Dr Schär Institute

Coeliac Disease

Part of an education programme on coeliac disease and the gluten-free diet developed by **The Dr Schär Institute**

ROYAL PHARMACEUTICAL SOCIETY ACCREDITED 2012

Learning Unit 1 *for pharmacists*

Glutafin GLUTEN FREE

os gluten free

Learning Unit 1
Coeliac Disease *for Pharmacists*

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Contents

Section 1

Foreword

As a pharmacist you are no doubt asked by your customers about a wide range of medical conditions and for your professional advice. This learning unit focuses on coeliac disease and its management using a gluten-free diet and what you can do to help your customers. It has been developed to support you in providing your customers with valuable and accurate information about coeliac disease and for you to talk confidently about a gluten-free diet. Learning Unit 1: Coeliac disease can help you to meet the General Pharmaceutical Council requirement to undertake Continuing Professional Development (CPD) each year. This learning unit has been accredited by the Royal Pharmaceutical Society and it's successful completion can provide you with approximately 3.5 hours of CPD (please note this is for guidance only).

This learning unit is the first in a series of three and the full programme comprises:

Learning Unit 1 - Coeliac disease

Learning Unit 2 - Common health problems in coeliac disease

Learning Unit 3 - Diabetes and weight control in coeliac disease

Remember, many more cases of this disease are being recognised. Understanding the long-term needs of your customers with coeliac disease allows you to develop valuable customer loyalty and gives you an opportunity to provide an optimal service.

How to use this learning unit

This programme of three learning units is for pharmacists but there is also a parallel programme available for pharmacy technicians provided by the Dr Schär Institute.

Working your way through the unit will allow you to support your pharmacy technician(s) with their learning programme.

Learning Objectives

On completion of this module you will:

- Recognise the clinical presentation of coeliac disease and, where appropriate advise a customer to seek medical advice.
- Be aware of the nutritional needs of a person with coeliac disease.
- Appreciate the implications of following a gluten-free diet, and be aware of the resources available for healthcare professionals and customers with coeliac disease.
- Be able to guide customers in their selection of gluten-free foods and direct them to useful information sources.

Answers to the activities used in this learning unit are to be found on page 34.

Introduction

As a pharmacist you may be the first health professional who comes into contact with a customer who complains of unspecific gastrointestinal (GI) symptoms. For example, intermittent diarrhoea may be a complaint where customers seek your advice. You might be interested to know that many of the symptoms of undiagnosed coeliac disease are often misdiagnosed as irritable bowel syndrome (IBS). Particularly with coeliac disease diagnosed in later life both stool and bowel habit can be normal. In the absence of bowel symptoms other features of coeliac disease such as anaemia and tiredness are often attributed to other causes. One clinical study found that the commonest presenting feature of coeliac disease was anaemia and subsequently recommended that a test, which screens for coeliac disease, be one of the first line investigations of unexplained anaemia in the community[1]. Whatever symptoms your customers may consult you about it is an important role of the pharmacist to refer them on to their General Practitioner (GP).

People with coeliac disease are intolerant to gluten and the treatment is strict adherence to a gluten-free diet. Once diagnosed the person with coeliac disease needs to organise a regular prescription for gluten-free foods. The diet is for life and most people tend to use the same pharmacy for repeat prescriptions. The pharmacist who knows their customer and is knowledgeable about their clinical condition is able to offer informed advice and instil confidence and trust. At the time of diagnosis most customers will need advice about what gluten-free items are available on prescription of which there is a wide range. Gluten-free food prescription guidelines indicate appropriate quantities for different age groups and genders[2]. Supplementary prescribers may be involved in the adjustment of repeat prescriptions for gluten-free foods following the establishment of an initital prescription by an independent prescriber. In respect of diet, understanding the changes that your customer with coeliac disease may go through can help you to better appreciate their needs.

Stage 1. Newly diagnosed, hungry for information.

Stage 2. Trialing foods, finding out what they like/dislike.
Trying out recipes.

