the enemy within

Infertility, skin rashes and anaemia can all be signs of coeliac disease. Fortunately, improved screening methods and increased awareness have led to higher detection rates for this hidden condition, writes **Alison Moore**

IMAGINE HAVING TO turn down most dinner invitations, having no choice of meals in the work canteen and not being able to take butter from a shared dish. These are the sorts of dietary restrictions that face sufferers of coeliac disease, one of the one most common genetic disorders. A lifelong diet is the only treatment – even down to avoiding the traces of bread left by knives in a butter dish.

Given the severity of the dietary restrictions, it is hardly surprising that many newly diagnosed coeliacs seek professional support and advice as they start this onerous regime. Dawn Elliot, chair of the RCN's Gastroenterology and Stoma Care Nursing Forum and a GI nurse in Northumberland, says: 'A diagnosis of coeliac disease is a roller-coaster psychologically. It does change your life and often your family's lives' too. Older people are the ones who have problems with compliance. They may say "I have eaten what I wanted all my life, why should I have to change it now? I'll just put up with the symptoms".'

Coeliac disease is a chronic inflammation of the small intestine, which occurs because the immune system of a coeliac sufferer mounts a response to proteins in wheat, barley and rye which damages the intestinal lining by destroying the villi, thus reducing the absorption of nutrients from food. Since the small intestine is the main site of digestion of carbohydrates, proteins and fats, some patients present with weight loss, diarrhoea, a puffed-up stomach, and foul-smelling stools which are full of undigested fat. Although there is no cure, the unpleasant symptoms and side-effects generally disappear when the proteins which lead to the inflammation are removed from the diet.

In recent years, it has become apparent that the majority of undiagnosed coeliacs may not suffer these classic gastrointestinal symptoms, presenting instead with other indicators such as anaemia (linked to malabsorption) and being 'tired all the time' (Hin *et al* 1999). Coeliacs can also suffer anxiety and depression plus a range of other symptoms from unexplained osteoporosis to mouth ulcers.

Given the diversity of symptoms, diagnosis is difficult. Ms Elliot says: 'Because GPs don't see it very often they tend to put any symptoms down to irritable bowel syndrome. Patients often come to us months or even years after they have put up with these symptoms.'

no respecter of age

Fifty years ago, coeliac disease was viewed as a condition affecting children only. Young babies who have only recently started eating gluten-containing solids frequently become sickly, bloated and fail to put on weight. In children, coeliac disease may present with diarrhoea or constipation, and a short stature.

But we now know that the disease can occur at any age. According to Coeliac Society statistics, most coeliacs are diagnosed between ages 30 and 45. The disease is twice as common in women as men – even more so when it is diagnosed in adulthood. Yet its true incidence remains unknown, and there is mounting evidence that the condition is undiagnosed. The

Wheat Field with Sheaves, 1898 Vincent Van Gogh

Coeliac Society suggests there could be as many as 500,000 sufferers in the UK, compared with the 50,000 people who have been diagnosed.

There is a strong genetic component to the disease because it clusters in families. According to Coeliac Society research, someone with a first degree relative suffering from the condition has a one in 16 change of having the disease themselves. With a second degree relative, the risk falls to one in 55.

blood tests and biopsies

Suspected sufferers are often subjected to a number of tests which enable the integrity of the villi to be examined as a gluten-free diet is introduced. For example, antiendomysial and antigliaden antibody blood tests are types of indicators used to arrive at an initial diagnosis and to screen close relatives. These may be initiated by a GP rather than in a hospital clinic. However, they do not reveal the extent of damage to the gut.

The gold standard for diagnosing the disease is a biopsy of the intestinal lining, usually done at a gastroenterology clinic, and sometimes with the patient mildly sedated. The patient swallows a small capsule attached to a polythene tube. An X-ray is made and a sample of the intestinal lining is then recovered through the tube. On examination, the villi that normally cover the lining will have disappeared if the disease is present.

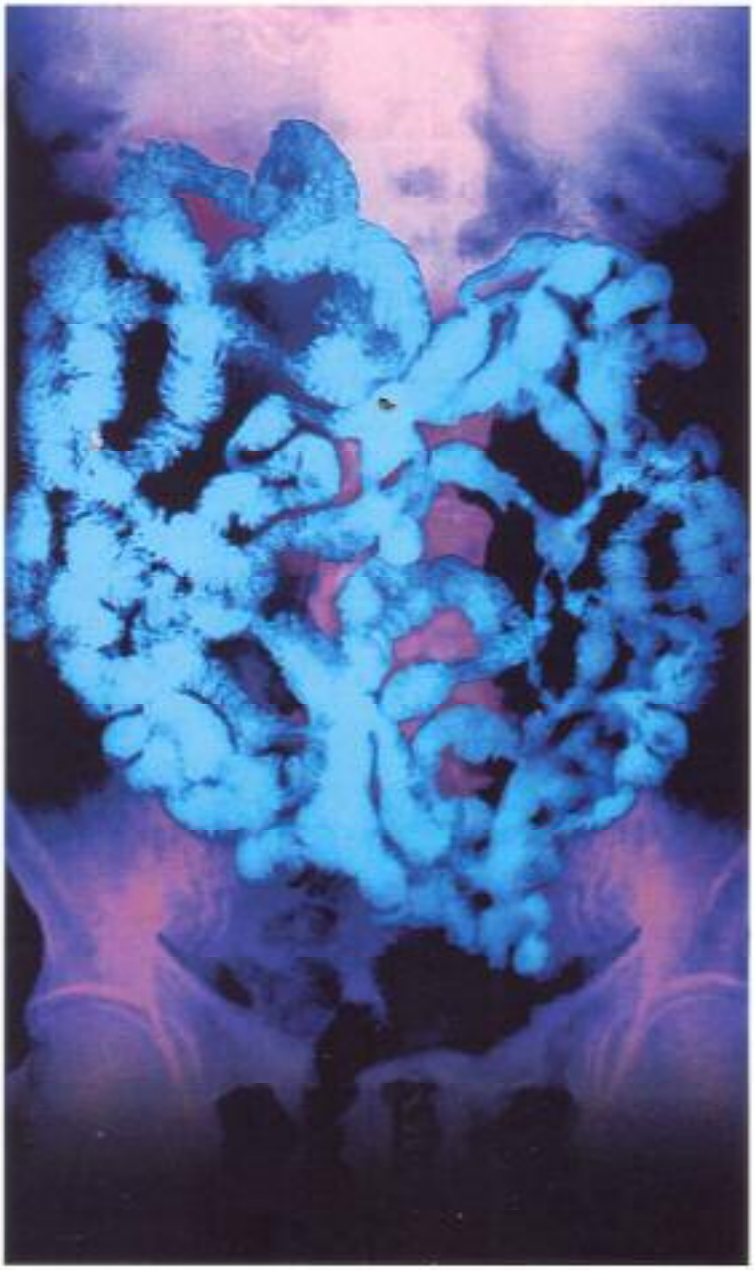
There have been calls for more widespread screening of potential sufferers and Professor Paul Ciclitira, a gastroenterologist at St Thomas's Hospital in London, goes so far as to advocate that whole population screening be introduced. If this can not be achieved he recommends screening priority groups such as diabetics – 8 to 10 per cent of whom are likely to have coeliac disease – and people suffering from osteoporosis, thyroid disease and infertility.

