

BRITISH BROADCASTING CORPORATION  
RADIO SCIENCE UNIT

CHECK UP 5. - **Coeliac Disease**

RADIO 4

THURSDAY 02/09/04 1500-1530

PRESENTER:

BARBARA MYERS

MYERS

Hello. People with coeliac disease have an intolerance to gluten, that's the protein found in wheat and other cereals. Eating common foods such as bread and pasta causes inflammation and damage to the lining of the gut. Symptoms can range from diarrhoea, to weight loss, to anaemia and brittle bones. The disease which affects up to one person in a hundred can't be cured, it can though be managed by a strict gluten free diet - of course that's tough if you want to eat with the family. And for everyone who's been diagnosed with coeliac disease it's thought there are ten times as many who remain undiagnosed. So what symptoms should alert you to the possibility of coeliac disease and what tests are available to confirm it? There is a simple blood test, so should we all perhaps be screened, given that the disease seems to be on the increase?

We'll call us now with your questions, our number, as ever, is 08700 100 444 or you can e-mail **[checkup@bbc.co.uk](mailto:checkup@bbc.co.uk)**

And my guest today, who's very welcome, is Professor Paul Ciclitira, he's professor of gastroenterology and that's at St. Thomas's Hospital in London.

Paul, coeliac is a serious disease but it does, in some senses, present with everyday symptoms - I've mentioned diarrhoea for example or fatigue, which lots of people experience. So how do you make the distinction and what should alert people to the possibility that they have coeliac disease?

CICLITIRA

Well coeliac disease is now known, as you have rightly said, to affect roughly one in a hundred of the UK population and therefore you're talking about a very significant number of sufferers altogether. The disease in children often presents as failure to thrive but now with the increasing use of blood tests and screening we're finding more and more cases in the adult group and particularly people with change of bowels - and you've already mentioned diarrhoea and occasionally they can present with constipation - and there's another group of people who have general tiredness or are found to be anaemic and other problems such as fertility problems as well. And all of these individuals should certainly be screened, probably in the first instance through their general practitioner with a readily available blood test and then if that's positive then referred on to an appropriate specialist for further diagnostic tests.

MYERS

Let's go to our first caller because Stan has been through this procedure, I think he's already had a diagnosis, in fact had a diagnosis very recently. Stan, what's the story?

STAN

Well I had it this morning, this very morning. It's sort of was confirmed this morning. I had a gastroscopy, which most people will know is the tube down the throat into the stomach and the intestine. And that was done a few weeks ago. And they did a couple of biopsies which were quite painless, not a terrible experience but anyway after that I was told possibly it was coeliac disease and I thought well I've got no problem with my digestion - I've no diarrhoea, I haven't constipation - but I do suffer from tiredness. And I thought well get to my age, which is 81, coming up to 82, I thought well you expect to be tired, particularly if you have a full life and I'm involved in all sorts of things, everyday

you might say. But I felt well that's just simply, you know, time passing by.

MYERS

So this was a surprise to you to have this diagnosis at your good age?

STAN

Yes, it was picked up by my GP that when I mentioned tiredness and he said let's have a look at your blood.

MYERS

So has this been a bit of a shock to you.

STAN

I must say, very much so because I enjoy my food, particularly crusty white bread or any other bread. But now I've got to look forward to something that's, well, second class as far as I'm concerned and I was wondering if there's was anyone who would say - hopefully your advisor today - would say what one should do, obviously there's diet I should have to be on, I'm going to see the dietician sometime and then I shall know what I can eat.

MYERS

Right over to Paul, as you say, our expert today. And sorry tale there - no more crusty white bread. But what is Stan going to eat in fact and enjoy in the future with this diagnosis now?

CICLITIRA

Well it was very interesting to hear, Stan, of your experiences here. It is unusual for coeliac disease to present in your sort of age group but it clearly - it can do and as you've so graphically described to us. Some people would argue about the use of a gluten free diet in your age group but in a situation where you've very clearly given a history of being symptomatic with tiredness I would strongly advise you to follow the advice that you've been given and that is to take a gluten free diet because in my experience you will find a considerable increase in your general amount of energy and feel much improved. And the gluten free diet isn't that bad - you can obtain gluten free bread from your pharmacy, which is available on prescription through your general practitioner .

STAN

Oh good, yes.

CICLITIRA

And I don't think you'll find it's quite as bad as you think.

STAN

No, I've tried one of the major stores and the bread was something similar to cake - very small texture - and not in any way easy to eat.

MYERS

Not very palatable, is what you're saying?

STAN

Well unless it was toasted, you can put other things on it then.

CICLITIRA

One thing you can do is to buy a breadmaker and get recipes for gluten free bread and then what I've - my own personal experience from talking to many patients is what they do is they either freeze it or slice it and then freeze it and then that actually keeps much

better and keeps it in a palatable form for a longer period of time.

