

## SCHOOL PACK

### Welcome

Welcome to your coeliac disease in school information pack. The aim of this pack is to provide you with information to allow your child's condition to be managed effectively in school. It includes information for you as a parent/carer, your child and for the school.

It is mainly aimed at primary school children in the state and independent sectors but it can also be used for children with coeliac disease in a secondary school setting.

Children's health can have a significant impact on their attainment and/or wellbeing but with the right arrangements in place, there's no reason why coeliac disease should impact on your child's experience at school.

This pack advises you on what you should expect from your child's school and things you can do to help ensure the right arrangements are in place for your child.

This pack contains:

- Care to expect at school
- Meeting with the school
- School meals
- School activities
- Resolving disagreements
- An information card (to print)

The Scottish Government recently produced guidance for schools and education authorities called Supporting Children and Young People with Healthcare Needs in Schools. While this is guidance rather than law, schools and education authorities are expected to follow it. In this pack, we draw attention to the parts of the Guidance that are relevant for children with coeliac disease. You may find it helpful to refer to this Guidance in discussions with the school.

The full guidance can be found at

[www.gov.scot/Publications/2017/12/3694/2](http://www.gov.scot/Publications/2017/12/3694/2)

### About Coeliac UK

Coeliac UK is the charity for people with coeliac disease and for anyone living without gluten. We carry out research, we campaign for a fairer deal, and we provide independent, trustworthy advice and support. And we do it all so that one day, no one's life will be limited by gluten. We will continue to put pressure on local authorities across Scotland to improve the school experience of children with coeliac disease and to improve the provision of safe and enjoyable gluten free school meals.

For more information about the charity and how we can help you, visit [www.coeliac.org.uk](http://www.coeliac.org.uk) or give us a call on 0333 332 2033.

## Care to expect at school

Children with coeliac disease should not be excluded from any activity at school, including school meals with their peers. Schools and caterers should work closely with parents to support children with medical conditions including food allergies and coeliac disease (which is an autoimmune condition not an allergy or an intolerance).

Head teachers, working with parents, are best placed to make decisions in the case of pupils who have special dietary requirements, taking into account local circumstances.

Scottish Government Guidance states:

**“Wherever possible, there should be forward planning and resourcing agreed between all partners - including parents - to meet the healthcare needs of their child, particularly in relation to reasonable adjustments that the child might need and require.”**

### Meeting with the school

If your child is at school and has recently been diagnosed with coeliac disease, or your child has coeliac disease and is about to start school, contact the Head Teacher to discuss how the condition will be managed in terms of their health and their social wellbeing.

Arranging a meeting with the school is a good way to ensure that everyone involved in the care of your child knows about their needs and the importance of a gluten free diet for your child.

At this meeting, you should expect a senior member of staff (Head Teacher or Deputy Head) to be in attendance along with the class teacher and also the school nurse (if the school has one).

The Scottish Government Guidance states:

**“Parents/carers should be allowed to work in partnership with their child, the school health team and school staff to reach an agreement about how their child’s needs will be met and the school should inform parents/carers of their right to participate in the decision-making process.”**

### Individual healthcare plan

At the meeting with the school, you should expect an Individual Healthcare Plan (IHP) for your child’s coeliac disease to be discussed and completed. This Plan puts in writing information about the condition, symptoms and the role the school should play in managing the condition.

At this meeting, you should discuss the healthcare needs of your child but also the importance of ensuring your child is socially included in class/school activities involving food.

In terms of healthcare, you should discuss with those present:

- What coeliac disease is and that as long as your child follows a strict gluten free diet they should not suffer

any symptoms (many schools will have or have had at least one pupil with coeliac disease).