a draconian diet

The only treatment for coeliac disease is to switch to a diet that avoids the proteins that cause damage to the intestine. Yet the ubiquitous nature of gluten in food makes this difficult. For example, gluten is present in sausages, beer, and breaded and battered food, and, because wheat is used in flour, small amounts of gluten are often found in processed and prepared foods such as sauces. Many patients find a gluten-free diet unpalatable, which leads to poor compliance.

Gluten-free foods are potatoes, rice, cornflour, buckwheat and all plain meat and fish, vegetables, nuts and pulses. Supermarkets often stock a range of gluten-free breads, biscuits and cakes, and some gluten-free food is available on prescription. Gastrointestinal clinics frequently engage a dietician in their care of coeliacs and the Coeliac Society has a list of around 13,000 gluten-free foods which is sent to members.

Not all coeliacs have the same level of intolerance to small amounts of gluten: some are unaffected by it, while others will suffer a relapse. Malt extracts and flavourings, for example, are derived from barley and contain small amounts of a gluten-like protein, but many coeliacs will tolerate malt in vinegars and breakfast cereals, while a small number may be sensitive to it.



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A picture of health: a colour-enhanced X-ray of a healthy small intestine following a barium meal.

Scanning Electron Micrograph of the wall of the small intestine, showing coeliac disease. Mucosa appears flat due to loss of villi. Yellow particles are inflammatory cells.

Science Photo Library

suffering the consequences

Many of the complications of coeliac disease arise when the condition is undiagnosed and the sufferer continues eating gluten. The most serious complication for those who do not adhere strictly to diet is an increased risk of certain cancers, mostly small bowel lymphoma. This increased incidence is thought to be due to greater numbers of immune cells circulating in the inflamed intestines of coeliacs. Yet, the risks of most adverse effects are substantially reduced once a gluten-free diet is followed.

Another worry is increased morbidity. Recent research published by an Italian team suggests that coeliacs have a higher risk of premature death than the general population (Corrao *et al* 2002), with much of the increased risk being due to the occurrence of non-Hodgkin's lymphoma. The study reports that the risk of premature death is much higher among coeliacs who have a long delay between symptom onset and diagnosis, and therefore delay in switching their diet.

Other complications include an increased risk of osteoporosis, which is thought to be due to poor absorption of nutrients through a damaged intestinal lining. Vitamin and mineral supplements are sometimes prescribed and some doctors will propose screening of unexplained osteoporosis cases to see if coeliac disease is implicated. Infertility is yet another side effect of the condition, and some coeliacs may only realise they are affected when they are referred for fertility problems. People with type I diabetes and autoimmune thyroid diseases are known to be at higher risk.

One particular disorder that is strongly associated with coeliac disease is *dermatitis herpetiformis* (DH), a skin disorder in which small groups of itchy blisters erupt on the body. Around 1 in 15,000 people in the UK suffer from DH (slightly more men than women) and it is now thought that all DH sufferers are intolerant of gluten even though they may lack the classic symptoms of coeliac disease. In fact, this cutaneous disease may be the only sign of otherwise asymptomatic coeliac disease. A range of antibiotics are used and the patient is encouraged to switch to a gluten-free diet.

a gliadin-free future

So what does the future hold for those diagnosed as gluten intolerant? It is the gliadin subfraction of gluten that is toxic, and new research has homed in on the particular section of gliadin that stimulates immune cells (Anderson *et al* 2000; Arentz-Hansen *et al* 2000). It may one day be possible to develop a compound that mimics gluten but lacks this gliadin section, and this could be used to make patients more tolerant of the natural product. Similarly, transgenic crops that lack this section could be used in foodstuffs. But for now, avoiding gluten is the only treatment, and nurses and other healthcare workers must be aware that coeliac disease may underlie some of the apparently unrelated conditions that ail their patients ■

Coeliac UK (The Coeliac Society) has a wide range of leaflets and publications, including a guide to gluten-free foods. Tel: 01494 437278. Web: www.coeliac.co.uk or write to PO Box 220, High Wycombe, Buckinghamshire, HP11 2HY.

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