

Proposals for new health services for coeliac patients in Somerset

Have Your Say



Your feedback will be used by Somerset Clinical Commissioning Group in considering additional services for coeliac patients.

Introduction

Somerset Clinical Commissioning Group is seeking the views of patients with coeliac disease, staff, and partner organisations on service improvements and additional new services that you believe should be provided to support patients in the diagnosis, treatment, and on-going monitoring of coeliac disease. Your feedback will be used to inform decisions on the services to be provided across Somerset for patients with coeliac disease.

If you would like more information on coeliac disease, please see the attached fact sheet.

The consultation starts on 9 September 2013 and will close on 23 October 2013.

During the consultation period, we will also be meeting with partner organisations and community groups to seek feedback on the proposals.

Completing the feedback form

For each question please tick clearly inside the box. Don't worry if you make a mistake, simply cross out the mistake and put a tick in the correct box.

Your response to this questionnaire is anonymous unless you choose to give us your name and address. We do ask that you provide some simple information about yourself and your interest in this new service.

Please forward completed feedback form to:

Please send us your comments by post or email to the address below.

Coeliac Disease Consultation
Ann Anderson
Director, Clinical Commissioning Development
Somerset Clinical Commissioning Group
Wynford House
Lufton Way
Yeovil
BA22 8HR

or email: ann.anderson@somersetccg.nhs.uk

An electronic version of the form can be downloaded from the Somerset Clinical Commissioning Group website at www.somersetccg.nhs.uk or be requested via the email above.

We would like to thank you for taking the time to give us your feedback. Your views and comments are really important and will help us ensure we provide services that are designed to meet patients' needs.

This document is available in other formats and languages by telephoning 01935 385020.

Thank you for your time

Proposals for new health services to support people in Somerset with coeliac disease

What support is currently available?

It is recommended that people with coeliac disease have their condition reviewed annually by a healthcare professional.

National guidelines suggest this annual review should include:

- A blood test, including those to check iron, vitamin b12 and folate levels
- Assessment of compliance with the gluten-free diet
- Assessment of symptoms (e.g. bowel function, weight loss etc)
- Assessment of and advice on how to manage the increased risk of osteoporosis

In Somerset, following a diagnosis of coeliac disease, patients are initially seen by the Gastroenterologist and a Dietitian based at the acute hospitals. However, the service offered for annual reviews is currently inconsistent, with some patients being reviewed by their Gastroenterologist, some their GP or a Dietitian or some not being reviewed at all.

Additional support for patients with coeliac disease is available via the 'Coeliac UK' website and telephone helpline. This UK leading charity for people affected by coeliac disease also runs a support group in West Somerset, however there is not currently one for the rest of the county.

Somerset Clinical Commissioning Group

Somerset Clinical Commissioning Group (CCG) is now authorised to take on statutory responsibility for commissioning NHS Services.

The purpose of Somerset CCG is to improve the experience of health and wellbeing of our local population:

- by fostering an environment that promotes people, families and communities taking responsibility for their own health and wellbeing and tackles inequalities
- by ensuring everyone can access integrated services which are flexible and responsive to their needs
- by commissioning services which deliver high quality, timely, efficient and cost effective care

In Somerset, the CCG wants resources to be used to the best effect to help people live healthier and longer lives.

Dietetic advice in Somerset is provided by hospital dietitians and dietitians in the community, through a referral from your GP.

Service proposals

The following new services and support are suggested for patients and are described in more detail below. We would like to know what you think will make having coeliac disease easier to deal with and, if you have any other ideas please add them in the box at the bottom of this section:

- Somerset based group education session to run twice a year by dietitians specialising in coeliac disease
- Annual assessment with community dietitian specialising in coeliac disease
- Local support groups to be run by volunteers
- Leaflet to provide information on gluten free foods available on prescription
- Information available via the internet, mobile phone apps, literature and Coeliac UK
- Improved training of health professionals including GPs and practice staff

Other services

When will new services be delivered?

Feedback information will be collated by Somerset CCG and new services for coeliac disease agreed.

