

# Coeliac Disease – Moving on to self-management

Information for young people

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## Looking after yourself

You are moving out of the Children and Young People's Coeliac follow-up service. This leaflet gives you advice to help you to look after yourself as a young adult. It covers:

- What to look out for
- Gluten-free food prescription service
- Pharmacy-led reviews
- Vaccinations
- Calcium and vitamin D
- Pregnancy
- Living on your own
- Sharing a room/flat/house
- Alcohol
- Travel
- Coeliac testing for family members.

## What to look out for

Coeliac disease is a condition you have for life. It needs you to follow a strict gluten-free diet. As you become an adult, it is important to keep looking after your health.

**If you notice any new or unusual problems, ask for help.** People with coeliac disease have a small but increased risk of other autoimmune conditions:

See your GP if you:

- are more tired than usual (possible iron deficiency or thyroid disease)
- are peeing more often, are thirsty, and have lost weight (possible diabetes)
- have changes to your poo e.g. ongoing loose watery poo, blood in poo, pale poos (possible pancreatitis, inflammatory bowel disease).

GP practices do not usually offer a routine annual follow-up and blood tests. It is very important to get advice if you are concerned.

## How do I get gluten free food on prescription?

As an adult, you can get gluten-free food prescriptions once a month via your local pharmacy. The table below shows you how many units you can have each month:

Child 15 – 18 years	18 units
Male 19 – 59 years	18 units
Male 60 – 74 years	16 units
Male 75 years or older	14 units
Female 19 – 74 years	14 units
Female 75 years or older	12 units
Female who is breastfeeding	4 units extra
Female in 3rd trimester of pregnancy	1 unit extra

Visit the NHS Inform website for more information about the gluten-free food service. Use the link, web address or scan the QR code: [www.nhsinform.scot/care-support-and-rights/nhs-services/pharmacy/gluten-free-food-service/](http://www.nhsinform.scot/care-support-and-rights/nhs-services/pharmacy/gluten-free-food-service/)

To scan the QR code:

- Open the camera on your mobile phone or tablet
- Point it at the QR code
- Tap the web link that pops up.



If you move outside Scotland, ask your local GP if gluten-free food services are available.

## How are pharmacy-led reviews done?

You can get a yearly check-up from your pharmacy because you have coeliac disease. This helps find and deal with any problems that may arise.

You can use this service even if you do not get gluten-free food on prescription. You could set a reminder once a year on your calendar or phone so you remember to book your review.

## What vaccinations do I need?

People with coeliac disease should get:

- All routine UK vaccinations
- A flu vaccine each year (if eligible) - for more details go to: [www.nhs.uk/vaccinations/flu-vaccine/](http://www.nhs.uk/vaccinations/flu-vaccine/)



If you got the pneumococcal vaccine as an infant, you do not need any more doses until you are 65. Then you will be offered a booster. Speak to your GP to make sure your vaccinations are up to date.

## How do I look after my bone health?

### Calcium

People with coeliac disease are at increased risk of fragile bones (osteoporosis). Sticking to a gluten-free diet helps your body to absorb calcium and protects your bones.

Adults should aim for **1000–1500mg calcium per day from food**. Good sources of calcium include:

- Dairy products like milk, cheese and yoghurt
- Calcium fortified non-dairy products e.g. soya/almond milk or soya/coconut yoghurts
- Fortified gluten-free bread
- Broccoli and green leafy vegetables
- Oranges
- Fish with soft bones you can eat e.g. sardines.

Check food labels to see how much calcium is in each food. It will show the amount per 100g and per portion.

For more information go to this website or scan the QR code below:

[www.bda.uk.com/resource/calcium.html](http://www.bda.uk.com/resource/calcium.html)



### Vitamin D

Vitamin D helps your body absorb calcium.

The body creates vitamin D from direct sunlight on the skin when outdoors from April to September, try to get 10-15 minutes a day but always remember to cover up or protect your skin if you're out in the sun for long periods to reduce the risk of skin damage and skin cancer.

There is only a small amount of vitamin D in food. Some foods that have vitamin D are:

- oily fish e.g. salmon, sardines, trout, herring or mackerel
- eggs
- red meat
- fortified spreads and gluten free cereals.

People with coeliac disease should take **10 micrograms (400 IU) of vitamin D every day**. This should be all year round. You can take this as a tablet, spray, or gummy. If you find daily vitamins hard to remember, you can take a once-a-week dose instead. A once weekly dose would be 70-75 micrograms (2800-3000 IU) of vitamin D, taken once per week.

