

# Patient Perspectives

The process of medicines optimisation places patients at the heart of the process. It seems only right, then, to seek the views of patients about their experiences with medicines, their medical condition in general and their contacts with health professionals. Understanding what it is really like for a patient to live with a particular clinical condition will hopefully assist healthcare professionals to become more effective with their interactions and communications with patients and improve the healthcare services provided.

This has been done by providing patients identified through healthcare contacts with a template of questions to be completed anonymously by the patient on the basis that no individual be named or identifiable from the content. What some people have to cope with and the way they do it will amaze you.

## Coeliac Disease

### Abstract

#### *Title*

Patient Perspective: Coeliac Disease

#### *Summary*

A patient's perspective of living with coeliac disease is described. The way contacts with healthcare professionals might have been better are outlined. The medicines taken, elements of service provision found to be most helpful and steps to improve the ongoing management of the condition are outlined. Key messages for healthcare professionals that have arisen from the patient experience are indicated.

**Keywords:** medical condition, medicines.

## About your medical condition

### What is the medical condition most important to you that is being presented here?

Coeliac disease

### Can you please explain the problems you experience with this medical condition?

When, like me, you have been able to eat what you like for 45 years with no symptoms, bar excessive fatigue, it is a shock when this comes to an end.

I was a silent coeliac. This means that I presented with no other symptoms apart from extreme fatigue and tiredness, which had been going on for the best part of three years. There was no clue that it was coeliac disease causing this, just a barrage of tests with results that weren't making any sense. They tested me for pernicious anaemia and that came back normal! Only then was I tested for coeliac disease, which I now know was positive.

I experienced a sense of loss. One of my favourite pastimes was trying out new food and eating out, but when I was diagnosed the bottom fell out of my world - everything I knew had been taken away.

This all happened one week before my birthday, three weeks before our wedding anniversary and one week before we had a German exchange student, who was the same age as my daughter, had come to stay. The school my daughter attended had told us to serve traditional English food for the exchange student (such as roast dinner or fish and chips). But, as a result of my recent diagnosis, nearly all my quick 'go-tos' had been removed. Normally, for all these type of occasions, going out to eat would have been one of my fun things to do, but this time it just wasn't possible.

In addition to this, I had also planned for everyone come to me for Christmas dinner (ten of them). However, I had no support whatsoever, and socialising became noticeably difficult as people were, and still are, used to me eating everything in sight. It's such

a shame that no-one seems to take much notice of the social effect a diagnosis has. It's caused me all sorts of problems.

Buffets are a nightmare for people with coeliac disease, but sometimes they are the easiest thing for hosts to do. My family also have a habit of going out for lunch on Boxing Day, not having any inkling of the stress that puts me under. The first time this happened I ended up with a not a very good meal, and consequently fell into a foul mood all day just because of the stress as I had no say in where we went. Then everyone was eating the one dish (pasta) that I couldn't have. That was four years ago, but it still grates that the emotional support wasn't there when my whole normal world had been turned upside down. However, through researching about the condition and obtaining information from the support group on the CUK (Coeliac UK) site, things have improved and we can now actually plan a dinner out.

Others will know the look of "oh great, another one on a fad diet" every time you go anywhere and ask for a gluten free menu, of being told "it's only an intolerance" and the infuriating "it's fine if you ring before you arrive", which rips all the spontaneity out of anything. This is never addressed by those who dish out the original diagnosis.

I am very lucky; I'm not allergic to any foods at all, so eating is fun and always has been, but it very nearly ripped the entire heart out of my life because I was never helped or supported to adjust.

### Can you please say how the medical condition was first diagnosed?

Via blood test and then an endoscopy into the small intestine.

### Can you please say when the medical condition was first diagnosed?

August/September 2012.

### If you look back, what would you say have been the main things you would have liked to have been different in terms of contact with health professionals?

Being listened to about feeling extremely tired and telling them that I felt anaemic. All anyone did for nearly three years was test my iron levels for anaemia, which always came back normal. I

was contacted by my GP on one of those occasions to say that my B12 was borderline low, was retested and then told it was nothing to worry about.

