priorities when recovering from an illness and don't want the hassle. TH suggested some work to encourage Coeliac UK members to feedback to hospitals and LHBs where they've had a bad experience. Further it was suggested there might be a piece of work to pursue involving partnering with CHCs to survey patient experience regarding special diets. TH further raised the possibility of engaging members of CISA in this as similar concerns.</p> <p>CC reiterated the challenge lay with the training of catering staff and nursing staff.</p> <p>ACTION: TH to speak with Coeliac UK Food Policy Lead & Research Manager ACTION: TH to raise with CISA. ACTION: TH to add to agenda for next meeting.</p>
6	<p>Endoscopy services</p> <p>a. Update on Health, Social Care and Sport committee report on the Endoscopy service (TH/DL)</p> <p>The Health, Social Care & Sport committee report into endoscopy services was published in April. Triggered by Bowel Cancer UK report highlighting serious delays in diagnosis in Wales. A new screening test (FIT) is being brought in and is likely to increase demand on an already stretched endoscopy service in Wales. Endoscopy services and a particularly the low number of Joint Advisory Group (JAG) accredited units in Wales is something the CPG looked into in 2016.</p> <p>Following the publication of the Endoscopy Task & Finish Group's report in 2014, the Welsh Government committed further funding and committed to supporting all units to attain JAG accreditation.</p>

	<p>Nevertheless waiting times remain an issue. Diagnostic endoscopy is subject to an 8 week diagnostic target (calculated from date of referral to date procedure is carried out) and the national strategy is still to be published. Demand is increasing annually 8-10% and demand is outstripping capacity.</p> <p>Despite a sharp decline from January 2018-March 2018 thanks largely to insourcing, these figures have fluctuated since with particular increase in recent months. According to the report The Welsh Government approach has been 'reactive' and 'short term' relying on expensive insourcing and outsourcing.</p> <p>The committee recommended measures to address capacity issues and waiting times in a more sustainable way as well as calling for a national approach. The full report and recommendations can be read here.</p> <p>b. Discussion:</p> <p>JS mentioned that Hayley Heard has now taken over as head of Endoscopy Services and that significant additional funds are to be provided to support units towards JAG accreditation.</p> <p>ACTION: The group agreed to write to the Health, Social Care & Sport Committee with comments including concerns re JAG accreditation.</p>
7	<p>New Coeliac UK CEO</p> <p>Coeliac UK has a new CEO in post – Hilary Croft. She has a background in business having worked in leadership roles with Capgemini, a global leader in consulting, technology and digital transformation services, where she worked with a variety of organisations, such as Virgin Atlantic, Sky, Lego and Royal Mail. She has knowledge and interest in the food and drink sector through previous positions with Marks and Spencer, Coca-Cola, Compass Group and World Duty Free Europe. More recently, as CEO of the Felix Project (a charity that helps provide food for free to people suffering hunger & food poverty via charities & schools) she developed significant partnerships with food suppliers and re-distributors to reduce food waste and food poverty across London. .</p>
8	<p>AOB</p> <p>a. BSNA correspondence: BSNA has responded to letter from CPG regarding previous correspondence and taken on board the Chair's comments.</p>
	<p>Dates for future meetings:</p> <p>6.30pm, 15 October</p>

Action Points:

Action	Member
Letter to Health, Social Care & Sport committee with thoughts on endoscopy services	DL & TH
Request meeting with Chief Pharmacist, Andrew Evans	TH
Meet with Hywel Dda UHB & Juvela	TH
Liaise with Coeliac UK Food Policy Lead & Research Manager on hospital food	TH
Add hospital food to agenda for next CPG meeting.	TH
Raise issue of hospital food with CISA.	TH