

INFORMATION FOR PATIENTS

Living with coeliac disease

A guide for newly diagnosed patients

What is coeliac disease?

Coeliac disease (also spelled celiac disease in some countries) is a permanent, immune-mediated condition where your body has an abnormal reaction to gluten. Gluten is a protein found in wheat, barley, and rye.

When you eat foods containing gluten, your immune system mistakenly attacks the lining of your small intestine. This attack damages the small, finger-like projections called villi that line your intestine. These villi are essential for absorbing nutrients from food. When they become damaged and flattened, your body cannot properly absorb vitamins, minerals, and other nutrients, even if you're eating a healthy diet.

Common symptoms include:

- Diarrhoea or constipation
- Abdominal pain and bloating
- Weight loss
- Fatigue and weakness
- Anaemia (low iron levels)
- Bone problems (osteoporosis)
- Skin rash (dermatitis herpetiformis).

However, some people have few or no digestive symptoms. Coeliac disease can affect people of all ages and backgrounds, with nearly 1% of people affected by the condition globally.

How is coeliac disease managed?

There is no medication or cure for coeliac disease at present. The only effective treatment is following a strict, lifelong, gluten-free diet. This means completely avoiding all foods and drinks that contain wheat, barley, and rye. When you follow a gluten-free diet:

- Your symptoms will improve, usually within weeks.
- Your intestinal lining will begin to heal.
- Your risk of complications will decrease.
- Most people feel significantly better within a few months. However, it can take up to two years for your digestive system to heal completely, especially in adults.

How to follow a gluten-free diet:

Gluten is found in:

- Wheat (including varieties like spelt, kamut, semolina, durum, farina).
- Barley (including malt, malt extract, malt vinegar, brewer's yeast).
- Rye.
- Triticale (a cross between wheat and rye).

You must avoid all foods containing these grains and will need to check food levels carefully. Below are examples of common gluten containing foods. You should avoid these unless the product states that it is gluten free:

- Bread, bagels, rolls, and buns.
- Pasta.
- Cereals.
- Crackers, cookies, biscuits, cakes, pastries.
- Pizza and pies.
- Breaded or battered foods.
- Beer and ale.
- Soy sauce (unless gluten-free).
- Some soups and sauces (which may use wheat as a thickener).

Hidden sources of gluten

Be especially careful with:

- Processed meats (sausages and deli meats may contain fillers).
- Gravies and sauces.
- Salad dressings and marinades.
- Flavoured chips and snacks.
- Some medications and supplements.
- Communion wafers.
- Lipstick and lip balm.

Foods you can eat

Many foods are naturally gluten-free:

- All fresh fruits and vegetables.
- Fresh meat, poultry, and fish (un-breaded).
- Eggs.
- Plain dairy products (milk, cheese, yogurt).
- Nuts and seeds.

Gluten-free grains and starches

These foods are safe to eat:

- Rice (all types).

- Corn and cornmeal.
- Potatoes.
- Quinoa.
- Buckwheat.
- Millet.
- Sorghum.
- Amaranth.
- Beans and lentils.

Is it safe to eat oats?

Most people with coeliac disease can safely eat gluten-free (GF) certified oats, but they should be introduced slowly after your condition is stable. While oats do not contain gluten, they often suffer from cross-contamination with wheat or barley. A small number of people with coeliac disease are also sensitive to **avenin**, a protein in oats which is similar to gluten.

What monitoring and support is required?

- After diagnosis you will see a registered dietitian who specialises in coeliac disease to help plan your diet.
- You will need to have your coeliac antibodies (called anti-TTG antibodies) monitored to make sure that they return to normal on a gluten free diet. We usually do this six months after you start your diet as they can take some time to normalise.
- If either your TTG levels, or symptoms fail to normalise within a year, you will need a further review with the gastroenterology team. In most cases it means that your diet is not completely free of gluten, but in rare cases some people don't respond to the gluten free diet. In this event we will need to repeat the gastroscopy test, re-biopsy the bowel and re-assess your diet.
- Once your coeliac disease is controlled you will have regular follow-up appointments with your doctor (typically annually) to monitor your antibodies, monitor symptoms, and check for nutritional deficiencies.
- We will arrange screening for bone density to make sure you do not need treatment for osteoporosis.

Further sources of information

NHS Choices: www.nhs.uk/conditions

Our website: www.sfh-tr.nhs.uk

Coeliac UK: www.coeliac.org.uk

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service:

King's Mill Hospital: 01623 672222

Newark Hospital: 01636 685692

Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

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