The start dates of new services will be found on the Somerset CCG website.
www.somersetccg.nhs.uk

Have Your Say

Please can you answer the following questions:

1(a) Potential services for people with coeliac disease

Please rank the proposed services in order of your preference, first, second and third.

Service Proposals	Order of Preference
Somerset based group education session, twice a year, delivered by a specialist coeliac dietitian. Topics to be covered would include: update on gluten free foods, information on prescriptions, dietary advice, latest research, hot topics. Individual annual assessment would not be included as part of this service.	
Annual assessment with specialist coeliac community dietitian, which would include blood tests and assessment of symptoms via questionnaire, with tailored personalised advice, with a one-to-one appointment with the dietitian if required, and on-ward referral to the GP or Gastroenterologist if necessary.	
Continuation with the current model of care with some patients being reviewed by their Gastroenterologist and some patients being reviewed by their GP or a Dietitian but with some patients not receiving an annual review.	

1(b) Potential additional support for people with coeliac disease

Please rank the proposed developments for additional support in order of your preference, first second, third and so on.

Further information proposals	
Local support groups to be run by volunteers	
Leaflet to provide up-to-date information on gluten-free foods available on prescription	
Provision of supporting information which is freely available via the internet, mobile phone apps, printed literature and Coeliac UK	
Improved training of health professionals, including GPs and practice staff	

If you have any additional ideas for a service, please state them here.

2 Does anyone else in your family have a diagnosis of coeliac disease?

- Yes No Don't know

3 How old were you when you were diagnosed with coeliac disease? _____ years old

4 Did you experience any symptoms before your diagnosis of coeliac disease?

- Yes No

If yes, please tick all the symptoms you experienced:

- Diarrhoea
- Faltering/slow growth
- Persistent nausea and/or vomiting
- Feeling tired all the time
- Recurrent stomach pains, cramping or bloating
- Sudden or unexpected weight loss
- Iron-deficiency anaemia or unexplained anaemia
- Other (*please state*) _____

5 Were you previously diagnosed with irritable bowel syndrome before your diagnosis of coeliac disease?

- Yes No

6 How long did it take for you to be diagnosed with coeliac disease from first seeing a doctor about your symptoms?

- 1 month 1 – 6 months 6 - 12 months 1 – 3 years
 4 - 6 years 7 - 12 years 12+ years

7 How was your diagnosis of coeliac disease confirmed? (please tick all that apply)

- Antibody blood test
- Genetic blood test
- Endoscopy
- Biopsy

8 Do you feel you were provided with sufficient information about your condition that was easily understandable?

- Yes No

Any comments you would like to make about the information you received

9 Following your diagnosis of coeliac disease did you join Coeliac UK?

- Yes No

10 Are you currently a member of Coeliac UK?

- Yes No

11 Have you seen any healthcare professional for your coeliac disease in the last year?

- Yes No

If 'Yes' who have you seen? (*tick all that apply*)

- Dietitian
 Gastroenterology Consultant
 GP
 Nurse
 Other, please state who _____

12 It is recommended people with coeliac disease have a review of their condition every year. If annual reviews were offered, who would you prefer to complete that review?

- Specialist Coeliac Dietitian based in the community
 Specialist Coeliac Dietitian based in the hospital
 Gastroenterology Consultant based in the hospital
 GP
 Other, (*please state who*) _____

13 What form of annual review would you prefer? (please tick one option)

- Completion of simple questionnaire via post
 Completion of simple questionnaire via internet
 Telephone review
 Outpatient appointment in an Acute Hospital (i.e.: Yeovil District or Musgrove Park Hospitals)
 Outpatient appointment in Community Hospital
 Other, *please state* _____

14 Do you have a blood test annually for your coeliac disease?

- Yes No Don't know

15 Do you receive gluten-free products prescribed by your GP?

- Yes No

16 Are you aware of what gluten-free food prescriptions are available to you?

- Yes No

17 Please list the 5 gluten-free products you use most (including prescribable and non-prescribable)

- (1) _____
- (2) _____
- (3) _____
- (4) _____
- (5) _____

18 How easy do you find it to manage your diet?

- Easy Usually ok Not easy Difficult

Any additional comments

A Bit About you

Your response to this questionnaire is anonymous unless you choose to give us your name and address.

