

COELIAC DISEASE QUESTIONNAIRE

This information allows us to provide relevant details in the subsequent publications but your personal details will be anonymised.

Name (please type out your name):

Date of Birth (please type out your date of birth):

Address and postcode (please type out your address and post code):

Height (can be in metres or feet):

Weight (can be in Kg or stones):

When answering questions in this first section of the survey, please tick the box or boxes that apply to you (or if filling out as word document put x in the box)

How old are you?

18-25 26-35 36-45 46-55
56-65 66+

Are you

Male Female

What is your occupation?

What is your ethnic origin?

White caucasian Afrocaribbean African
Asian Chinese Other

What is your highest educational qualification?

Higher or masters degree	<input type="checkbox"/>	Bachelors degree	<input type="checkbox"/>
HND or university diploma	<input type="checkbox"/>	A Levels	<input type="checkbox"/>
GCSE / O Levels	<input type="checkbox"/>	Work-based NVQ or on-job training	<input type="checkbox"/>
No qualifications	<input type="checkbox"/>		

What is your marital status?

Married or living as married	<input type="checkbox"/>	Single	<input type="checkbox"/>
Divorced	<input type="checkbox"/>	Widow	<input type="checkbox"/>

Have you ever had any of the following medical conditions?

Type 1 Diabetes	<input type="checkbox"/>	Type 2 Diabetes	<input type="checkbox"/>
Anaemia	<input type="checkbox"/>	If so do you know what type?	

Under-active Thyroid	<input type="checkbox"/>	Over-active thyroid	<input type="checkbox"/>
Osteoporosis	<input type="checkbox"/>	Primary Biliary Cirrhosis	<input type="checkbox"/>
Epiepsy	<input type="checkbox"/>	Migraines	<input type="checkbox"/>
Diverticular Disease	<input type="checkbox"/>	Reflux	<input type="checkbox"/>
Other bowel disease	<input type="checkbox"/>	If so what type?	

Have you experienced any of the following in the last twelve months?

Bloating	<input type="checkbox"/>	Abdominal cramps	<input type="checkbox"/>
Indigestion	<input type="checkbox"/>	Diarrhoea	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	Excessive flatulence or wind	<input type="checkbox"/>
Excessive belching	<input type="checkbox"/>	Weight loss	<input type="checkbox"/>

Floating stools

Haemorrhoids

Nausea

Vomitting

If you have experienced persistent abdominal pain or irritation over the last THREE months please answer the questions below (if not move on please)

- a) Was this pain or irritation relieved by opening your bowels?
- b) Did the persistent abdominal pain or irritation come about at the same time as a change in how many times a day you open your bowels?
- c) Did the persistent abdominal pain or irritation come about at the same time as a change in the consistency of your stool?

1. If you have ticked one or more boxes to questions a), b), or c) above then please answer the following questions below (if not move on please)

Do any of the following apply to you:

Recurrent abdominal pain on average at least 1 day per week during the previous 3 months

A change in stool frequency?
(*Going to the loo more than three times a day or less than three times a week?*)

A noticeable difference in the form of your stool?
(*Going from what is normal for you to watery, lumpy, hard, poorly formed?*)

Pain related to defecation (doing a poo)?

A feeling that your abdomen is bloated?

A feeling like you have not emptied your bowels completely **or** straining to empty the bowels **or** feeling an urgent need to rush to the toilet to open your bowels?

Have you ever been diagnosed by a doctor as having IBS or Irritable Bowel Syndrome?

No

Yes Alternating diarrhoea and constipation?

Predominantly constipated IBS? Predominantly diarrhoea IBS?

How many years is it since you were diagnosed with Coeliac Disease by a doctor?

What type of symptoms were you experiencing at the time you were diagnosed with Coeliac Disease?

Gut symptoms like bloating, diarrhoea, abdominal cramps etc

Non-gut symptoms like headaches, being tired all the time, "pins and needles"

You had no symptoms whatsoever and were found "by accident"

If you recall a period of time between first experiencing these symptoms and being correctly diagnosed with Coeliac Disease by the doctor, can you please tell us how long this was roughly in years or months

Years Months

Tick this box if you have ever had Dermatitis Herpetiformis

Do you eat gluten voluntarily? (only fill out questions that apply to you)

Yes

No (if no go to the next question)

If yes

A normal portion

Or just a taste

If just a taste:

Often

Rarely

When you eat out, do you tell the person who is cooking about your coeliac disease?

Yes

No

Do you check the labels of packaged foods?

Yes

No

Do you only eat packaged food guaranteed by Coeliac UK (cross grain symbol)?

Yes

No



Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN / DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY / DEPRESSION

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

We would like to know how good or bad your health is **TODAY**. This scale is numbered from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine.

Please mark an X on the scale (or make bold the number) to indicate how your health is TODAY.

0--5--10--15--20--25--30--35--40--45--50--55--60---65--70--75--80--85--90---95—100

Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The next series of questions are about the effect that your coeliac disease may have on you?

Do you make yourself Sick because you feel uncomfortably full?

Yes No

Do you worry you have lost Control over how much you eat?

Yes No

Have you recently lost more than One stone in a 3 month period?

Yes No

Do you believe yourself to be Fat when others say you are too thin?

Yes No

Would you say that Food dominates your life?

