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► Mabel Chew talks to David Sanders about non-coeliac gluten sensitivity at bmj.com/multimedia/podcasts



Information leaflets for patients aren't worth the paper they're written on: the internet has taken over
Des Spence, p 49

PERSONAL VIEW **Luca Elli**

Where's the evidence for gluten sensitivity?

Recently I have noticed a huge increase in the use of the term gluten sensitivity, which is alleged to cause non-specific and usually mild gastrointestinal symptoms. Abdominal pain and discomfort, dyspepsia, bloating, and meteorism are symptoms commonly attributed to functional disorders of the gastrointestinal tract (irritable bowel syndrome, or IBS).

Dietary change is well known to provide benefits in irritable bowel syndrome,¹ and the condition sometimes responds well to a gluten-free diet. This is despite the absence of the histology and serology typical of coeliac disease—duodenal villous atrophy, intraepithelial lymphocytosis, crypt hyperplasia, and the presence of anti-transglutaminase type 2 IgA antibodies in sera.

Genetically, coeliac disease and gluten sensitivity partially share the same susceptibility, although the HLA-DQ2/DQ8 haplotype is not necessary to develop gluten sensitivity.² Gluten sensitivity implies

gastrointestinal or extraintestinal symptoms that respond to withdrawal from gluten but with no autoimmune mechanism typical of coeliac disease or other autoimmune disorders. The consensus, based on published papers, is that a diagnosis of gluten sensitivity is possible only after exclusion of coeliac disease and other food allergies or food related disorders and the symptomatic response to change in diet.³

There are no objective findings or markers to support a diagnosis of gluten sensitivity, and its pathogenesis remains obscure. The mechanism is theorised to be based on the stimulation of the innate immune system without an increase in interleukin 17. This is thought to be caused by gliadin; other proteic fractions of wheat; or a direct cytotoxic effect on enterocytes inducing apoptosis, imbalance of the cellular oxidative state, and modification of the cytoskeleton.^{4 5}

The new term gluten sensitivity has rapidly diffused into scientific literature and the mass media, leading to many patients inquiring about it. The last resort in perceived

gluten sensitivity should be a gluten-free diet. A gluten-free diet is begun not to reduce the autoimmune reaction towards transglutaminase type 2 and prevent eventual complications, as in coeliac disease, but to resolve symptoms to try to improve patients' quality of life. However, a gluten-free diet itself reduces quality of life, and we do not know about possible complications or how strictly or for how long the diet should be adhered to.

Some aspects of gluten sensitivity need to be clarified before "treating" people for this new "disease." Financial interests might account for the estimated prevalence of 4-7%.³ A recent article from the United States reports that marketers estimate that 15-25% of healthy consumers (approximately 46 to 77 million people) want gluten-free products because they consider a gluten-free diet healthy.⁶

Estimating monthly consumption in Western countries of 1000 g of gluten-free pasta per person, with an average cost of \$11, values the market at around \$500m (£310m) to \$850m a month. Also, research into drug treatments for coeliac disease that may enable people to reintroduce gluten in their diet may be worrying for the manufacturers of gluten-free foods.⁷ In fact, the gluten-free food industry now advertises with the intention of expanding its customer base beyond patients with coeliac disease.

Gluten sensitivity needs investigation before gluten-free foods are promoted as a remedy on a large scale. Is gluten sensitivity different from irritable bowel syndrome or simply a variant that benefits from a common therapeutic approach? If gluten sensitivity exists, what is its mechanism?

Before generating new terms and diseases we must investigate their characteristics and specific markers to avoid misdiagnosis and inappropriate treatment. Patients often relate the start of their symptoms to eating foods, be it gluten, peppers, or beans, and we ought to be wary of labelling all such perceived reactions as food sensitivities that must be treated.

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References are in the version on bmj.com.

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The gluten-free food industry now advertises with the intention of expanding its customer base beyond patients with coeliac disease



BETWEEN THE LINES Theodore Dalrymple

A call for convalescence

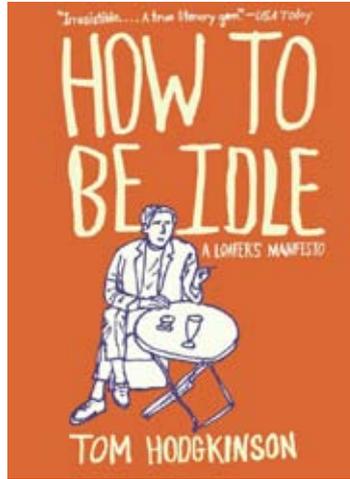
In theory I am in favour of idleness, for without it there can be no contemplation, and without contemplation there can be no wisdom. But good as I was in my youth at being idle, I now find it difficult in practice to be idle. There is, besides, the difficult question of just how idle one should be, and for how much of the time; like many a joy, that of idleness quickly palls.