- That coeliac disease is not contagious nor an allergy, emphasising that your child will not suffer a life threatening anaphylactic reaction if they eat gluten.
- What will happen if your child eats gluten by mistake so they are aware of what to expect. The most common symptoms include diarrhoea, nausea, vomiting, tummy ache and wind.
- What steps should be taken where a child is showing symptoms of a gluten reaction. This could be the school offering some treatment such as water to prevent dehydration or paracetamol for pain relief and/or contacting the parents to take the child home.
- That the reaction to eating gluten varies. Symptoms don’t tend to happen straight away; they can take hours or up to a couple of days to develop and can last several days, while other children might not get any symptoms.
- Which foods can be eaten and which foods need to be avoided – it may be useful to provide the school with a print out of this pack and the Gluten free Checklist which is available from the Coeliac UK website: [www.coeliac.org.uk/gfchecklist](http://www.coeliac.org.uk/gfchecklist).
- That young children may make mistakes or swap food with other children so it is vital that supervising staff are aware of the importance of a gluten free diet for children with coeliac disease.
- That if your child vomits or has diarrhoea in school time as a result of eating gluten, the 48-hour sickness rule of not returning to school should not apply as it is not the result of a contagious bug.

For the discussion on inclusion at this meeting, it is also important to make sure the Individual Healthcare Plan includes how it will deal with the social and educational element of being on a gluten free diet in a school setting so that your child is not excluded from any classroom or wider school based activity involving food. For example, class bake sales, school summer BBQ, class birthday celebrations, class/school parties. The most vital point to get across is for the school to commit to giving you, the parent, enough advance notice of upcoming food based activities so you can advise the school:

- a) What gluten free options are required so your child





- can take part and, where appropriate, offering to supply gluten free items.
- b) How to factor in the gluten free food safely to the activity so there is no risk of cross contamination with food containing gluten.
  - c) How to blend the gluten free items into the activity so the child is not made to feel different.

The Individual Healthcare Plan should be reviewed annually to allow for any information to be updated. This may involve a meeting or it may simply involve the Individual Healthcare Plan document being given to the parent to add in any new updates. In addition, every new teacher your child has should also be made aware of how the condition and gluten free diet is managed in school. It is worth meeting with the new teacher to discuss the Individual Healthcare Plan face to face and to answer any questions.

It is important the school views you the parent as a partner in the care of your child at school, working together to manage the condition. This is backed by Scottish Government Guidance.

**“The main purpose of the individual healthcare plan is to identify the level and type of support that is required to meet a child or young person’s healthcare needs at school. Where it is identified that an individual healthcare plan is required, the school health team should work with the school management team, parents/carers and the individual child or young people to draw it up.”**

The Individual Healthcare Plan will form the basis by which your child’s dietary, social and educational needs are catered for while at school and you should expect the school to abide by what is stated in the Plan. However, when you know there is a food based activity coming up, it is worth being prepared to remind the school of its responsibilities and/or offer assistance for ensuring the activity works for your child with coeliac disease (as some of those involved the delivery of that activity can sometimes forget to plan appropriately while others involved may not be aware of what’s in the Individual Healthcare Plan).

### School meals

Eating with friends is an important aspect of social development. While a packed lunch is always an option, children with coeliac disease should not be excluded

from having cooked school meals due to their diet and this especially applies to those in P1 to P3 who are entitled to a free school meal.

Ask the school via the Head Teacher or Office Administrator about how it can provide school meals for your child. You should expect this to result in a meeting between you and one of the local authority catering managers along with the school cook.

At this meeting, it will be outlined to you which parts of the menu are gluten free. It should also be outlined to you the kitchen procedures for minimising risks of cross contamination. The meeting should cover:

- Discussing adjustments to ingredients that could be made to the weekly menu to provide gluten free choices such as using gluten free stock to make soups and sauces.
- Discussing whether the local authority is willing to supply substitute GF items to replace gluten items in certain meals. For example, GF pasta, pastry or pizza will mean your child can have a meal that looks very similar to what other children are having. Where the Council cannot supply this, some parents may be willing to provide these GF substitute items themselves, and you may wish to ask whether this is an option at your child’s school.
- Discussing with the cook the importance of understanding the risks of cross contamination and that of other catering team members too.
- Discussing how the catering team understand how to read labels to help them identify whether a packaged food contains gluten or not. Information on reading labels can be found at [www.coeliac.org.uk/labels](http://www.coeliac.org.uk/labels).