Stage 3. Conservative consumption – repeat prescription where order doesn't vary much, other than trial of new foods

Activity 1

a. Gluten-free foods are ACBS approved. Please provide 5 examples of foods available on prescription. (You can use an up to date copy of the Drug Tariff to help with this activity).

b. Consider a standard food product, how could you tell if it is gluten-free?

Notes

Section 2

Coeliac Disease

History

Derived from the Greek 'Koiliakos' coeliac literally means 'suffering of the bowels'. The condition was first documented by a Roman physician Aretaeus almost two thousand years ago. This physician observed that children with fatty diarrhoea, weight loss and who passed undigested food in their stools did not benefit from having bread in their diet. Bread was described as being a food 'rarely suitable'[3].

Just fifty years ago the harmful effect of certain cereal foods in coeliac disease was first recognised. During the Second World War, a Dutch paediatrician, Professor Dicke, noticed how children with coeliac disease paradoxically seemed to clinically improve during the time when wheat, rye and oat flours were almost unavailable. However, once hostilities ceased and food relief reached these children they relapsed and symptoms of the disease returned. In the 1950s Dicke continued his work in this area and showed that it was the protein component of wheat (gluten) that causes the symptoms of coeliac disease[4].

Definition

It is now known that coeliac disease is an autoimmune disorder, in which the ingestion of gluten, a protein found in wheat, rye and barley*, results in damage to the small intestine. It is a lifelong condition and can occur at any age in genetically-susceptible individuals. Immune-mediated damage to the small intestinal mucosa causes villous atrophy and consequently the individual has an impaired ability to digest and absorb nutrients from food adequately. This leads to malabsorption of essential nutrients such as calcium and iron[5]. Strict adherence to a gluten-free diet is the cornerstone of treatment and once diagnosed the person with coeliac disease needs to organise a regular prescription for gluten-free foods. Rice, potato and maize are naturally gluten free.

For further information on this please refer to Section 3 of this learning unit: What does following a gluten-free diet really mean?

Wheat contains gluten

Barley contains gluten

Maize is gluten-free

*** Oats contain a type of protein that is similar to gluten. Historically experts were not certain whether or not oats should be included in a gluten-free diet. However, the new European Regulation concerning the composition and labelling of foodstuffs suitable for individuals intolerant to gluten allows all foods which contain 20 parts per million (ppm) of gluten or less, the threshold level for the labelling term 'gluten free', to be labelled as 'gluten free'. This includes pure, uncontaminated oat products[6]. Those with coeliac disease should check with their gastroenterologist or dietitian for specific advice on oats.**

Epidemiology

The change in incidence (rate) figures in recent years and the wide variety of incidence figures seen throughout Europe may reflect differences in consumption of gluten-containing cereals, genetic factors and varying levels of awareness amongst doctors and other health professionals. In the UK, the estimated incidence of coeliac disease is thought to be 1 in 100 (1% of the general population) with most common age of diagnosis in people between the ages of 40-60 years of age[7].

Underdiagnosis of Coeliac Disease

Historically, coeliac disease was perceived as a disease of infancy and childhood and was thought to be relatively rare. However, approximately, 25% of newly-diagnosed cases of coeliac disease have been found to occur in adults over 60 years of age[8]. Interestingly, there is an equal prevalence of coeliac disease in both men and women, however the rate of confirmed diagnosis is thought to be two to three times more common in women[9]. This may be because women are more likely to have accessed healthcare before men, for example, a full blood count (revealing anaemia) checked routinely during pregnancy. In 2006, Coeliac UK, the national patient charity for people with coeliac disease and dermatitis herpetiformis, undertook a survey amongst 2,000 of its members. It found that on average it took 13 years to be diagnosed with coeliac disease and an average of 13 visits to the GP[10].

Whilst the estimated incidence of coeliac disease in the UK is 1 in 100 (1%) of the general population, only about 10-15% of people with the condition are currently diagnosed[8,11]. Whilst the improved and widespread availability of serological screening tests have contributed to the recognised increase in the prevalence of coeliac disease it is thought that it is a lack of awareness by healthcare professionals of the spectrum of clinical presentation which often contributes to delayed diagnosis.

