NHS
Royal United Hospitals Bath
NHS Foundation Trust

Looking after your Coeliac Disease in adult life

Coeliac disease is a life-long condition triggered by gluten in food. This leaflet is aimed at young people with coeliac disease who are leaving paediatric/children's coeliac services and moving to adult health services.

Why is it important to look after your coeliac disease?

Coeliac disease can cause a wide range of symptoms such as abdominal pain, vomiting, bloating, headaches and tiredness. If not managed carefully it can also lead to long-term complications such as anaemia, fertility issues, increased susceptibility to infections and poor bone health. There is also an increased risk of some cancers in untreated coeliac disease. The good news however is that a strict gluten-free diet prevents symptoms and also prevents the long-term complications.

The long-term care of coeliac disease:

- Keep to a strict gluten-free diet
- Have regular 'coeliac reviews / check-ups', including blood tests every 1-2 years
- See a dietitian if any dietary concerns, ongoing symptoms or blood test results that suggest problems with the gluten free diet or nutrition issues
- Take a vitamin D supplement during winter months
- Keep up to date with vaccinations
- Be aware of how family members can be tested

Following a strict gluten-free diet

It is really important to continue a strict gluten-free diet lifelong. Gluten is found in wheat, barley, rye and 'contaminated' oats. There is lots of information about following a gluten free diet, reading food labels etc. on the Coeliac UK website www.coeliac.org.uk. We recommend being a member of Coeliac UK to get sent updates and to access their gluten-free food directory and food app. There are also some excellent videos produced by dietitians from somerset which are worth checking: www.patientwebinars.co.uk.

You can also find lots of other websites and social media sites with gluten-free recipes, ideas about good places to eat out and new gluten-free products.
If any advice seems confusing or differs from what you have previously been told it is worth checking with Coeliac UK as they have very reliable information.

Keep registered with a GP:

In order to arrange any reviews, blood test or dietitian appointments you will need to stay registered with a GP and for them to be able to contact you.
Inform your GP surgery if your phone number or any other details change. Register with a new local GP surgery if you move house, move home for university or work etc. www.nhs.uk has information about how to find a GP surgery.

It is worth keeping any copies of any recent clinic letters from paediatric services about your coeliac disease to show if needed. Clinic letters from when you were under 16 will have been sent to your parent or carer so ask them to pass those to you.

How to organise a coeliac review or blood tests:

It is advised that all people with coeliac disease have a review with a health care professional every 1-2 years. This review may be with a GP, dietitian, a nurse or occasionally with a hospital specialist (gastroenterologist).

As an adult you are usually have to organise these appointments yourself. Contact your GP surgery by phone or online explaining you have coeliac disease and ask for your coeliac profile bloods to be done. After you have had these make sure someone gets back to you with the results and ask if there is anything you don't understand. As part of the check-up your weight should be checked, you can do at the GP surgery or at home or in pharmacies etc. If you are having any symptoms or problems you should ask for an appointment with a GP, nurse or dietitian to discuss this.

How to organise a dietitian appointment:

A review with a dietitian is advised if you have any concerns about your diet, if you are struggling to keep gluten free or if your blood tests show any potential issues. A review may also be helpful if you make changes to you diet such as becoming vegetarian, or have to exclude other foods because of allergies, or if you become pregnant. We would also suggest asking for a dietitian review if you have not seen a dietitian for many years as advice does change.

You can ask your GP surgery to refer you to a dietitian. Some community dietitian services allow you to self-refer online so check local websites to see if that is possible.

What are 'coeliac profile' blood tests?

It is advised that as part of a coeliac review/check-up that blood tests are sent every 1-2 years to check that the condition is under good control, that nutrition is optimal and there are no signs of complications. The tests usually done as part of a coeliac profile are:

TTG This is the main blood tests to monitor coeliac disease (full name 'IgA Tissue transglutaminase antibody'). If the level is increased this suggests that there has been gluten in the diet.

FBC (Full blood count): checks for anaemia as well as white cell levels which fight infection

Ferritin: A measure of iron stores in the body

Calcium or 'bone profile'; Checks calcium and other minerals

Vitamin D: Important for bone health but also lots of other body systems

Folate & B12: Vitamins that may not be absorbed as well if coeliac is not well controlled

Liver function tests: Occasionally coeliac disease can be linked to liver issues

+/- Thyroid function test: This may be done routinely or just if you have a known thyroid problem or symptoms

Vitamin D supplements and bone health:

It is advised that everyone in the UK takes a vitamin D supplement during the winter months (October to March). Vitamin D comes from food but also from sunlight on the skin. Vitamin D supplements are even more important for people with coeliac disease to regulate calcium in the body to maintain good bones, teeth and muscle health.

Vitamin D supplements can be bought in pharmacies, supermarkets and health food shops. Look for one containing 10micrograms (10µg) per day, either by itself or as part of a multivitamin.

Bone density (DXA) scans: In the past adults with coeliac were sometimes routinely advised to have bone scans. This is no longer felt to be needed. They are still used if there are specific reasons such as someone on long term steroid medicines or who has had a fracture due to possible bone density issues. Your GP would be able to discuss this further if needed.

Vaccinations and infections:

Coeliac disease can make it a bit harder to fight infections so it is recommended you keep up to date with any vaccinations offered. If you have missed any during childhood and would like catch-up vaccinations contact your GP to discuss arranging this.

If a gluten-free diet is not followed this can make your spleen, which is part of your immune system, not work properly to fight infections. A strict gluten-free diet keeps your spleen working well.

Family testing:

As coeliac disease runs in families it is suggested that close relatives of the person with coeliac disease are offered testing, even if they don't have obvious symptoms. Close relatives include brothers, sisters, parents and any children you may have in future. More distant relatives should be encouraged to have a test if they have any symptoms.

For family testing two blood tests are currently used; the TTG test, plus 'HLA DQ2/8' which is a type of genetic or tissue type test. The DQ2/8 test is used in testing family members to see who is at risk. It cannot be used to diagnose coeliac disease by itself as more than 40% of all people are HLA DQ2/8 positive. There is lots more information about family testing on the Coeliac UK website and there is an RUH leaflet.

These tests can be organised by the relative contacting their GP. It may be helpful for them to show information from Coeliac UK or the RUH family testing leaflet as not all GPs will be aware of the details about the tests currently recommended.

Where to get further Information

Coeliac UK: Lots of information about coeliac disease including diagnosis www.coeliac.org.uk

RUH leaflets about a wide range of conditions are on the RUH website. This includes further information about coeliac disease and testing for family members
www.ruh.nhs.uk/ChildrensLeaflets - or scan QR code

www.nhs.uk For information about vitamins, vaccinations, blood tests etc and also about NHS services including registering with a GP

www.patientwebinars.co.uk Information and webinars (videos) made by dietitians about coeliac and other conditions

This leaflet is intended to be used together with specific advice from a health professional. Please contact your GP, dietitian or nurse if you have any further questions or if you are worried.
If you are still under 18 and have been seen by the paediatric coeliac team at the RUH you can email for advice on ruh-tr.paediatriccoeliacteam@nhs.net.

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Please contact the Patient Support and Complaints Team (PSCT) if you require this leaflet in a different format or would like to feedback your experience of the hospital.

Email ruh-tr.psct@nhs.net or telephone 01225 825656.

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