You should leave this meeting with a clear outline of how the school menu can be adapted to accommodate your child’s GF diet. You should also leave this meeting feeling confident that the catering team understand what is required to provide a safe school meal for your child. If you do not feel happy and/or reassured by what you have heard then you are under no obligation to send your child for school meals. The decision is yours.

If you do decide to send your child for school meals, you are entitled to ask for further meetings with the school cook along with the local authority catering manager to review how things are going and particularly if you think your

child is being exposed to gluten. Also, it is not uncommon for school cooks to be replaced. Where this happens, you should request a meeting with the new cook and the local authority catering manager to discuss your child's dietary requirements.

It is also worth highlighting to the catering team helpful Coeliac UK resources:

- Coeliac UK's Gluten free Checklist, Guide to Common Grains and information available on the Coeliac UK website: [www.coeliac.org.uk/gfdiet](http://www.coeliac.org.uk/gfdiet).
- The Food Industry Professionals section of Coeliac UK's website is designed to help people to cater for those with coeliac disease and includes links to a catering training module. Ask the school catering team to take a look at [www.coeliac.org.uk/food](http://www.coeliac.org.uk/food).

The provision of school meals is the responsibility of each local authority in Scotland. Within each local authority area, the weekly menu is the same across all primary schools (and typically rotates on a three weekly cycle).

For information on school meal provision where you are, visit [www.gov.scot/Topics/Government/local-government/localg/usefullinks](http://www.gov.scot/Topics/Government/local-government/localg/usefullinks), click on your local authority area to access its website, then search for 'school meals'.

#### Case study: Fife Council

In 2016, Fife Council changed its menu for all primary school pupils to exclude gluten in dishes where it was not necessary such as in soups, stocks and sauces. It also changed other dishes to be gluten free where it was simple and cost-effective to do so such as burgers, sausages and fish fingers. It also provided each school cook with a stock of gluten free pasta to be used for pupils with coeliac disease when pasta dishes are on the menu.

The menu is now much more accessible for pupils with coeliac disease allowing them to share hot meals alongside their friends.

Coeliac UK is campaigning to make sure local authorities across Scotland provide a positive school meal experience for every pupil with coeliac disease.



## School Activities

### School trips

Children should not be excluded from school trips because they have coeliac disease.

If the school is providing the catering, speak to the child's teacher about how the school will provide gluten free options in a safe and inclusive way. Often school trips will simply require children to bring a packed lunch with them.

If the trip involves external caterers, ask to speak to the caterer direct or ask the school to provide you with details of how the caterer will provide safe, inclusive gluten free food for your child.

Scottish Government Guidance states:

**"Plans for school trips and other outdoor learning should take the healthcare needs of all children and young people into account from the outset. School staff may wish to work with children and young people with healthcare needs and their parents, who will have experience of taking their children on trips and outings."**

### Social fundraising activities

There are occasions when the class or school will have social activities that involve food. For example, some schools may allow children to bring in sweets or snacks for their birthdays or other celebrations. In other schools, teachers may give out sweets or snacks. It is worth asking the school what their policy on this is and, if need be, ensure the teacher has some gluten free alternatives to hand so that your child is included in such moments.

For other occasions, such as bake sales, school BBQ, and class/school parties, the Individual Healthcare Plan should outline the process for including your child e.g. that the school will give parents advance notice and discuss how best to make sure your child is included.

Scottish Government Guidance states:

**"Children and young people with healthcare needs should be encouraged to fully participate in class social and fundraising activities. Some of the activities are likely to involve food, such as charity bakes sales, which can bring potential risks to children with food allergies. Teachers should be aware of these allergies with the aim of eliminating the risk of children coming into contact with food they are allergic to when purchasing food for a special event such as a class Christmas party. School staff should also consider those healthcare needs when inviting pupils and/or parents to bring in home baking for class bake sales."**

### Cookery classes

Primary school children often make small cakes, cookies or other food dishes as part of the curriculum and with some forward planning there is no reason why your child cannot take part.