Clinical Presentation of Coeliac Disease

The NICE Clinical Guideline on the Recognition and Assessment of Coeliac Disease, published in May 2009, recommends offering serological testing for coeliac disease to adults and children with any of the following signs or symptoms[11]:

- Chronic or intermittent diarrhoea
- Failure to thrive or faltering growth (in children)
- Persistent or unexplained gastrointestinal symptoms including nausea and vomiting
- Prolonged fatigue ("Tired all the time")
- Recurrent abdominal pain, cramping or distention
- Sudden or unexpected weight loss
- Unexplained iron-deficiency anaemia or other unspecified anaemia

This guideline recognises that increasingly the typical presentation of coeliac disease, for example malabsorption symptoms such as diarrhoea and weight loss, are less common. Conversely, the atypical symptoms of the condition, for example, anaemia and fatigue, are increasingly common.

As previously mentioned there are a number of conditions associated with coeliac disease. The NICE Clinical Guideline on Recognition and Assessment of Coeliac Disease recommends considering offering serological testing for coeliac disease to children and adults with any of the following[11]:

- Chronic or intermittent diarrhoea
- Amenorrhoea
- Apthous stomatitis (mouth ulcers)
- Autoimmune liver conditions
- Autoimmune myocarditis
- Chronic thrombocytopaenia purpura
- Dental enamel defects
- Depression or bipolar disorder
- Down's syndrome
- Epilepsy
- Low-trauma fracture
- Lymphoma
- Metabolic bone disease (such as rickets or osteomalacia)
- Microscopic colitis
- Persistent or unexplained constipation
- Persistently raised liver enzymes with unknown cause
- Polyneuropathy
- Recurrent miscarriage
- Reduced bone mineral density
- Sarcoidosis
- Sjorgen's syndrome
- Turner syndrome
- Unexplained alopecia
- Unexplained subfertility

Serological testing for coeliac disease should also be offered to adults and children with any of the following conditions:

- Autoimmune thyroid disease
- Dermatitis herpetiformis
- Irritable Bowel Syndrome (IBS)
- Type 1 diabetes

or

- First-degree relatives (parents, siblings or children) with coeliac disease

Activity 2

a. Based on the figure that there is 1 person with coeliac disease in every 100 of the UK population. Approximately how many people in your shop's catchment area could have coeliac disease?

b. How does this compare with the number of customers with coeliac disease you currently have?

Interestingly, a Coeliac UK survey undertaken amongst 1600 of its members in 2009 found that 60% were initially diagnosed with irritable bowel syndrome (IBS) prior to being diagnosed with coeliac disease[12]. As previously alluded to some people with coeliac disease may be asymptomatic despite having the characteristic gut damage. This is described as 'subclinical coeliac disease'. Many of these patients are only diagnosed as a result of screening programmes, for example, in family studies or when they have an associated condition such as Type 1 diabetes mellitus. There is evidence that coeliac disease has an increased prevalence (2-10%) in people with type 1 diabetes[11]. This subject will be covered in more depth in learning unit 3. Although not a dominantly inherited condition the prevalence increases in families where there is a history of this disease.

Approximately one in ten first-degree relatives (parents, siblings or children) of people with coeliac disease will be at risk of coeliac disease[11].

Diagnosis

Patients in whom coeliac disease is suspected should continue to consume gluten until investigations are undertaken in order to correctly diagnose the condition. Commencing a gluten free diet prior to testing is likely to yield a false negative result. There is little published evidence to suggest the quantity and duration of gluten exposure that would be necessary to produce an accurate result for a patient suspected of having coeliac disease but who has already implemented a self-imposed gluten free diet. Some experts recommend a formal gluten challenge should consist of 10g gluten/day (equating to approximately 4 slices of bread) for a minimum of 4-6 weeks[13]. Although necessary to make an accurate diagnosis, this suggestion is likely to be extremely unpopular amongst symptomatic individuals.