- Please indicate if you would like to receive a copy of the final engagement report and put in your name and address below.

Name _____

Address _____

_____ Postcode _____

We will keep your personal information held securely and use it to send you information about the results of your involvement and inform you of future involvement opportunities.

The final engagement report will be available on the Somerset Clinical Commissioning Group website.

Somerset CCG is committed to providing equal access to healthcare services to all members of the community. To achieve this, gathering the following information is essential and will help us ensure that we deliver the most effective and appropriate healthcare. There are some guidance notes on the next page. **Responding to these questions is entirely voluntary and any information provided will remain anonymous.**

What is your age? please write in the box below	<input type="checkbox"/> Prefer not to state
What is your gender?	<input type="checkbox"/> Prefer not to state
<input type="checkbox"/> Male <input type="checkbox"/> Female	
Do you/have you ever identified yourself as trans or transgender?	<input type="checkbox"/> Prefer not to state
<input type="checkbox"/> Yes <input type="checkbox"/> No	
What is your status?	<input type="checkbox"/> Prefer not to state
<input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Divorced	
<input type="checkbox"/> Widow(er) <input type="checkbox"/> Separated <input type="checkbox"/> Co-habiting (living together)	
<input type="checkbox"/> Civil partnership (same sex partnership) <input type="checkbox"/> Other	
Are you a carer? for a relative or friend	<input type="checkbox"/> Prefer not to state
<input type="checkbox"/> Yes <input type="checkbox"/> No	
Are you pregnant or have you had a baby in the last six months?	<input type="checkbox"/> Prefer not to state
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable	
Which of the following best describes how you think of yourself?	<input type="checkbox"/> Prefer not to state
<input type="checkbox"/> Heterosexual (attracted to the opposite sex) <input type="checkbox"/> Bisexual (attracted to both sexes)	
<input type="checkbox"/> Lesbian/Gay (attracted to the same sex) <input type="checkbox"/> Other	
Do you consider that you have a disability?	<input type="checkbox"/> Prefer not to state
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I don't know	
If yes, how would you describe your disability?	<input type="checkbox"/> Prefer not to state
<input type="checkbox"/> Sensory <input type="checkbox"/> Learning <input type="checkbox"/> Mental Health	
<input type="checkbox"/> Physical <input type="checkbox"/> Other _____	
Do you have a religion or belief?	<input type="checkbox"/> Prefer not to state
<input type="checkbox"/> Buddhism <input type="checkbox"/> Islam <input type="checkbox"/> No Religion	
<input type="checkbox"/> Christianity <input type="checkbox"/> Judaism <input type="checkbox"/> Other Religion/Belief _____	
<input type="checkbox"/> Hinduism <input type="checkbox"/> Sikhism	
What is your first language? please write in the box below	<input type="checkbox"/> Prefer not to state
Please tell us your ethnic group	<input type="checkbox"/> Prefer not to state
White <input type="checkbox"/> British <input type="checkbox"/> Irish	
<input type="checkbox"/> Gypsy, Romany or other traveller heritage	
<input type="checkbox"/> Any other White background, please state _____	
Dual-Heritage <input type="checkbox"/> White and Black Caribbean	
<input type="checkbox"/> White and Asian <input type="checkbox"/> White and Black African	
<input type="checkbox"/> Any other Dual-Heritage, please state _____	
Asian or Asian British <input type="checkbox"/> Indian <input type="checkbox"/> Pakistani	
<input type="checkbox"/> Bangladeshi	
<input type="checkbox"/> Any other Asian background, please state _____	
Black or Black British <input type="checkbox"/> Caribbean <input type="checkbox"/> African	
<input type="checkbox"/> Any other Black background, please state _____	
Chinese or other ethnic group <input type="checkbox"/> Chinese	
<input type="checkbox"/> Any other ethnic background, please state _____	

Guidance notes to help you complete the form

If there is any information that you do not want to provide just tick the box **Prefer not to state**

Do you/have you ever identified yourself as trans or transgender?