Can there be any idler pleasure than leafing through second hand books? I picked up a small volume recently while doing so called *How to Be Idle*, by a philosopher of idling and founder of the *Idler* magazine, Tom Hodgkinson. It was a signed copy, and I must say that an idler signature I have not seen. It looks as if a tiny snake with ink on its belly has made its way across the page. I like a man who is true to his principles even in small things.

Illness, provided it is nothing serious, is one of the author's recipes for idleness: "That being ill can be a delightful way to recapture lost idling time is a fact well known to all young children." Alas, we are not even very good any more at taking advantage of illness: "Once upon a time, it seems, we knew how to be ill. Now we have lost the art." This is because being ill serves no purpose, and we feel obliged to get better as soon as possible so that we can resume being busy: a condition that we often confuse with productiveness. As for convalescence, it is a state unknown to modern medicine; doctors discharge their patients as cured as soon as possible. The author doesn't mention that they do so to improve their statistics.

"We need more idler-friendly doctors," the author says. "Instead of prescribing drugs and trying to blitz illness in the shortest possible period of time, they would order their patients to take long periods off work. Three days would be the minimum; but they

In 2004, 2.7 million people were claiming incapacity benefit, half a million more than were injured in the first world war



could prescribe a rest cure of up to two months."

Here, I am afraid, the author, whose book was published in 2004, displays an unawareness that doctors were already prescribing very long periods off work, or at least setting their seal of approval upon such periods. In that year, 2.7 million people were claiming incapacity benefit, half a million more than were injured in the first world war, and four times as many as were claiming its equivalent in the mid-1970s. Surely the health of the population had not declined so drastically in the meantime?

Doctors were and are not averse, then, to prescribing "rest cures," far from it. The problem, rather, is in the nature of the idleness, whether it is enforced or voluntary, a permanent state or a necessary or salutary relief from activity, and hence a time for reflection. "Why are we all so desperate for 'jobs,' by the way?" asks the author, a question with whose answer millions could now supply him, and could have supplied him when he asked it.

How to Be Idle, then, is for people whose default setting, if I may so put it, is to long hours of work. Idleness where there is no alternative is not delicious, it is dispiriting, as can be seen in uncomfortably much of our country.

Theodore Dalrymple is a writer and retired doctor. This is his final Between the Lines column.

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MEDICAL CLASSICS

Families Without Hope: A Controlled Study of 33 Problem Families

By Tonge WL, James DS, Hillam SM

Published by the Royal College of Psychiatrists, 1975

When Jesus said "the poor always ye have with you," he presumably wasn't joking, but governments keep trying to try to prove him wrong. Each time a new underclass disaster makes the news, the social work equivalent of the SAS is mobilised to help the family become, well, "more like us," but it rarely works. *Families Without Hope* explains why and describes some typical families.

"The front garden is characteristic. An overgrowth of natural flora competes with broken bottles, sodden cardboard and the rusting remains of once-expensive toys, prams, cycle parts and other scrap. A well-worn earth path leads from the dominant door to the pavement by the most direct route which involves a hole in the hedge or a section of shattered fencing. Furnishings were usually basic, dilapidated and inadequate, while priorities for spending were often given to luxury items, even when essentials were lacking." Families bought expensive chocolates "given inconsistently to their untrained children to placate their temper tantrums" or "spent a considerable portion of [their] assistance money on drink," but the main problems were attitudinal, not material. "It takes forethought to do all that these families failed to do. This is a style of life which shuts its eyes to the future." The television set was prominent, but its value "lay more in its capacity to distract than to inform."

This very depressing study took place in Sheffield, at a time when society was arguably less broken than it is now and fewer women drank heavily. Its findings were not unique. An earlier researcher concluded: "The most striking characteristic of these families is that they are *families of children*... You could hardly distinguish the adults from the children except for the fact that the former were taller." Overt mental illness was largely absent, unless we regard unhappiness, improvidence, and ignorance as illnesses. The several agencies specifically designated to help had tried hard, but problems simply increased to occupy the facilities for their alleviation, in a mocking, therapeutic version of Parkinson's Law. Similar problems had often characterised previous generations of the same families, yet most literature "avoids... discussion of constitutional factors, perhaps in an attempt to deny the pessimism of the eugenicists." Pessimism, nevertheless, is hard to avoid. More money might increase the chocolate supply, so to speak, but "would leave many other difficulties untouched."

