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SHROPSHIRE CCG CUTS GLUTEN FREE PRESCRIPTIONS WITHOUT CONSULTATION

National charity Coeliac UK is shocked to learn about the cuts to gluten free prescriptions announced by Shropshire CCG which have been implemented without consultation, a decision that will result in health inequality and have a disproportionate impact on the most vulnerable.

Coeliac disease is a serious autoimmune condition caused by a reaction to gluten, a protein found in wheat, barley and rye. Coeliac UK is concerned that any cuts to gluten free prescriptions will leave vulnerable patients with coeliac disease without support which will affect their ability to stick to the gluten free diet - the only treatment for the condition.

The government has recently closed a national consultation on the future of gluten free prescribing, the charity's full response to that consultation can be read <u>here</u>. Chief executive of Coeliac UK, Sarah Sleet said: "The national consultation has now ended but a decision has not yet been made. Surely the decision by Shropshire CCG to remove gluten free prescribing locally, and without consulting the patients affected by this is decision, is irresponsible, especially when this is currently under review at a national level - with their results due to be published in the autumn."

"We wrote to Shropshire CCG in June this year to highlight the legality of not undertaking a consultation. The need to consult with patients about changes to local services is documented in the Health and Social Care Act 2012 and was also confirmed in the Westminster Hall debate in the House of Commons on 2 November 2016. When David Mowat MP, the Parliamentary Under Secretary of State at the Department of Health said:

"CCGs should not withdraw gluten-free products without a consultation. My understanding is that in all cases where that has happened, a consultation has taken place. If he can provide me with evidence of that not being so, I will follow up and take action. The information I have been given is that consultations should always have taken place."

"A letter published on the CCG's website and sent to care home managers, states that the CCG has informed Coeliac UK of the decision but we have received no response to either of our letters.

As there was no consultation we, nor patients in Shropshire, have had the opportunity to put forward our position on gluten free prescribing, meaning a decision to cut this vital service has been made on unfounded information and not facts." continued Ms Sleet.

There is an economic case for retaining access to gluten free prescribing in primary care. National Institute of Health and Care Excellence (NICE) Health Economic analysis estimates the basic cost of gluten free food on prescription is £194.24 per patient per year [1] making it an extremely low cost treatment in the management of coeliac disease. By contrast, treatment of an osteoporotic hip fracture costs on average £27,000 [2] – the equivalent to 138 years of prescribing gluten free staples for an individual.

"Given that around 40% of adults with coeliac disease have osteoporosis or osteopenia at diagnosis there is a real risk that short term savings will result in long term expense."

"For someone medically diagnosed with coeliac disease there is no choice but to stick to a gluten free diet, day in day out for life and so access to gluten free staples is critical, and is not as easy as you might think. The expansion of Free From aisles in large supermarkets masks the reality of very patchy provision. The removal of access to gluten free core staples on prescription has a disproportionate impact on the most vulnerable. With lack of availability in convenience and budget stores, which are often used by the most disadvantaged, and high prices putting them beyond the reach of many on low or fixed incomes" said Ms Sleet."

In May 2017, the cheapest gluten free loaf of bread cost 36.4p per 100g – compared to gluten containing bread which cost 4.4p per 100g. Those shopping for the cheapest gluten free loaf will be paying more than 8 times the price. For example, a woman of pension age annual spend on the cheapest gluten free bread would be £87.60 per annum compared to just £10.54 for gluten containing bread. See <u>here</u> for further details and examples on costs.

"Any reduction in the gluten free prescription services for people with coeliac disease is being based on budgets rather than patient need or clinical evidence. The provision of gluten free staple food on prescription is a vital element of the support offered to all patients by the NHS and it is essential to prevent long term damage to health," explained Ms Sleet.

In England, prescriptions for gluten free food are not free of charge unless someone already qualifies for free prescriptions. Currently around 74% of CCGs across the country allow access to gluten free food on prescriptions.

- 2. NICE, Clinical Guideline CG124: The management of hip fractures in adults. 2011.
- 3. Office for National Statistics, Family spending in the UK: financial year ending March 2016. 2016.

^{1.} NICE, NG20 Coeliac disease; recognition, assessment and management Appendix G HE Report. 2015.

^{4.} Violato, M., Humanistic and Economic Burden of coeliac disease in the UK, a follow up study. As yet unpublished.

Notes to editor

- Coeliac disease is a serious illness where the body's immune system reacts to gluten found in food, making the body attack itself.
- 1 in 100 people in the UK has coeliac disease
- A wide range of case studies are available on request from Coeliac UK.
- Average time to diagnosis is 13 years.
- 1 in 4 people diagnosed with coeliac disease had previously been diagnosed with IBS.
- Gluten is a protein found in wheat (including spelt), rye and barley. Some people are also sensitive to oats. Obvious sources of gluten include breads, pastas, flours, cereals, cakes and biscuits. It is often used as an ingredient in many favourite foods such as fish fingers, sausages, gravies, sauces and soy sauce.
- Coeliac UK has a Helpline on 0333 332 2033 and further information can be found at www.coeliac.org.uk