I saw a really switched on locum, whilst we were waiting for our new GP, who tested me for everything when I mentioned again that my B12 was low and raised the possibility of pernicious anaemia. The results came back as normal for pernicious anaemia but my folic acid and B12 levels were extremely low. This led to the treatment for B12 and folate deficiency anaemia and a blood test for coeliac disease.

The locum listened to what I said, identified that I was eating all the right things but something didn't add up. Hence the test for pernicious anaemia and then coeliac disease.

I think I also would have liked a bit more information about coeliac disease (by this time our GP had arrived) and, to be fair, I was given the website for Coeliac UK ([www.coeliac.org.uk](http://www.coeliac.org.uk)) by my GP.

No one helped me to sort my diet except my husband.

I didn't know that bread had to be ordered in by the pharmacy. I also wasn't told that I could finish the food that I had just bought that day to feed my family on a budget. I also wasn't given any sensible advice as to how long sorting my diet out was going to take.

All of these things below I had to ask for which, in reality, should have happened automatically under NICE guidelines:

- referral to dietitian
- referral for DEXA scan
- an annual blood test and review (still having to ask for that now, five years later; it's not automatically done, like it should be).

As a Coeliac I feel sometimes that we are not taken seriously and that our illness isn't valid. Everyone thinks it's easy to be on a gluten free diet - I can assure you, it isn't.

## About your medicines

### Please list the medicines you taking for your medical condition.

I am on a very strict gluten free diet as there is no other medication for coeliac disease. I do order my food on prescription, especially bread, as it is specially formulated for our diet and takes note of our malabsorption problems.

If I am 'glutened' (i.e. I have eaten something containing

gluten), I take the following and, on a couple of occasions, I have still needed the paramedics (but that's the exception, not the rule):

- buscopan (high strength) for the cramps
- paracetamol for the pain and, if that's not enough
- tramadol.

I also take vitamin B supplements every day to try and keep that going and Vitamin D supplements every other day to try and counter the effects of the bad absorption before I was diagnosed. I now have mild osteopaenia in my left hip due to the coeliac disease.

### **Have you had any particularly bad experiences with regard to your medication? If so, explain and indicate how this could have been avoided in the future.**

The pharmacy and the GP surgery have misread and misinterpreted what I have ordered in the way of food, giving me the wrong amount of one food and not enough of the basics (like bread). It took a bit of time but we did eventually iron things out.

### **Have you any good experiences of your medications? If so, please explain.**

The pharmacy and GP surgery now very rarely make mistakes, and due to the fact that I have a good relationship with my local pharmacy they will now ring me if they think something is not quite right. This doesn't happen much now at all, as all of us know what we're doing.

## **About the services you received**

### **What have you found to be most helpful to you in terms of the services you have received?**

The help I have received from the pharmacy and the companies that provide my specialist food - nothing is too much trouble. Other than that, apart from Coeliac UK's website, nothing was really helpful at all.

### **To what extent have the health professionals you have come in contact with appreciated what it was like from your position as a patient?**

They haven't. I had a lot of issues with a sense of loss and frustration, which caused some mental health issues. Nobody thought about the fact that this could be to do with the diagnosis and the impact it had on my social life around fairly major celebrations. The emotional impact is very real, but I don't feel that anyone appreciated it at the time or appreciates that now.

### **To what extent was the information you were given about your medical condition sufficient for you?**

It wasn't. I wasn't helped to shop, to sort out labels or told what I should or shouldn't be looking for in terms of avoiding gluten. I also wasn't briefed on cross contamination or the effects that could have. I was literally given a prescription for bread and pasta but not told it would need to be ordered in and, therefore, that it could take up to four days to obtain. I went back to the surgery to ask for some help and got to see a nurse who told me that I could still eat couscous - which is pasta, so I couldn't but if I had not known that the consequences could have been dire.

Even the people who were supposed to help didn't seem to know what gluten was, never mind what it was in! Very poor.

I needed support in this journey and it wasn't forthcoming.