STAN

Well that sounds hopeful anyway.

MYERS

Stan, thank you very much, please stay listening, I think there will be some more questions about this gluten free diet but if it relieves your symptoms - in this case of tiredness - then that can only be a good thing and leaving you to get on with life. Let's go to Buckinghamshire now next and Claire is waiting to talk to us, having been diagnosed with coeliac disease three years ago? What's your question please for Paul Ciclitira?

CLAIRE

Oh hello. Firstly, can I just reassure your previous caller, a good way to get to know what breads are more palatable is to contact all the makers and they tend to give you a free sample box with lots of all the different products in.

MYERS

Good tip.

CLAIRE

So get a list from your doctor [indistinct word] and you get to sample and find out what's best for you.

MYERS

Good.

CLAIRE

My question, I had two, one is about whether or not there are degrees of severity of coeliac disease or is it just black and white - you've got it or haven't? And the second was to do with weight gain and weight loss as a coeliac.

MYERS

Okay, what about your own degree of severity - is it a big problem for you?

CLAIRE

Not at all and in fact I was similar to your previous caller - it was only through chronic fatigue and consistently low iron levels since having had my daughter that the doctor got on to the idea of coeliac disease. I've never had stomach problems and in fact even now I find if I inadvertently consume something with gluten in I don't know I've done it, whereas my sister, who is also coeliac, will get a pretty quick and painful reaction.

MYERS

It is interesting - sorry just to interrupt - that a bit of a paradox - I guess if you're talking about an inflammatory condition in the gut, common sense says that it would hurt, you would have abdominal symptoms but both you and Stan are saying no that's not the case. So let's ask Paul about that and whether there's a whole - if you like a whole range of symptoms and the degree of severity of those symptoms is also quite wide.

CICLITIRA

Your question really was are there degrees of coeliac disease? I think the answer to your question really is that coeliac disease is a clearly defined entity but different people have different degrees of symptomatology. For example, previously when I was an undergraduate, the prevalence of the disease was thought to be 1 in 1800 of the population and virtually all the presentations were in infants of about four to six months or around that time, where solids were introduced into their diet and when they present -

when they had gluten and then they developed symptoms. Now those are clearly relatively severe cases. Now in Stan's case, which we've already heard, someone who's presenting at 81 and the evidence would suggest that this is a lifelong condition, obviously has a lesser degree of symptomatology than the young person. But to extend that also and to compare you and your sister - and the research studies - because my group does a significant amount of research in this area - if you took 10 people with coeliac disease and gave them gluten over a short period of time roughly half of them would have symptoms and the other half would not and this is evidenced by yourself, you've presented with anaemia and tiredness, whereas your sister, you infer, actually presented or clearly has symptoms with gluten. So these are different spectrums. And we now - or spectra - that we have a situation where the increased use of screening blood tests have shown that the prevalence of the condition is of the order of one in a hundred of the population. So this is clearly a very common condition.

MYERS

Well can I ask what's going on - whatever the symptoms you may personally experience, Paul, with someone diagnosed with coeliac what is the underlying pathology that is cause for concern and that means that you have to go on a gluten free diet so as to avoid some of the consequences to your health further down the line?

CICLITIRA

In - the definition of coeliac disease is an abnormal biopsy of the small intestine - that's the part of the intestine just beyond the stomach. And it's, in my opinion, very important that people actually have the definitive diagnosis. And you get a flattening of the mucosa, where you normally get little villi, which look like sort of fingers which allows for absorption of food products.

MYERS

It's in the lining of the small intestine.

CICLITIRA

. of the lining of the small intestine. And if those individuals who are affected take gluten the villi become damaged and you get loss of the villi so that the mucosa becomes flat and that there is a very considerable decrease in the amount of absorption of foods. And this results in, as you've classically described, vitamin deficiencies and you've described to us that you get recurrent iron deficiency and it's for that reason and others that it's very important that the condition is treated, and there can be other complications within the gastrointestinal tract which clearly those are avoided by taking a gluten free diet.

MYERS

Claire you also wanted to ask about weight loss.

CLAIRE

Yes. Because I wasn't underweight to begin with - I know a lot of people have weight loss, which is another symptom - in fact I was already overweight. But what I discovered - what I found was that since diagnosis I actually put on a lot of weight in the first four months since being diagnosed. I put a lot of that down to the fact that I was finally absorbing things and I'd obviously been - I don't know whether I'd been overeating beforehand to try and get some energy and finally things were being absorbed and put to good use and my weight seemed to balloon. But also because I was not adjusting to a gluten free diet and was turning to more convenient foods in the absence of bread, like crisps and things like that. But since then I've found it very hard to lose weight and the dietician advised me to avoid foods that were high on the glycemic index but when I got a list of those foods they seemed to me to be the staples of a coeliacs diet - being sort of corn and rice based products, baked potatoes and things like that. And the biggest problem of course is breakfast because cornflakes and rice crispies about the only things you can have in the cereal world but they seem to be high glycemic index foods. So I'm

now stuck as to where to go for things that I can eat that will help me in a diet.

