Survey to Discover What Life with Coeliac Disease is Really Like

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A large-scale survey to find out what it is really like living with coeliac disease will be launched by researchers at the University of Birmingham. Coeliac disease is an autoimmune disease in which the body's immune system attacks its own tissues in response to the presence of gluten, found in wheat, barley & rye.

The project, funded by Coeliac UK, (the national charity supporting those with the condition) is one of the first such research projects carried out in the UK that explores psychological and social factors impacting on the lives of people with the disease. This includes what people understand about the disease, how people feel about it and what they find particularly difficult or easy about it. Sarah Sleet, Chief Executive of Coeliac UK explains why Coeliac UK are involved with this project: "Gaining an understanding of the reasons why people adapt to their diagnosis in different ways will be an essential part of developing our services in the future. We are pleased to support this research which identifies a gap in our knowledge of the psychological effects of coeliac disease in the UK."

Dr Ruth Howard, Clinical Psychologist at the University of Birmingham's School of Psychology explains why the study is so vital: "It is thought that coeliac disease affects at least one in 100 people in the UK. That is a significant proportion of the population. Research conducted in other countries suggests that some people find living with the disease more difficult than others and that levels of associated anxiety and depression can be higher in these individuals than in those without coeliac disease.

"To date, there has been very little research conducted in the UK looking at these things and we feel it is important to understand more about the experiences of individuals with coeliac disease living in the UK."

The research team are calling for input from four distinct groups: adults with a confirmed diagnosis of coeliac disease, young people with a confirmed diagnosis, parents of children or young people with the condition and partners of adults with a confirmed diagnosis of coeliac disease. There may be individuals who fall into more than one category, in which case people may fill in a questionnaire in more than one capacity.

The study is entirely questionnaire based. The questionnaires for adults and partners are available both online and as a paper pack, whilst the parent and young person questionnaires are available as paper packs only.

Dr Howard concludes: "We hope the results of the study will help us to identify some of the reasons why some people find coeliac disease more difficult to live with than others. We can then look at ways of helping and supporting people who find it more difficult to manage the condition and the gluten-free diet."

Those interested in taking part should contact Dr Jane Petty at coeliac.study@gmail.com or on 0121 414 4935. From 1st October there will also be information and a link to the survey on the Coeliac UK website (www.coeliac.org.uk/researchsurvey).

Further information about coeliac disease can be found at www.coeliac.org.uk or by calling the Helpline on 0870 444 8804.

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Notes to Editors:

1. Average length of diagnosis for coeliac disease is 13 years.

2. 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.

3. The symptoms of coeliac disease range from mild to severe and can vary between individuals. Not everyone with coeliac disease experiences gut related symptoms; any area of the body can be affected.

4. Symptoms can include bloating, abdominal pain, nausea, constipation, diarrhoea, wind, tiredness, anaemia, headaches, mouth ulcers, recurrent miscarriages, weight loss (but not in all cases), skin problems, depression, joint or bone pain and nerve problems.

5. Further information can be found at www.coeliac.org.uk or by calling the Helpline on: 0870 444 8804

For further media information:

Kate Chapple, Press Officer, University of Birmingham, tel 0121 414 2772 or 07789 921164. Anna Mitchell, Press Officer, University of Birmingham, tel 0121 414 6029.

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