### **To what extent did the health professionals you came in contact with communicate effectively with you?**

Basically they didn't. My GP was helpful to a point and met every one of my requests, but to this day does not understand how difficult it is for me. As for other professionals, the consultant at the hospital didn't even tell me what was going on; I found that out in a letter, then a phone call from the GP and ultimately an appointment to tell me I had coeliac disease.

When I asked for support the person they sent me to didn't have any idea what was safe and what wasn't, and didn't seem to understand that I needed some help to sort out my diet. The dietitian put a recommendation that I needed an annual blood test in writing. I had to write to the practice manager telling them that it was necessary and why as they originally told me that they wouldn't sanction that!

### **What have been the best experiences you have had with the services you have received?**

Since my letter to the practice manager, I have never been refused any service I have asked for - I always back up my requests with evidence from Coeliac UK, without that support I would not be very confident today.

## About other medical conditions

**Do you have any other medical conditions that make life problematic for you? If so, please list them and explain the main problems you experience with each one.**

**Medical condition: main problem experienced**

Asthma: Hayfever, causing constant coughing

Depression: I have a history of this. The diagnosis of coeliac disease increased stress levels and had an impact on my mental health, which was not taken seriously.

Menopause: Night sweats, mood swings, stress anxiety (asthma trigger).

## About going forward

**What would you like to happen at this stage that would make living with your condition easier for you?**

Firstly, to stop telling everyone that the supermarkets cater for all our needs. They don't. Nothing on the 'Free From' shelves is fortified with anything, which is daft when you consider that most Coeliacs have issues with absorption of minerals and vitamins and are very often deficient of them.

The price of gluten free food to come down. It is extortionately expensive.

That people acknowledge that coeliac disease is a serious autoimmune condition and is treated as such by professionals in particular.

The general public is under the impression that a Coeliac is not a Coeliac for life and that you can grow out of it; we need to change the perception.

Coeliac UK are doing a fantastic job, but maybe if the professionals took it a little more seriously and listened to their patients concerns we could change some attitudes.

**If you could give a brief message to healthcare professionals, what would it be?**

Do not dismiss coeliac disease as nothing to worry about. Listen to your patients and, above all, if you are at all suspicious order a blood test. If I had been tested eight years ago, I would not have been wrongly diagnosed with IBS. It affects everyone differently, but don't just ignore the person who keeps coming back saying they feel anaemic; look beyond the basic iron levels.

Support groups for locals with the condition so they can help each other. There may be people in the same boat who could be mentors or who you could ask to go shopping with to help and advise.

Don't just leave us floundering around in the dark with no support, which is what happened to me.

**Please add any other comments or observations that would be helpful to health professionals who are responsible for providing services for you.**

Any patient would need support with a change in lifestyle. Coeliac UK's website was a good start, but you need to be aware of the social impact. Nearly everything we do culturally in this country revolves around food. The diagnosis makes the patient the outsider and makes them feel very incredibly isolated.

Do not ignore the grieving process, or the problems associated with people not understanding food.

Referral to a dietitian at the earliest possibility would probably have been a lot more helpful to me than it was as I had to wait and request this myself. If that had happened automatically I would have had support when I needed it.

Coeliac disease needs to be taken more seriously than it is, it has a very big impact on the patient as well as everyone around them.

**What are the three most important things that health professionals should learn from your experiences?**

- 1) Listen.
- 2) More emotional support.
- 3) Referrals straight away.

## Declaration of interests

**You will have been offered a fee for your contribution to be submitted within a specific timescale. In the spirit of being open and transparent, would you please disclose any other payments, interests or activities that could be perceived as influencing what you have written or state 'none'.**

None

### KEY LEARNING POINTS FOR HEALTHCARE PROFESSIONALS IDENTIFIED AT THE EDITING/PEER REVIEW STAGES

- Do not underestimate the sense of frustration and isolation that a coeliac patient can experience if they have undiagnosed problems and feel that they are not being listened to. It might be helpful to raise awareness of the Coeliac UK support group.
- The social consequences of a medical condition also need to be taken into account – a referral may be appropriate for advice to improve a patient's quality of life.
- Be prepared to check if a patient feels they have enough information about their condition and, if not, update your knowledge or refer them to someone who can help.