

YORK LOCAL GROUP

Newsletter February 2023

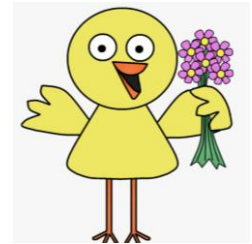


Welcome to our latest newsletter

A note from your Newsletter editor:

I hope you are all well and had a good Christmas and New Year.

In the last newsletter I remarked that gluten-free food prices seemed to be increasing more steeply than other foods. Now a report from the Allergy Group has been published saying the same thing. See page 5 for more on this. As ever, I welcome any comments or experiences relating to this for the next newsletter.



Our next coffee morning is on Monday 6th March at the Theatre Royal café in York. See page 7 for further details.

Please send any items for inclusion in future newsletters to york@coeliac.org.uk

Best wishes, Sue

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Being Coeliac: the Early Days

This is a fascinating story from one of our members.

My name is Adrienne Bailey and I was born on the 12th January 1944.

Nine months after I was born, I was admitted into Cell Barnes hospital in St Albans. My weight was 6lb 7ozs. We had a doctor from Barts Hospital who came to study us. I was kept in hospital for the next 18 months but, after a while, I was allowed to go home at weekends. While in hospital I had an incision under my left arm where I was fed intravenously. I still have quite a large scar to this day. I was also given a blood transfusion into my right ankle. At this time my father was serving in the Royal Air Force in Canada. He managed to arrange, via his commanding officer, for bananas and dried deer meat to be sent via the RAF. My mother told me that the green bananas were hung around the ward until they went black. We were not allowed to eat them until they were black.

There were six children in my ward and we stayed in touch with one of them but she ended up having a hump in her back, possibly due to bone density problems. I was lucky because I only ended up with a swollen tummy, which is part of life of being a coeliac. When I was seven, my mom was told I was OK even though I was still having diarrhoea and feeling tired all the time. The coeliac condition was not recognised again for years even through my three pregnancies.

In 1974 I was living in Huntingdon, Cambridgeshire when I became a patient of Dr Haslem. I was telling him I was tired and had tummy trouble and that I had previously been diagnosed as a coeliac when I was a baby. He was very surprised that I was not on a gluten free diet. He told me to stop eating my normal diet for two weeks then eat normally for the following two weeks. I also had several medical tests.

I was then referred to a consultant in Peterborough who specialised in the coeliac condition. He carried out tests which confirmed that I was indeed coeliac. I have been on a gluten free diet ever since. It was quite hard being on the intolerance diet for three weeks before I was allowed to introduce gradually one new food, to identify which foods had side effects. Over time I learned which foods to avoid and ended up with fairly normal diet substituting gluten free ingredients for non-gluten free ones. From this time onwards my health improved apart from the occasional problems. I sometimes have problems when I get stressed but now my problems are quite rare.

At this time I was getting bread in large metal tins and rice cakes which didn't taste very nice. I did take the rice cakes back because they tasted like polystyrene. It is amazing how the range, availability and quality of gluten free foods has improved. Gluten free food would never have been available in the supermarkets in the early days.

Restaurants can be a problem. When we go to restaurants, they get suspicious when we say "Can you ask the chef?" A good establishment will have a gluten free or allergy menu. When we find a good restaurant, we use it regularly.

Finding the Coeliac group in York has been helpful because the group has already checked out the local establishments for gluten free suitability, so we have found some lovely new places to go.

Coeliac UK News

Cost of Living with Coeliac Disease

We have had a significant response from our members about the increasing difficulty in affording gluten free items during this cost-of-living crisis. We know from previous research that bread and flour can be three to four times as expensive - even more so for budget loaves. For this reason, we continue to work with policy makers and our commercial partners to raise awareness of the challenges facing the community and urge them to use the resources at their disposal to better support the coeliac community. This is a key priority for us going forward and our Evidence and Policy team are currently undertaking a project looking at cost in more detail.