These difficulties are formidable. "Rules are ignored... discomfort is ignored... long term consequences of action are ignored... education is distrusted." If we hear more about such families today than in the early 1970s, it may be because social mobility has rewarded others who were equally poor but whose members had no major and persistent personality defects, leaving the untreatable even more glaringly exposed as monuments to our continuing impotence.

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Difficulties were due to attitudinal, not material, factors

GETTY IMAGES

FROM THE FRONTLINE **Des Spence**

Leaflets for patients are worthless

In the 1990s our offices were crammed with stuff: plastic joints, stress balls, wall clocks, and broken lamps—nobody was seemingly able to resist pharma's freebie tat, however useless. I also had a pile of textbooks, but most clinical knowledge remained in the head of the local specialist. But the greatest space culprit was the patient leaflets, deemed the "must have" for the empowerment of patients. Filing cabinets were jammed closed with leaflets for everything, spewing across the desks and on to the floor.

Research indicated that patients retained nothing that they were told in consultations. But I could never find the right leaflet, giving young men the menopause and HRT ones and children the smoking cessation ones. Anyway, the health centre car park was not only full of empty chip papers and cigarette ends but also hundreds of unread information leaflets. And most leaflets were just pharma marketing propaganda, masquerading as education.



The internet empowers patients in a way that leaflets never did

Twitter

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In 1996 I plugged a computer into a deafeningly noisy modem; the world opened up, a Damascus moment. All knowledge was now a few clicks away. What I thought I knew was out of date or just plain wrong. I binned my textbooks. When an avalanche of leaflets crashed over my floor, I realised that leaflets were no longer relevant either, riddled and rotten with bias. I sentenced them all to landfill too. The antique web browser AltaVista became my tutor, and expert knowledge soon lost its coinage.

Today the difference in clinical practice between doctors is one of mere opinion. And this medical opinion is based not only on experience but more importantly on the doctor's own health beliefs. For example, a belief in the benefit of breast screening means certain doctors promote screening despite the conflicting evidence.

So my room is largely empty. I might on occasion print out a leaflet for a

patient. But in the main I suggest that people research conditions themselves on the internet from many sources, starting with NHS sites, though many other opinions—blogs, charities, discussion forums, and so on—are worth reading.

Medicine has no definitive answers, just opinion and uncertainty. The internet might be dangerous from the perspective of patients trying to diagnose their own problems, but once they have a diagnosis it empowers patients in a way that leaflets never did.

The recent debate about official leaflets for breast screening is an irrelevance. Even official leaflets are never truly impartial, always open to the bias of the authors' clinical beliefs. The genie is out of the bottle. The power once derived from knowledge is dead, and patient leaflets aren't worth the paper they are written on.

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LAYING FOUNDATIONS **Oliver Ellis**

Jet packs

"My generation never got the future it was promised . . . 35 years later, cars, air travel—it's exactly the same. We don't even have Concorde anymore. Technology stopped." In *The West Wing* one of the characters was complaining about how technology hasn't lived up to the promises of science fiction. "Where's my jet pack, my colonies on the moon?"

Most healthcare institutions are run on paper notes and dictation. I'm used to it now, but as a generation Y, digital native type I remember arriving at my first medical school placement and being shocked at how archaic the systems were.

I defy anyone to defend dead tree notes. Unless you are a fan of paper cuts they are inferior in every way to a well implemented computer system. Yes, well implemented. You have spotted the flaw in my utopian dream.

For some reason, IT and healthcare seem not to mix. The NHS IT project was a great idea but has been scaled down in ambition to be essentially the world's most expensive email system.

Existing applications are not much better: the over-riding sense is that they've been created by people who have never actually set foot in a hospital. Every IT application I have used falls into one of two categories: clunky and weird, or clunky and impossible. In the first is software that looks as if it was knocked up in an afternoon by a high school student and that crashes with such astonishing regularity that you have to wonder if the design brief was to give users hypertension. In the second are systems with interfaces so non-intuitive that they may as well be hieroglyphics. There are buttons for everything, and most are labelled



Every IT application I have used falls into one of two categories: clunky and weird, or clunky and impossible

with an icon whose function can only be guessed at. That red blob might get you blood results; it might redirect an organ to Bognor Regis.

None of this is the institutions' fault. IT projects are expensive, difficult, and risky. So a centralised, concerted effort, led by doctors, is needed to create better systems. With the right technology, care could be made so much safer and efficient.

No more wasted outpatient slots because a patient was admitted. No more unreadable management plans or unknown allergy status. That's got to be something that doctors should get behind. And once that's sorted, then maybe we can have the jet packs.

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Competing interests: I have a relative who was employed on the NHS IT project several years ago.

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