



For Support Group Coordinators

Information Pack



# Introduction

## Welcome to the Coeliac Society of Ireland

Founded by volunteers, the Coeliac Society of Ireland (CSI) is the national charity providing support and information for people who are diagnosed with coeliac disease. We're here to help.

Our mission is to:

- improve the quality of life for coeliacs
- raise awareness of the disease and it's symptoms
- ensuring coeliacs have information and support to live a healthy life

The majority of funding is received through membership fees and product sales. As such the Society is run by and for our members.

Members are not limited to just Coeliacs themselves but include:

- Those on gluten-free diets for related conditions and other health reasons
- Family members
- Health professionals (GPs, hospital physicians, health nurses, dieticians, pharmacists)
- Gluten-free businesses (manufacturers, retailers and hospitality including restaurants, cafés, caterers)
- Gluten-free food provision (hospitals and care homes, schools, work canteens).

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## About this Information Pack...

This pack is designed to empower you to create your local community Coeliac Support Group. Local support groups are a great way to meet with fellow coeliacs; to share experiences and gain support in living a gluten-free lifestyle. Staff at the Coeliac Society are always glad to help with any questions you may have.



# Coeliac Support Group

## Why Create a Support Group?

On first diagnosis you may feel shocked and overwhelmed, with more questions than answers.  
What do I do now?  
Where can I get information?  
How do I explain my disease to family and friends?

You may feel lonely in your diagnosis, uninformed or just need some advice on living your new gluten free life to the full.

Support Groups can help you:  
o Identify and meet coeliacs in your area. There's no badge of honour so who knows how many coeliacs are in your neighbourhood!  
o Share recommendations of

local restaurants and stores catering for gluten free diets  
o Share recipes & experience of the latest gluten-free foods on the market  
o Offer peer support, especially to newly diagnosed coeliacs or those struggling with the gluten-free diet  
o Improve awareness of coeliac disease at a community and wider level.

## A Note on Membership

Support Group Coordinators must be members of the Society.

Membership ensures that you are receiving the most current information on living with coeliac disease and that you are running your group with the full support of the Society.

To help us to develop services and to continue to operate why not recommend membership to coeliacs you encounter.

The Coeliac Society of Ireland is 76% self-funded, with membership and fundraising essential for continuing provision of support, information and advocacy work on behalf of all coeliacs in Ireland.

# Getting Started

## Getting Started

Each support group needs two coordinators. This is for practical reasons; it ensures the group can keep meeting even if one coordinator is on holiday etc. Your Community Coordinator can help you find an interested member in your locality, if needed.  
**Email: [community@coeliac.ie](mailto:community@coeliac.ie).**

## Growing your Support Group

The most effective way to develop and grow your support group is by holding events as well as meetings. We suggest a minimum of 3 or 4 seasonal events per annum, such as:

- Meetings in local venues (pub, coffee shop, supermarket coffee dock)
- Doctor/ Dietetic talks
- Cookery Demos
- Coffee mornings
- Barbeques
- Christmas lunches
- Meals out in venues that cater for the gluten-free diet

## Steps to organising your first meeting



Find a venue (Hotel, Coffee Shop, Restaurant, local hall or sports club). Low cost or preferably free of charge.



The Coeliac Society of Ireland Office will promote your events online.



The Society will send an email to existing members in the

local area to notify them of forthcoming events.



You can promote your event via local notices, i.e. supermarket notice boards, library, local papers & radio, use of posters and word of mouth



Provide a list of suggested topics for discussion e.g. tips for eating out, gluten free Christmas/ holiday/ Halloween tips.

## REMEMBER:

let the Society help spread the word!  
Email: [info@coeliac.ie](mailto:info@coeliac.ie)  
with details of your event 3 weeks in advance.

# Growing Your Support Group

## Contacting Manufacturers

***Please do not contact the manufacturers directly.***

The Coeliac Society has built up business relationships with many gluten free manufacturers. We work with businesses on long-term plans to ensure sustainability. The society will therefore act as the only contact with these manufacturers.

If you would like to arrange for a manufacturer to attend your support group meeting/event contact Community Co-ordinator at **community@coeliac.ie**

## Managing the Finances of your Support Group

The support group is self-funded. This means that profit realised from self-funded events, are retained by your group.

Coeliac Society of Ireland adheres to the Governance Code for charitable organisations and also the Statement of Guiding Principles for Fundraising.

Support groups need to keep proper financial records. Records are maintained for easy handover should a coordinator step down. The Community Coordinator is here to assist you with this

process. You will need to submit quarterly income & expenditure reports for the attention of the Finance Manager in the CSI's office. In this way accurate records are maintained. This also makes for an easy handover process should a coordinator need to step down.

In the future, as your support group grows, there may be need for a bank account. The Society will provide any assistance required with this process. However, consider if this is necessary as bank charges will be incurred.

## Our Commitment to Support Group Coordinators

The Coeliac Society will provide support or advice in the following areas:

- Information and support for the financial running of the group
- Advice on running group events
- Support with promoting or advertising group events
- A dedicated Community Coordinator

# Let us Know, We're here for you!

## Tell the Coeliac Society About Your Event

When running events it is essential that staff at the CSI office are informed in good time. That way, we can provide support and help promote your event to a wider audience.

The Society can inform members of events and meetings through the following channels:-



Email newsletter  
- Coeliac News Online



Website [www.coeliac.ie](http://www.coeliac.ie)  
- latest news & events section



Members' Forum on website  
- <http://coeliac.ie/webboards/>



Facebook and Twitter  
- [www.facebook.com/CoeliacSocIreland](http://www.facebook.com/CoeliacSocIreland)

We can also assist you in creating a press release for local media – radio, press and community noticeboards. (see sample)

### Sample Press Release:

#### PRESS RELEASE

Date goes here

HEADLINE SHOULD GO HERE

Sub-heading, if necessary, to go here

**First paragraph** – should only be approximately five to six lines long and should include the details on what you are doing, who will be there (and who it is targeted at – children, adults, third-level), when it is being held (time, day, date), where the event is being hosted and finally why it is being hosted.

**Second paragraph** – should highlight one key newsworthy area i.e. what the event will actually entail. Details of the areas to be spoken about or demonstrated, and key news angles of the event.

**Third paragraph** – focussing on additional details such as secondary details of the event (is it one-off or will it take place a number of times?) and supporter details. Give some information on why this event is taking place: as part of our Coeliac Support Group we will be looking at using the Food List

**Fourth paragraph** – technical details: how people can come along to the event, when these will be available to book, whether the event is restricted in numbers.

#### For further information:

This section is for the journalist writing the story and should include your name, contact landline telephone number and mobile phone number if they should need to contact you.

**LET US KNOW!**  
Remember!  
Additional insurance cover may be required for larger events. Contact [community@coeliac.ie](mailto:community@coeliac.ie) for advice.

# Contact Details

## Our Address

Coeliac Society of Ireland  
Carmichael Centre, 4 Brunswick Street, Dublin 7

**Tel:** 01 872 1471

**Email:** [info@coeliac.ie](mailto:info@coeliac.ie)

**Website:** [www.coeliac.ie](http://www.coeliac.ie)

**Facebook:** [www.facebook.com/CoeliacSocIreland](http://www.facebook.com/CoeliacSocIreland)

**Twitter:** [www.twitter.com/CoeliacIreland](http://www.twitter.com/CoeliacIreland)