## What if I plan to become pregnant?

If you plan to become pregnant, it is important to manage your coeliac disease well with a strict gluten-free diet. This helps your fertility and the chance of a healthy pregnancy.

Women with coeliac disease should take **5mg of prescribed folic acid every day** at these times:

- The 12 weeks before becoming pregnant and
- The first 12 weeks of pregnancy.

This higher dose helps protect the baby's spine and brain. Speak to your GP to arrange a prescription of folic acid.

## What tips are there for living on my own?

Living on your own needs confidence in managing your condition. Here are some tips to help:

- Plan your shopping lists and meals each week
- Order your own gluten-free prescriptions
- Practise gluten-free cooking
- Learn to check food labels carefully
- Practice speaking to restaurant staff about gluten-free options, this will help you feel more confident
- Register with a new GP as soon as possible if you move out with your home town.

## What tips are there for sharing a room/flat/house?

If you move into shared housing, **tell your housemates about your coeliac disease**. Let them know that even small amounts of gluten can make you unwell. Here are some tips:

- Store gluten-free food away from foods that contain gluten
- Use containers for open foods in shared fridges
- Choose meals that are naturally gluten-free when cooking together
- Ask accommodation staff (e.g. university halls) for things like a separate cupboard or toaster.

## Can I drink alcohol when I am 18 years old?

Many alcoholic drinks are gluten-free. These include:

- cider
- wine
- most spirits
- gluten-free beer.



Check labels carefully, especially for flavoured spirits or pre-mixed drinks. **Stay within safe drinking limits**. Plan ahead to make sure you can have gluten-free food if you are out.

More information: [www.coeliac.org.uk/living-with-coeliac-disease/food-and-drink/food-and-drink-information/alcohol/](http://www.coeliac.org.uk/living-with-coeliac-disease/food-and-drink/food-and-drink-information/alcohol/)

## How do I plan for travelling?

Planning ahead is key:

- Find out about restaurants that cater for coeliacs
- Bring gluten-free snacks for travel days
- Consider self-catering properties
- Use gluten-free travel cards in the local language to explain your dietary needs
- Inform your travel insurance provider that you have coeliac disease.

## What about other people in my family?

**Close relatives (parents, siblings, children) have a higher risk of coeliac disease.** The National Institute for Health and Care Excellence (NICE) recommends they are offered testing. The test only tells them if they have coeliac disease at that point in time. They may develop it later in life.

Children are not born with coeliac disease, but they may develop it once they start eating gluten. Speak to your GP if anyone in your family needs testing.

**Managing coeliac disease as an adult can feel overwhelming at first but with the right information and support, you can lead a full and healthy life.**

**Speak to your GP or pharmacist if you need support or have concerns.**

### It's OK to Ask

When you understand what's going on with your health, you can make better decisions around your care and treatment.

[www.nhsinform.scot/campaigns/its-ok-to-ask/](http://www.nhsinform.scot/campaigns/its-ok-to-ask/)



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## Useful websites

<p><b>Coeliac UK - Moving on Pack</b> can be ordered online using the website below. This pack is designed for young people over 18 who are moving out of the family home, going travelling, heading to university, or starting a new job.</p> <p><a href="http://www.coeliac.org.uk/living-with-coeliac-disease/children-and-young-people/moving-on-pack-form/">www.coeliac.org.uk/living-with-coeliac-disease/children-and-young-people/moving-on-pack-form/</a></p>	
<p><b>Coeliac Disease – NHS</b></p> <p><a href="http://www.nhs.uk/conditions/coeliac-disease">www.nhs.uk/conditions/coeliac-disease</a></p>	
<p><b>Coeliac UK</b></p> <p><a href="http://www.coeliac.org.uk">www.coeliac.org.uk</a></p>	
<p><b>NHS Inform Gluten Free Diet</b></p> <p><a href="http://www.nhsinform.scot/healthy-living/food-and-nutrition/special-diets/gluten-free-diet">www.nhsinform.scot/healthy-living/food-and-nutrition/special-diets/gluten-free-diet</a></p>	
<p><b>NHS Inform Gluten Free Food Service</b></p> <p><a href="http://www.nhsinform.scot/care-support-and-rights/nhs-services/pharmacy/gluten-free-food-service/">www.nhsinform.scot/care-support-and-rights/nhs-services/pharmacy/gluten-free-food-service/</a></p>	
<p><b>GUTs (Gluten Free Under Thirties)</b></p> <p><a href="http://www.facebook.com/coeliacUKguts">www.facebook.com/coeliacUKguts</a></p>	