The IgA endomysial antibody (EMA) test has established its role in serological screening tests due to its specificity for coeliac disease, which is close to 100%. Its sensitivity is also approximately 90%. However, a negative result may be seen in 2% of people with coeliac disease, who have IgA deficiency. It is therefore important to request a total IgA level at the time of the EMA test. In the presence of IgA deficiency an IgG antibody screening test (IgG EMA or IgG tissue transglutaminase-tTG) should also be considered. Another problem with EMA is that it may not be positive if the degree of small bowel inflammation is less than total (i.e. partial or subtotal villous atrophy).

A more recent serological screening test is the enzyme-linked immunoassay (ELISA) for tissue transglutaminase (tTG), now recognised as the autoantigen for the EMA. IgG and IgA anti-tissue transglutaminase antibodies are highly sensitive markers and have been found to be present in 90% of patients with untreated coeliac disease.

Other patients may have a positive EMA and a negative tTG result. This may be explained by the differences in sensitivity of the serological tests or the fact that other proteins exist which influence anti-endomysium activity.

The sensitivity of both EMA and tTG is greater than 90%. However, the tTG is not as specific and positive results have been seen in patients who do not have coeliac disease. Many centres now use either EMA or tTG (with a total IgA level), or both. Some centres have a preference to use tTG first as it is a quantative assay, whilst EMA testing involves subjective interpretation of the test. These centres proceed to EMA testing if the tTG is positive and only then in the presence of a positive EMA do they consider a duodenal biopsy.

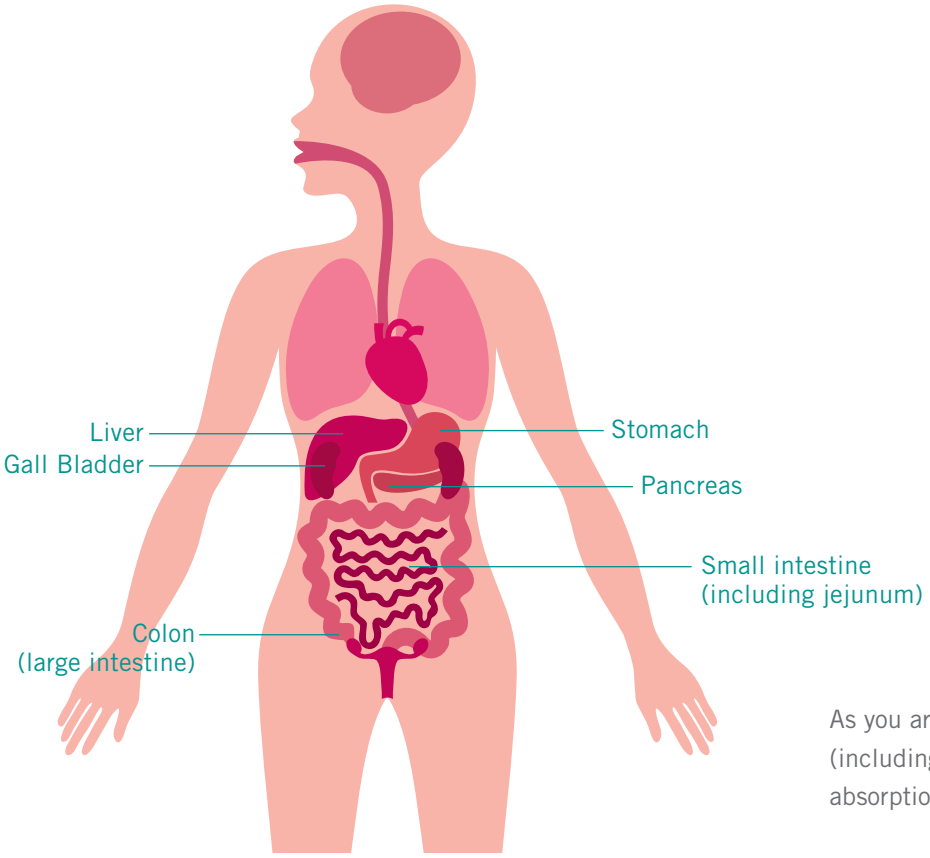
The NICE Clinical Guideline recommend laboratories should[11]:

- Use IgA tTG as the first choice test
- Use IgA EMA testing if the result of the tTg test is equivocal
- Check for IgA deficiency if the serology is negative (if the laboratory detects a low or very low optical density on IgA tTG test or low background on IgA EMA test)
- Use IgG tTG and/or IgG EMA serological tests for people with confirmed IgA deficiency

Small intestinal biopsy remains the gold standard diagnosis for confirmation of coeliac disease.