The process of transitioning from one gender to another. A person who is transgender is someone who expresses themselves in a different gender to the gender they were assigned at birth. Although legislation covers gender reassignment, for the purposes of analysis we adopt the term 'trans' to encompass the wider community.

What is your status?

Marriage is defined as a 'union between a man and a woman'. Same-sex couples can have their relationships legally recognised as 'civil partnerships'. Civil partners must be treated the same as married couples on a wide range of legal matters.

Are you a carer?

Carers provide care for anyone (such as a parent, child, other relative, an elderly person, friend or neighbour) who has any form of disability (sensory loss, physical, learning disability, mental health problem) long or terminal illness.

Which of the following best describes how you think of yourself?

Whether a person's sexual attraction is towards their own sex, the opposite sex or to both sexes.

Do you consider that you have a disability?

The Equality Act 2010 says that a person has a disability if they have a physical or mental impairment which has a long term and substantial adverse effect on their ability to carry out normal day to day activities. Physical or mental impairment includes sensory impairments such as those affecting sight or hearing.

Do you have a religion or belief?

Religion has the meaning usually given to it but belief includes religious and philosophical beliefs including lack of believe (such as atheism). Generally, a belief should affect your life choices or the way you live for it to be included in the definition.

Please tell us your ethnic group

Refers to the protected characteristic of race. It refers to a group of people defined by their race, colour and nationality (including citizenship), ethnic or national origins.

Fact Sheet on Coeliac Disease

What is coeliac disease?

Coeliac disease is a common digestive condition where a person has an adverse reaction to gluten. The body's immune system mistakes gluten (a protein found in wheat, barley and rye) as being harmful and attacks it. This causes damage to the lining of the gut so the body can not absorb the nutrients from food properly.

Coeliac disease is known as an 'autoimmune' condition as the body's immune system is attacking itself.

What are the symptoms of coeliac disease?

Symptoms of coeliac disease can vary from person to person, and can range from very mild to severe.

Possible symptoms may include:

- Diarrhoea and/or constipation
- Recurrent stomach pains or bloating
- Weight loss
- Tiredness
- Nutritional deficiencies, including iron, vitamin B12 or folic acid deficiency

Who gets coeliac disease?

Coeliac disease affects up to 1 in every 100 people in the UK, although only about 10-15% of people with the condition are clinically diagnosed.

Coeliac disease is more likely in those with type 1 diabetes (insulin-dependent) or with an under-active thyroid, osteoporosis, or ulcerative colitis. People with a close relative with the condition also have a 1 in 10 chance of developing coeliac disease.

Reported cases of coeliac disease are two to three times higher in women than men and can develop at any age, although symptoms are most likely to develop:

- during early childhood – between 8-12 months old
- in later adulthood – between the ages of 40 and 60 years

Some people with coeliac disease have few or no symptoms making it more difficult to diagnose. So many people may be walking around with the condition but not be aware of it. Currently, screening for coeliac disease is not routinely carried out in England. It is usually only recommended for people at an increased risk of developing the condition, such as those with a family history of the disease.

Coeliac UK research shows the average time it takes to be diagnosed is 13 years.

In Somerset there are currently 1,261 patients registered with coeliac disease out of a population of 550,000.

How is coeliac disease treated?

There is no cure for coeliac disease, however it can be treated effectively with a strict gluten free diet. When people with coeliac disease remove gluten from their diet, it allows their gut to heal and helps control symptoms and prevent long term consequences of the condition.

It is important to make sure the gluten-free diet is healthy and balanced. An increase in the range of available gluten-free foods in recent years has made it possible to eat both a healthy and varied gluten-free diet.

For further information on coeliac disease, visit the website of the UK's charity for coeliac disease 'Coeliac UK' at:

www.coeliac.org.uk

What is Coeliac UK?

Coeliac UK is the UK's leading charity for people affected by coeliac disease. Their website contains a range of useful resources, including information on gluten-free diets, specific products, and information on local groups, volunteering and ongoing campaigns.

The charity also has a telephone helpline on 0845 305 2060 (open Monday to Friday, 9am-5pm).

Whilst there is a support group in West Somerset there is not currently one for the rest of Somerset.

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