Our team have been collecting prices since March 2022. This has involved searching for products across all major supermarkets' websites and comparing gluten free and gluten containing loaves of bread, staples and a full food shopping basket across time. We have had the help of some brilliant volunteers who have assisted with collecting data of substitute items.

The hope is to be able to better evidence the impact of cost over time and how the cost-of-living crisis might be adversely affecting the coeliac community in particular. We plan to publish the report soon and will be sharing this with policy makers and commercial partners. This will underpin campaign work on the issue through 2023. While the evidence we are collecting is really important, your personal stories show the day-to-day difficulties you contend with and the urgency of this issue.

We know it may be difficult to share your personal story, but if you would be happy to share your experiences with our community, please let us know. Please contact publications@coeliac.org.uk

[See also the separate newsletter item about the Allergy Group report on prices of foods]

Celebrating 10 years of commitment to gluten free food safety!

2023 will mark the 10-year anniversary of the Coeliac UK Gluten Free accreditation scheme and we'll be celebrating this major milestone starting in February! Keep your eyes peeled on our website and social media channels for further details.

Coeliac UK News *(continued)*

New app launch!

We are excited to announce that our new Coeliac UK Live Well Gluten Free app is now live! We've combined our award-winning Gluten Free Food Checker and Gluten Free on the Move apps into one all-purpose app to make your gluten free life easier.

If you already have our award-winning apps, you don't need to do anything; your existing app will automatically switch over and you'll just need to look out for the new Coeliac UK app icon on your device screen. To make sure your dietary preferences are up to date, simply log in and update them if required.

Our app is an essential part of the membership package and provides you with peace of mind when shopping and eating out gluten free. It ensures you are fully informed about ingredients in thousands of food and drink items while our dietary filters mean product choices are tailored especially for you. The venue guide – containing over 3,000 venues accredited by us – lets you enjoy socialising while prioritising your health.

Check out all the valuable features:

- Product scanner featuring over 150,000 products
- Set your dietary preferences (gluten, plus other key allergens) – to ensure your product search results are tailored to you
- Over 3,000 Coeliac UK GF Accredited venues plus thousands more recommended by our community

2023 will see further improvements and the launch of many new and exciting features that we know you'll love.

If you're a member and you haven't already downloaded the app, you can find it in the Apple App Store for iOS devices or the Google Play Store for Android devices.

Please note that the existing Gluten Free on the Move app will remain working until the end of March 2023 but we suggest you start using the new app for all venue searches straight away.

Launch of All Party Parliamentary Group on Coeliac Disease and DH (APPG)

The All-Party Parliamentary Group on Coeliac Disease and DH is a special interest group in Parliament in Westminster which MPs and Peers can join. It allows a forum for issues affecting people with coeliac disease to be discussed.

Chaired by Sharron Hodgson MP, the group will bring together politicians from across the political spectrum to investigate, discuss and drive policy change around coeliac disease. An initial meeting was held on 26 October 2022.

In June 2022, Coeliac UK lobbied the Government to set up this group, and will take on the role of Secretariat, supporting the group to set the agenda and provide crucial evidence to support its work. The APPG will be pursuing an inquiry into the condition, calling on expert witnesses on a range of challenges facing the community.

Cost of living with food allergies "becoming unbearable"

Excerpts from BBC News item 29 Jan 2023

Food prices are rising for families across the country. But for some, the costs are even higher. Families with restricted diets are now paying up to 73% more for their supermarket shop than those who do not need to buy "free from" products, according to analysis by **The Allergy Team**, the online community supporting people with food allergies. The team tracked average basket values of common family foods such as bread, pasta, milk and cheese, and their alternatives. It found that gluten-free penne pasta at Morrisons jumped by 125% in 12 months, from 60p in January 2022 to £1.35 this month.