Yes No

Please provide any mental health concerns or diagnosis you may have been given or consider that you have :

In the past two weeks:

Score 1 to 5 (1 is completely agree and 5 is completely disagree)

...I have regretted eating and drinking things which have made my Coeliac Disease symptoms worse

1 2 3 4 5

...my enjoyment of a particular food or drink has been affected by the knowledge that it might trigger my Coeliac Disease symptoms

1 2 3 4 5

...my Coeliac Disease has meant that I have had to leave the table while I am eating to go to the toilet

1 2 3 4 5

...I have not been able to predict how long it will take for my body to respond to something I have had to eat or drink, due to my Coeliac Disease

1 2 3 4 5

...certain foods have triggered symptoms of my Coeliac Disease

1 2 3 4 5

...my Coeliac Disease has meant that I have been nervous that if I eat something I will need to go to the toilet straight away

1 2 3 4 5

...I have avoided having food and drink I know does not agree with my Coeliac Disease

1 2 3 4 5

...I have felt relaxed about what I can eat and drink despite my Coeliac Disease

1 2 3 4 5

...I have felt in control of what I eat and drink in relation to my Coeliac Disease

1 2 3 4 5

...I have struggled to eat the way that is best for my Coeliac Disease because of other commitments during the day

1 2 3 4 5

...I have been frustrated about not knowing how food and drink will react with my Coeliac Disease

1 2 3 4 5

...I have had to concentrate on what I have been eating and drinking because of my Coeliac Disease

1 2 3 4 5

...I have been worried that if I eat I will get symptoms of my Coeliac Disease

1 2 3 4 5

...I have felt the way that I eat and drink for my Coeliac Disease has affected my day-to-day life

1 2 3 4 5

...the way I have had to eat for my Coeliac Disease has restricted my lifestyle

1 2 3 4 5

...I have had to concentrate on what food I buy because of my I Coeliac Disease

1 2 3 4 5

...it has been on my mind how my Coeliac Disease will be affected by what I eat and drink

1 2 3 4 5

...my Coeliac Disease has prevented me from getting full pleasure from the food and drink I have had

1 2 3 4 5

...I have felt that I need to know what is in the food I am eating, due to my Coeliac Disease

1 2 3 4 5

...I have felt that I have to be careful about when I have eaten, because of my Coeliac Disease

1 2 3 4 5

...I have had to be more aware of what I am eating, due to my Coeliac Disease

1 2 3 4 5

...I've missed being able to eat or drink whatever I want, because of my Coeliac Disease

1 2 3 4 5

...I have felt that I would like to be able to eat and drink like everyone else Coeliac Disease

1 2 3 4 5

...I have been happy to eat and drink around people I do not know despite my Coeliac Disease

1 2 3 4 5

...I have felt that I have been eating and drinking normally despite my Coeliac Disease

1 2 3 4 5

...I have found it hard not knowing if a certain food will trigger Coeliac Disease

1 2 3 4 5

...my Coeliac Disease has meant I have had to make an effort to get all the nutrients my body needs

1 2 3 4 5

...I have felt that I haven't known how my Coeliac Disease will react to food or drink

1 2 3 4 5

...my Coeliac Disease has meant that I have had to work hard to fit my eating habits in around my activities during the day

1 2 3 4 5

Who do you see to monitor your coeliac disease?

Hospital Doctor GP Dietitian No one

If you do have follow up for your coeliac disease, how often are you seen?

Once per year More than once per year Less than once per year

Do you find the clinic appointment useful (1 not at all useful and 5 being very useful)

1. 2. 3. 4. 5.

How useful are the following aspects of clinic (1 not at all useful and 5 being very useful). Please answer even if you don't have a clinic appointment.

General Reassurance

1. 2. 3. 4. 5.

Annual check up, symptom review, blood test

1 2 3 4 5

The opportunity to review your diet

1 2 3 4 5

The chance to ask questions regarding the condition

1 2 3 4 5

The chance to ask more questions about your diet eg, checking food, eating out, going on holiday

1 2 3 4 5

Other

1 2 3 4 5

Please specify:

If you see a doctor at the hospital, is it a different one every time?

Yes No

If yes does this make it less useful?

Yes No

Which one of the following options (in order of 1 to 6) would you prefer for the long term follow up of your coeliac disease? (1=preferred 6=least preferred, place the relevant number in the boxes below)

Hospital follow up seeing a doctor

Hospital follow up seeing a dietitian

Hospital follow up seeing a dietitian with the opportunity to see a doctor if needed

GP Follow up

No Follow up

Access when needed

Would you see a telephone clinic appointment as equally useful to your first choice?

Yes No

Is this because of difficulty for parking? Yes No

Is this to avoid burdening the NHS? Yes No

Is this to avoid time off work? Yes No

Is this because of difficulty with getting to hospital? Yes No

Is this because of a perceived increased risk of covid infection by coming to hospital or GP practice?

Yes No

Is this because the clinic appointment previously has not been helpful or of value to you?

Yes No

Is this because of waiting times in clinic?

Yes No

Are there any other reasons we have not considered?

Free text: (please type in what you would like to say):

If you wanted to have any form of Follow Up for your coeliac disease- how often do you think that should be?

Once per year?

Less than once per year?

More than once per year other?

You have reached the end of the survey.

We really appreciate you taking the time to complete this survey.