MYERS

Well I mean it obviously gets complex because of the many issues involved and clearly a dietician really needs - or you really need to see a dietician I daresay but Paul, in general, is there something useful you might be able to say to Claire?

CICLITIRA

Well this is a common problem and particularly in women what's been happening previously is their metabolism has effectively become inefficient and therefore they're useful to taking more calories than they would normally require. And because you've got this regrowth of the villi, with absorption then - much more efficient absorption of food there is often a problem with weight increasing. And the only way to - I fear - to deal with that is to reduce the calorie intake. The only other comment that I'd like to make in relation to the breakfast cereals is that I see a number of patients who actually have problems because patients with coeliacs disease, in my opinion, should avoid malted cereals, particularly cornflakes, because they contain significant amounts of gluten.

CLAIRE

Oh really.

MYERS

Okay thanks very much for that Claire. And we'll move to another call - sorry to have to cut you short there - but we'll go to Vicky who's waiting in Leeds. Hello Vicky, your turn.

VICKY

Hi there.

MYERS

Hi.

VICKY

My question is my two and a half year old daughter was diagnosed via a positive blood test about two and a half weeks ago, she'd been ill for about two months quite chronically really with fatigue, vomiting, anaemia, irritability, bloated, weight loss - lots of things really. And only when we sort of got a private referral did we get this blood test done. And she's scheduled for the intestinal biopsy on Tuesday and I've got a couple of questions really. The first one being is it absolutely necessary to put a child, such a young child, through this because obviously she'll have to have either a general anaesthetic or sedation?

MYERS

So you've in a bit of a state of shock I'm thinking at the moment with this news are you?

VICKY

Yes absolutely.

CICLITIRA

Can I come back to you there? You said that the diagnosis was made with the blood test, I would suggest that that should be used as a positive screening test rather than an absolute diagnosis. My own view on this is that it's very important to have the definitive test and that is an endoscopy, which I appreciate the problems with a child which would require a general anaesthetic, but I think it's important to actually define the abnormal pathology with an endoscopy and a small intestinal biopsy because there are some individuals who have a positive blood test without the abnormalities in the intestine. And it's my personal experience that it can then become extremely complicated and not - and unfortunate to place a child on a lifelong relatively restrictive diet without actually having

a definitive diagnosis. So I would encourage you to actually attend for that test and to have a definite definitive procedure.

MYERS

Any words of reassurance though because obviously Vicky and her daughter are going through quite a difficult time, I mean is this a bit of a life sentence for them or can one be more positive than that?

CICLITIRA

Well first of all the risks of the endoscopy and the anaesthetic are absolutely minimal, so that I would reassure you as strongly as I can. And in relation to the ongoing lifelong aspects of it, clearly one will need to go on the - if the child almost certainly has got coeliac disease and will therefore need to go on a gluten free diet. But I don't think you should regard that as a disaster, it's something, in particular in children, they rapidly get used to and can be relatively managed by yourself in relation to obtaining prescriptions for gluten free products through the general practitioner.

MYERS

Vicky I hope that helps and perhaps we'll get a call from someone who's been on a lifelong gluten free diet and can again confirm that it's not such a big problem. But let's see what our next caller has got to say and we go now to Oxford and Charlotte is waiting to speak to us. Hello Charlotte.

CHARLOTTE

Hello.

MYERS

And your question please.

CHARLOTTE

Well my problem - I, my sons and my mother were diagnosed about five years ago and my problem is not so much of the diet but how more people that I meet can actually get the diagnosis because I meet so many people who say - Oh I think I or my son or my sister might have a problem with gluten but my doctor said oh you can't have coeliac disease because you haven't lost weight or your son hasn't got diarrhoea or even people - GPs - who say you're not Irish. And they seem, a lot - too many GPs still seem to view the condition as very rare and the blood test as expensive. So I'd like to ask Professor Ciclitira two questions. Firstly, given that 1% of the population perhaps has this condition and that he himself has called for GPs to test for it as routinely as for diabetes and thyroid disorders, how can GPs be persuaded to do this?

CICLITIRA

I think there has been a problem here because of the change in our awareness of the prevalence of the disease, as I've said previously we've gone from a situation of roughly 1 in 2,000 to roughly 1 in a hundred, and clearly if people have symptoms pertaining to the tiredness or the anaemia or diarrhoea then they clearly should be screened. And that is a relatively straightforward thing that should be available through a general practitioner's surgery and I think the general practitioners should be asked if they would be willing to provide a blood test for the patients. You touch on another aspect that - of being Irish and you obviously appreciate that there is an increased prevalence of the condition in the Irish, both north and southern Irish and it's been shown that it affects in excess of 1 in 80 of the population.