What changes are seen in the small intestine?

The cause of coeliac disease is not yet fully understood, however there is evidence to suggest that it is an autoimmune disease. Gluten acts as an antigen triggering damage to the small intestinal mucosa.

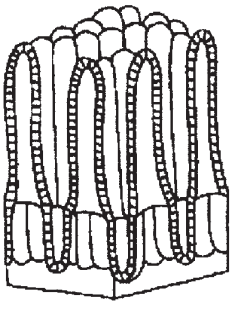


As you are aware the small intestine (including jejunum) is important in the absorption of nutrients into the circulation.

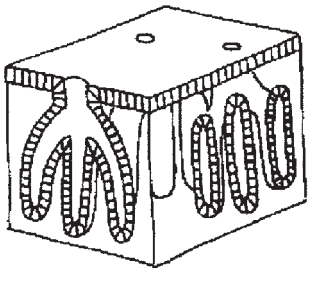
Rather than having finger-like projections, the surface of the mucosa is flat. In addition to villous atrophy other characteristic changes are seen, such as crypt hyperplasia and a raised intraepithelial lymphocyte count. The absorptive capacity of the small bowel is greatly reduced and patients can present with variable degrees of nutrient malabsorption. This in the long term can lead to overt nutritional deficiencies.

Intestinal Villi

Normal



Villi damaged by gluten



Histology of Villi

Normal

Villi damaged by gluten

Enzymes produced by cells on the surface of the mucosa or brush border such as disaccharridases and proteases complete the digestion of carbohydrate and protein, respectively, permitting their absorption throughout the villi. An example of this is lactase, the enzyme responsible for hydrolysing the milk sugar, lactose. Secondary lactose intolerance is often found in individuals with untreated coeliac disease due to the mucosal damage incurred. Individuals may well self-report an intolerance to lactose prior to the diagnosis of coeliac disease.

On diagnosis and treatment of coeliac disease, secondary lactose intolerance can resolve following reparation of the gut and subsequent production of lactase.

The jejunum is also the site for the absorption of fats, which have been emulsified by bile and broken down by pancreatic lipase. The small intestine is also important in the absorption of vitamins and many minerals (in particular calcium).

Activity 3

Having briefly reviewed the aetiology of coeliac disease, can you identify the causes of the presenting symptoms of this disease? Each symptom may have more than one of the following causes: ***Malabsorption, Decreased calcium absorption, anaemia.***

Symptom	Causative Factor
Fatigue	
Steatorrhea	
Weight loss	
Risk of osteoporosis	
Breathlessness	
Muscle wasting	
Short stature (children)	

Malignancy

Whilst recent population-based studies have shown that individuals with coeliac disease have a lower risk of gastrointestinal malignancy than previously thought, individuals still have a higher risk than the general population[14,15]. This risk has been demonstrated to fall as time from diagnosis increases, in those patients that are compliant with a gluten-free diet. One study demonstrated that adherence to a gluten-free diet over five years returned the risk for the individual (with adult coeliac disease) to that of the general population[14]. The fact that there is no reported increase in risk of malignancy in children diagnosed with coeliac disease may support these findings and suggests that early diagnosis may avoid this complication.

Although many gastrointestinal malignancies are reported, Non-Hodgkin's lymphoma and small bowel adenocarcinoma are particularly recognised as having an increased occurence in coeliac disease[15,17].

It is important to note that for those patients who are asymptomatic, or only experience mild symptoms, there may be less incentive to strictly adhere to a gluten-free diet than for those symptomatic patients who experience unpleasant symptoms very soon after ingesting gluten.

Patients with coeliac disease are at risk of developing a number of complications if they do not strictly adhere to a gluten-free diet. These complications are looked at in more detail in learning unit 2.