Food allergy affects between 3 and 6% of children in the developed world, according to the British Society for Allergy & Clinical Immunology (BSACI). In the UK, an estimated two million people are living with a diagnosed food allergy, and 600,000 with coeliac disease. In December, the Food Standards Agency found that households with food hypersensitivity - food allergy, intolerance and coeliac disease - spent an extra 14p for every pound compared to those who didn't need to buy alternative and "free from" products.

Shouldering the rising cost of these foods is "becoming unbearable" for many families, according to Sarah Knight, The Allergy Team's founder, who has two children with severe allergies. "When your supermarket shop is already so costly, increases in food prices hit families living with food allergy even harder," she told the BBC. "I don't have any choice but to buy more expensive 'free from' foods for my family. For my children it's a matter of life or death."

'May contain' labelling

Current labelling practices restrict choice for these families even further, she added, saying: "'May contain' statements don't show a true reflection of the ingredients included and are more helpful to the manufacturer than to the allergic consumer. "The sheer scale of the problem merits a meaningful revision of food labelling to open up food choices beyond the 'free from' fixtures for many families."

Why are "free from" products more expensive?

It mainly comes down to the strict production processes. The claim "free from" should only be used following a rigorous assessment of the ingredients, process and environment, according to guidance from the Food and Drink Federation. "Free from" producers also cater to smaller markets, and are less likely to be able to benefit from economies of scale.

The Allergy Team report is at <https://theallergyteam.com/the-financial-and-caring-burden-of-living-with-food-allergy/>

Gluten free experience on MSC Red Sea Cruise

We had read mixed reviews of MSC Cruises but we really wanted to visit Petra in Jordan and the pyramids in Egypt. This cruise took us from Genoa, down the Italian coast, two ports in Greece and through the Suez Canal and several Red Sea ports.

Our ship, the Splendida was indeed splendid! I loved everything about the ship, not least the food! They have a separate kitchen to prepare gluten free meals and the menus were extensive. Of the thirteen days, we were on board, there was never the same menu twice. There was always a choice of three or four starters, five or six main courses and a choice of cheese, fruit or cake and sometimes ice cream. You could have all of them if you wanted!!

I had to eat in the two main restaurants and not the buffet. Despite trying to get my husband and our friends to eat in the buffet while I went alone to the restaurant, they would not hear of it, as they loved the service and friendliness of the waiters in the restaurants.

Not all MSC ships have a separate kitchen for gluten free food preparation so do check if you are thinking of booking with them. We have booked to go to the Fjords in May on MSC Virtuosa so I can report back to let you know how that experience compares.

Linda Deadman

Review of post-Christmas lunch at Cote restaurant, York

A small but cheery group of us met at Cote for a relaxed and sociable lunch on 22nd January. Most of us had not met each other before, but by the end of the meal were great chums! Cote has a separate gluten free menu, with plenty of choices. Even the Muggles among us chose most of their courses from this menu, with the Normandy belly pork (£17.95) and the crème brûlée (£6.95) both proving very popular. The service was excellent, unhurried, polite but engaged, and the staff were obviously well trained in coeliac awareness. We would definitely recommend Cote for a treat!

Forthcoming events

Coffee mornings

Our next coffee mornings are as follows, all starting at 10am.

- Mon 6th March Theatre Royal café, York
- Tues 4th April Waterfront café, Naburn Marina
- Mon 1st May Bar Convent café, Blossom Street, York

We look forward to a coffee and a natter with you. No need to let us know whether you are coming, just turn up.

Gluten-free Afternoon Tea at Ashfield's restaurant, York College on Thursday 9th March 1pm

This can run if we can guarantee a minimum of 20 bookings. The fee is £12.00 per person, payable on the day. The food will be produced by the College's Level 2 patisserie and confectionery students. Please complete the form at the end of this newsletter to confirm your interest **by Wednesday 1st March**

Cocktail and food pairing evening meal at Ashfield's restaurant, York College on Thursday 11th May

The menu for this is being prepared, and we shall send out details as soon as they are available. The fee will be £28.00 per person, and advance payment will not be necessary. Ashfield's cannot offer exclusivity of the restaurant that evening but if we can confirm a minimum of 25 guests, then the manager would close bookings to others and would tailor the menu to gluten free options. For this reason, would you please complete the form at the end of this newsletter to confirm your interest **by Sunday 30th April**

Heads-up about a Children's Event on 1st July 12pm

We shall send more details and a booking form for this in the next newsletter (out in May). But this is a heads-up so you can keep the date in your diary.