The Individual Healthcare Plan should ensure that the school flags up to you in advance when a cookery session is being planned. Discuss with the teacher what food is being planned and what adjustments can be made to include gluten free including the steps required to avoid cross-contamination. Discuss also how your child can take part in a way which is inclusive.

Top tips to avoid cross contamination:

- Keep utensils separate during preparation and cooking of gluten free food
- Don't fry gluten free food in the same oil as foods that contain gluten
- Use a clean grill pan
- Separate toaster or toaster bags when making gluten free toast
- Separate the preparation of gluten free foods from gluten containing foods.
- Use separate butter for gluten free use only

### Playtime

Some paints, crayons and glues can contain gluten but as gluten needs to be eaten to cause symptoms this should not be a problem for pupils with coeliac disease unless such items are accidentally eaten. As young children will often put things in their mouth, using materials made without gluten is a sensible option.

Preschool children will often make art and instruments with dried pasta (which contains gluten). As this may be tempting for small children, it is advisable to use gluten free pasta or supervise the child.

Play Doh™ is not always gluten free. However, it is easy to make play dough without using gluten. A gluten free recipe is available on the Coeliac UK website at [www.coeliac.org.uk/playdough](http://www.coeliac.org.uk/playdough).

### Resolving Disagreements

If your child gets glutened or is excluded from an activity, have a quiet word with the class teacher and/or head teacher and discuss how this can be avoided in the future. However, if your child is regularly being glutened, repeatedly being excluded, or the school continually fails to give advance notice to parents of scheduled food based activities, request a meeting with the class teacher and the Head Teacher to discuss why this is happening and agree corrective action. If this does not resolve matters, approach the chair of the PTA/Parent Council or, in some cases, school Governors for help. If neither of these things work, approach one of your local elected councillors that represent the school for assistance (they can be found on your local authority website).

Scottish Government Guidance states:

**“Where there are any concerns regarding the educational provision or support of children and young people with healthcare needs, the aim will be to resolve any disagreements as early and at as local a level as possible. Concerns should be raised with the school management team in the first instance but, children over 12 with capacity, young people and parents have the right to access**

**more formal processes of dispute resolution for issues related to additional support for learning and discrimination [such as mediation, independent adjudication or Tribunal].”**

## Educating others at school about coeliac disease and the gluten free diet

Coeliac UK has created a Young Champions pack which aims to give children the confidence to talk about their coeliac disease at school and extracurricular activities. Through raising awareness, we hope that your child's peers and their parents, teachers and leaders will gain a better understanding of the condition and become more aware of what life is like on a gluten free diet.

In this pack we have included lots of activities for children to do with their class, school, friends, family or community group, with supporting materials. As this is aimed at children aged 5 to 11, we have tried to include a mix of activities so there is something for all ages. Order your pack at [www.coeliac.org.uk/get-involved/youngchampions](http://www.coeliac.org.uk/get-involved/youngchampions).

## Further Information

You can find more information on a wealth of topics on the Coeliac UK website:

- About coeliac disease: [www.coeliac.org.uk/coeliac-disease](http://www.coeliac.org.uk/coeliac-disease)
- The gluten free diet: [www.coeliac.org.uk/gfdiet](http://www.coeliac.org.uk/gfdiet)
- Caring for children with coeliac disease: [www.coeliac.org.uk/children](http://www.coeliac.org.uk/children)
- Catering gluten free: [www.coeliac.org.uk/catering](http://www.coeliac.org.uk/catering)
- Coeliac UK training: [www.coeliac.org.uk/courses](http://www.coeliac.org.uk/courses)

## Information card

My name is:

I have coeliac disease. This means I can't eat wheat, rye, barley or oats.

I can eat fruit, vegetables, meat, fish, milk, eggs, cheese, rice, potatoes, pulses and nuts.

**coeliacuk**  
live well **gluten free**

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[www.coeliac.org.uk](http://www.coeliac.org.uk)