

SECTION 3:

RAISING

AWARENESS



RAISING AWARENESS FOR COELIAC UK

Please note that this section should be read in conjunction with the Policy: Representing The Local Group.

Raising awareness in your local group

Compared to the tinned bread of the 1970s, awareness of coeliac disease has increased tremendously in the last few decades – in no small part due to the fantastic work of our members and volunteers. However, problems remain around diagnosis, routine care, eating out and maintaining a healthy and affordable diet. Even today only one in eight people with the condition are diagnosed – leaving over 500,000 people in the UK who have coeliac disease but don't know it.

In order to meet the charity's mission to see a world full of choice for people with coeliac disease and dermatitis herpetiformis we need to make sure everybody knows what the condition is and how to treat it. After all, the more people talking about a specific topic, issue or concern the more seriously it is taken. As such we encourage all local groups to play an active role in raising awareness in their local area.

Raising awareness focuses on educating the public about:

- coeliac disease
- dermatitis herpetiformis
- the symptoms
- how to get diagnosed
- post diagnosis care
- the gluten free diet
- catering for people with the condition
- common obstacles faced by people living on the gluten free diet.

And there are a huge number of ways through which this can be done:

1. Holding a stand

Holding a stand allows you to talk directly with the public. You can answer individual questions, raise the issues you feel most strongly about, hand out leaflets and point people to additional support eg their GP or the Coeliac UK Helpline. Popular locations for local group stands include:

- hospital foyers / receptions
- supermarkets
- farmers' markets
- summer fetes
- food fairs.

2. Giving a talk

Confident public speakers may wish to link up with other local organisations, charities, local support groups or schools and give a talk. Not only is this a great way to raise awareness to a large audience but it can also work well with fundraising projects eg asking a school to host a mufti day on behalf of your local group. Talks should focus on your own personal experience, the work of your local group and, if fundraising, what you will do with the money raised.

3. Engaging with non members

Making your events open to the public or hosting specific public events aimed at non members can widen the reach of your local group. There are a number of ways you can do this:

- host a coffee morning in your local supermarket café, open to all shoppers
- host a "bring a friend" meeting encouraging members to bring somebody new
- organise a healthcare professional event, specifically inviting GPs, dietitians and pharmacists to attend an informal social where they can talk to (and learn from) members.

4. Displaying posters and distributing leaflets

Simple but effective, a poster highlighting symptoms linked to coeliac disease in your GP waiting room may be all it takes for somebody to open a discussion with their GP about unresolved symptoms. Similarly, A5 leaflets on the counter at your local pharmacy will do the same.

We have a selection of posters available at Coeliac UK or if you are creative, why not make your own? Just make sure you comply with our Brand Guidelines.

Liaising with the local media

No matter the event, let your local paper or radio station know. Ask them to advertise your upcoming events and meetings and send them a summary afterwards (ideally with photos). They probably won't feature all of your events but for every event they do feature, you get to highlight your activities and the condition to a new audience.

Top tips when raising awareness

1. Preparation is everything

- choose three key topics in advance that you wish to discuss
- keep your message short and succinct
- write some simple notes to help jog your memory and keep you on topic
- rehearse what you are going to say so you feel confident
- do your homework, for example if you are handing out samples from a company make sure you are confident with the ingredients and know basic facts about the company.

2. Keep to what you know is true

- share your own story and personal experiences or those of friends, family and members of the local group
- not only will you be more confident of the subject matter but it also prevents speculation, exaggeration and hearsay
- personal stories also help people relate to the topic keeping their interest

- avoid using jargon, keep to simple language
- become familiar with the Charity's key messages
- refer to the Coeliac UK Key Facts and Standard Responses found under Supporting Documents
- don't give medical advice instead refer people to their GP, pharmacist or dietitian
- remember to give contact details including your email address, the Coeliac UK website and the Coeliac UK helpline number.

Representing others

When raising awareness you are speaking on behalf of:

- yourself
- the local group committee
- members in your area who actively engage with the local group.

You are not speaking on behalf of Coeliac UK or Coeliac UK members in general.

Whilst we are happy for you to create your own posters and information, you are not to use the Coeliac UK logo on such materials – please use your own local group logo instead.

Campaigning

The charity has an active campaign schedule to help us meet our ambitious targets aimed at improving diagnosis, eating out and good food, found more easily.

There are three ways that Coeliac UK engages with local groups on campaigning:

1. Awareness Week

Every year Coeliac UK sets aside one week focused specifically on raising awareness amongst the public, healthcare professionals and the media. Local groups automatically get sent an Awareness Raising information pack filled with tools and ideas to help you make a difference. Make sure Awareness Week is featured in your local group's plan of events.

2. The Campaign Network

The Campaign Network is the route through which the charity engages those most passionate about making a difference. Through regular updates and calls for action, we keep those on the Network informed and actively involved with our campaigning opportunities across the year. Committee members can join the Campaign Network as individuals or as representatives of their local group. To join the Campaign Network email volunteering@coeliac.org.uk.

3. Ad hoc campaigns in your area

Every now and then our campaigns focus on a specific community or region. In such cases we work closely with local groups to ensure:

- the committee is up to date with the nuances and developments in the campaign
- committee members are able to take part in meetings and consultations when possible
- members are consulted and their views reach the people who matter most.

Campaigning with Coeliac UK means you will:

- be informed of the key messages, statistics and recent findings
- be told of the companies, organisations and other charities we are working with
- have an understanding of the history of the campaign and our specific aims for each year
- benefit from the tools and supporting materials we create alongside each and every campaign
- be supported by the Charity's Policy, Research and Campaigns Team
- have the backing of Coeliac UK in all you do.

Any other campaigning activity which you wish to engage with can only be carried out with the agreement and support of Coeliac UK. For more information on raising awareness and campaigning please refer to the **Representing the Local Group Policy**