We have booked a Ninja Warrior Party at the Agility indoor fitness park which is at Millfield Lane, Poppleton (almost opposite Manor CoE Academy). This consists of one hour (exclusive to us) on the obstacle course and 45 minutes in the party room. They provide a coach who takes the participants through the obstacles. Food is provided in the party room and this will all be gluten-free. Our one hour on the obstacle course starts at 12.15 pm, but all participants must be there by 12 noon for a briefing and for waivers to be signed.

We have booked for 10 to start with, but can increase this if there is further interest. The cost is £18.95 per participant, but the Coeliac Group committee has agreed to subsidise this, and we are only asking participants to pay £10 each.

Recommendations

Chris and Hazel who were at the Cote meal recommended this fish restaurant very highly: **Walkers Fish Restaurant** at East Ayton near Scarborough
<https://walkersfishrestaurant.co.uk/>

Namasdough gluten free bread and cakes made in York

A new bakery has been set up in York producing gluten free items, as well as items for other food allergies. I have tried the sourdough bread and liked it. Some items from the bakery are available at the Greengrocer of Acomb on Front Street. Maddie who runs the bakery single-handed is still working on the website, but you can see a list of items (including a wonderful Swedish Kallebrod) at <https://namasdough.co.uk/>

Brass Castle Brewery, 10A Yorkersgate, Malton

David Crawford writes: While walking near Malton with a group of friends, I visited the Taphouse of the Brass Castle Brewery at 10A Yorkersgate. All of the beer brewed is gluten-free and vegan. However, I should just point out that the company's website states that although all the beers are brewed to gluten-free recipes, only the Brass Castle canned beers and Hoptical Illusion in casks or kegs are laboratory tested and certified gluten-free.

Please let Sue have any recommendations for the next newsletter. I'd particularly like to know if anyone has used the Kelly's Food for You home delivery service:

<https://www.kellysfoodforyou.com/gluten-free>

Voluntary donations

We would be extremely grateful for a voluntary donation to the local group's funds, so that we can continue to provide events and other items like this newsletter. Our recommendation is for £5 per subscriber, but any amount would be very welcome. Coeliac UK are changing the way we bank, and we shall now be charged £5 a month. So your donations will be even more important than usual.

You can donate in either of the following ways:

1. Online via BACS or by going into your Branch and giving them the following BACS details:

Bank Account: Coeliac UK-York

Sort Code 30-94-28

Account No 63201060

quoting **Donation 2023** as reference

2. Send a cheque made payable to: **Coeliac UK – York** to: Lynda Moody, 13 Sandstock Road, Heworth, York YO31 1HB

Many thanks

Booking request forms for events at Ashfield's restaurant, York College

Gluten-free Afternoon Tea at Ashfield's restaurant, York College on Thursday 9th March 1pm

I wish to attend this event.

Name:

Number of participants:

Please send these details to Lynda Moody in one of the following ways:

- By sending this form by post (see address below)
- By emailing Lynda at lyndamgf@icloud.com
- By phoning Lynda at 01904 341866

Please could you let Lynda know by Wednesday 1st March

Cocktail and food pairing evening meal at Ashfield's restaurant, York College on Thursday 11th May

I wish to attend this event.

Name:

Number of participants:

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- By sending this form by post (see address below)
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- By phoning Lynda at 01904 341866

Please could you let Lynda know by Sunday 30th April

Lynda Moody's address is **13 Sandstock Road, Heworth, York YO31 1HB**