Royal United Hospitals Bath
NHS Foundation Trust

Support for Families and Young people with Coeliac Disease

It can be difficult for young people to accept their diagnosis, especially if diagnosed during their teenage years. It is important to know that you are not alone.

Gather as much information as you can to help you make sense of the diagnosis. We recommend joining Coeliac UK.

See this page on Coeliac UK:

- https://www.coeliac.org.uk/information-and-support/coeliac-disease/once-diagnosed/

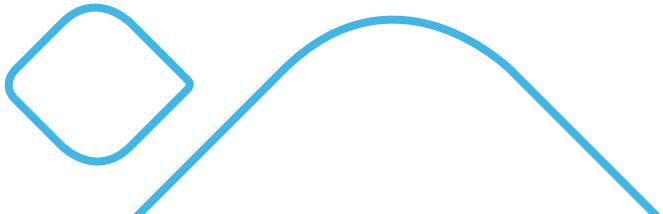
Here are some suggestions to help you:

Educate yourself and stay informed

1. **Understand the diet:**
   - Learn to identify gluten in foods, which is found in unexpected places like some sausages, soups, and sauces, and check all food labels.
   - Learn about gluten-free products:
   - Explore your local supermarkets and online for a wide range of gluten-free options.

2. **Focus on the positive:**
   - Remember that a strict gluten-free diet can lead to significant health improvements and symptom relief.

3. **Connect with a community (more information below)**
   - **Find local or online groups:** Join a support group to connect with others who can share tips, recipes, and support for living gluten-free.
   - **Talk to others:** Speaking with someone who has already gone through the process can be very helpful for emotional support and practical advice.



4. **Manage your health long-term**

- **Stay positive:** Recognise that although it can be challenging at first, coeliac disease is a manageable condition.
- **Stay in control:** You are in control of your health, and the more you understand and manage your condition, the better you will feel.
- **Request follow-ups:** Ask about a follow-up appointment to ensure you are managing well.

Signposting

Videos

- **Coeliac UK YouTube channel: https://www.youtube.com/@UKcoeliac**

  On the channel there are plenty of videos with explanations, and patient stories which will be helpful to hear.

- **About support groups and how they can help:** https://youtu.be/8VlNnovfJvc?si=hyIvantVcaVcfFOQ
- **For younger children:** Operation Ouch videos: https://youtu.be/Ag0Y_7zPDxc?si=bncTHbtyxOgcN8pT

Connecting with communities

- Teen Online Clubs meet up 4 times a year, more information here: https://www.coeliac.org.uk/information-and-support/living-gluten-free/teen-virtual-club/
- Facebook groups may be helpful: search Coeliac Disease UK on Facebook
- Follow Coeliac UK on Facebook, Instagram, X for social media accounts https://www.coeliac.org.uk/get-involved/join-our-community/our-social-community/
- Make contact with social media ambassadors and reach out to see if there are groups for you to join
- There may be local groups you could join in person. https://www.coeliac.org.uk/local-groups/ https://www.coeliac.org.uk/local-groups/somerset/

How to contact the team if you have any concerns or questions:

Please e-mail: ruh-tr.paediatriccoeliacteam@nhs.net

There are other leaflets including about family testing on the RUH website www.ruh.nhs.uk/ChildrensLeaflets - or scan the QR code

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If you would like this leaflet in email form, large print, braille or another language, please contact the Patient Support and Complaints team on 01225 825656.

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