MYERS

Any idea why that might be?

CICLITIRA

It's thought that the increased prevalence is because the main staple of diet in Ireland has been potatoes and if you have very severe coeliac disease you have problems with fertility and therefore - but the natural selection process has not actually occurred so much in Ireland because the wheat wasn't previously present until it was introduced relatively later than in the UK.

MYERS

And across other ethnic groups is this also equally prevalent?

CICLITIRA

It's prevalent in virtually all ethnic groups with the exception of Afro-Caribbeans where it's relatively uncommon. And in particular people of Asian extraction it also is common. But this is clearly relevant as to what they're taking with their diet - for example, if you have Chinese who are actually purely eating rice then it doesn't present as a problem, but if you investigate them then you find that the prevalence in many of these populations is the same.

MYERS

So you're going along with what Charlotte is suggesting that screening tests, simple blood tests, at the GP, if you have some cause for concern would be a perfectly reasonable request for a person to make on their own behalf or on behalf of a child?

CICLITIRA

Absolutely and I would agree with Charlotte. I mean Charlotte obviously has read about this because there is an increased prevalence in diabetes of roughly 8% and in thyroid disease of 6%. And also if anybody is symptomatic and who has a first or second degree relative with the condition I believe it is important that they be screened because again we're talking about in first degree relatives a prevalence of 10%.

MYERS

And the importance of picking up the condition is what exactly?

CICLITIRA

Well that is very interesting and I think an excellent question because why should people be treated? We've already heard that Stan has tiredness at the age of 81, I personally believe that's very important to treat because I suspect strongly that Stan will actually improve and feel that he's got generally more energy. We've heard about the two year old child with vomiting, some diarrhoea and generally failure to thrive, now that child will be much improved, assuming that the diagnosis is confirmed, by going on to a gluten free diet and otherwise would have major problems with growth retardation. And also those people who are symptomatic, for example, we heard of Claire previously, asymptomatic, alright it's only iron deficiency but there are a number of vitamin deficiencies that occur and particularly things like thin bones, which improve with a gluten free diet. And for that reason I think it is very important that people with a diagnosis do actually take a gluten free diet.

MYERS

And just to back up what you're saying there, we've got an e-mail from a listener who says she had anaemia for many years, heavy periods were blamed, after menopause though they looked again and at that point when she was diagnosed with osteoporosis they tested for coeliac and lo and behold she has had coeliac. So of course she's making the point too, these things should be picked up, as she calls them, the missing coeliacs should be found and treated with a gluten free diet.

CICLITIRA

Absolutely and that only confirms what I've previously said. But not only that but many of these problems, such as the osteoporosis and the anaemia and the vitamin

deficiencies, although they should probably be treated in the first instance for themselves but will improve with a gluten free diet and therefore the simple expediency of taking the correct dietary regime will resolve many of these problems.

MYERS

Now there's a question about oats in all this, is that a gluten rich food? Salvador Potter is, I think, going to be questioning that. You've got coeliac disease yourself have you Salvador?

POTTER

Yes indeed, I was diagnosed some 20 years ago with coeliac disease, although I think I suffered from it probably from the age of six or seven, looking back on it. I had a couple of points to make, as well as that, I think that the first one is that the coeliac recommended list of food certainly includes cornflakes and I'm sure many coeliacs will be a bit alarmed to hear the doctor say that probably cornflakes shouldn't be eaten. The second point is, I think, I've been on coeliac diet now since I was 30, that's 20 years, and things have improved dramatically - the availability of gluten free foods in places like the major supermarkets is a tremendous improvement. And thirdly, the question about oats - I was diagnosed in the Cambridge area by Dr John Hunter who I think is very well known in this area and he has told me that oats are now recommended, or available, to coeliacs, I just wondered how clear that message was and should be?

CICLITIRA

Can I interrupt at that point because we're coming towards the end of the programme? Oats in the majority of coeliac patients is fine, as long as it's obtained from a reputable supplier and there is definitely no contamination with gluten. There has been a recent study, however, suggesting that 1 in 20 people with coeliac disease may have some sensitivity to oats and therefore it needs to be monitored carefully. I applaud the fact that the supermarkets actually have many gluten free products but it should not be forgotten that they're available from chemists on a prescription, so at a much reduced cost. And the cornflakes and certainly in most marketed cornflakes there are large amounts of malt and I see a considerable number of people who have problems with that.

MYERS

I've got to stop you there. Thank you all very much indeed. More information, as ever, on our website and you can phone our free and confidential help line - 0800 044 044. Next week it's angina.