The diagnosis of a disorder requiring life-long treatment is a daunting prospect and it is important that support is available. Both newly-diagnosed patients and those who have lived with the condition for a number of years should be encouraged to talk to their GP, gastroenterologist, dietitian and pharmacist. They should be advised to join Coeliac UK and take advantage of the starter packs available from manufacturers of gluten-free foods. Pharmacists are well placed to assist patients in adhering to their gluten free diet through the provision of information, guidance on product choice and long term support.

Activity 4 Case Study

Introduction

Evelyn is a 63 year old lady and a regular customer at her local pharmacy. She has hypertension and is prescribed enalapril, atenolol and frusemide for hypertension. About 3 months ago she came into the shop and asked to speak to the pharmacist. Evelyn explained that for the past few months she had been feeling very tired and had experienced some abdominal pain and bloating. She also has noticed she has lost some weight but is unsure of how much. She asks the pharmacist for advice and something that might help her. The pharmacist suggests a visit to the GP who undertakes a tissue transglutaminase test. The results of the blood test are positive and strongly suggests a diagnosis of coeliac disease. Evelyn is the referred to the local gastroenterology clinic and a biopsy is taken of her small intestine, this confirms the diagnosis of coeliac disease.

Evelyn is informed that she will have to follow a gluten-free diet for life. Evelyn asks how rare her condition is as she hasn't heard of it before and not surprisingly she is very anxious.

Evelyn reappears in your shop to thank you for suggesting she sees the doctor, tells you her diagnosis and presents you with her prescription for gluten-free bread, pasta and crackers. The dietitian at the hospital not only advised her on following a gluten-free diet but told her she should put the weight she's lost back on once she is established on her diet, she looks quite frail. In addition Evelyn has o increase her intake of calcium as people with coeliac disease have an increased risk of developing osteoporosis and also have an increased daily calcium requirement compared with that of the general population.

Why do you think Evelyn is at risk of developing osteoporosis?

The dietitian also told Evelyn about Coeliac UK a support organisation. Evelyn is a 'Silver Surfer' (someone of more mature years who surfs the Internet) and she looked on the web site (www.coeliac.org.uk) and couldn't believe how much information there was.

Notes

Section 3

What does following a gluten-free diet really mean?

Dietary Management of Coeliac Disease

A gluten-free diet is the cornerstone of treatment. It is based on lifelong dietary exclusion of gluten, a protein found in wheat, rye and barley, as well as hybrids of these grains (e.g. kamut, tritcale), and possibly oats. A life-long gluten-free diet must be strictly and permanently adhered to in order for[18,19]:

- Improvement of associated symptoms and individuals health outcome
- Achievement of a nutritionally-balanced diet
- Promotion of growth and development in children
- Normalisation of gastrointestinal mucosa
- Reduction in the risk of associated long-term complications such as anaemia, osteopaenia, osteoporosis, infertility and malignancy

Once a gluten-free diet is commenced weight gain often occurs as the intestine begins to recover and absorption returns to normal (Weight control with coeliac disease will be covered in Learning Unit 3).

Following diagnosis, it is important that the patient is referred to a state-registered dietitian. The dietitian will outline what a gluten-free diet is and provide advice on how the patient can adapt their diet accordingly, based on individual needs and ensuring the diet is healthy and well balanced.

However, other factors also need to be considered and in order to reduce the risk of developing anaemia and osteoporosis there may be additional needs for other nutrients such as iron and calcium. Many of the foods avoided on a gluten-free diet provide dietary fibre. Fibre is important for bowel function and low intakes may result in constipation. Wholegrains, fruit and vegetables are sources of fibre and patients with coeliac disease need to ensure an adequate intake of fibre from their selection of gluten-free foods and fruit and vegetables. There are a number of staple prescribable gluten-free foods that are high in fibre and fortified with key nutrients such as calcium.

Do you know if your local medical centre/surgery has access to a dietitian?

Factors affecting nutritional status at diagnosis

- Degree of weight loss if more than 5% should be monitored and greater than 10% is significant and requires further investigation from a GP or dietitian.
- Degree of damage to the small intestinal lining.
- Dietary response to symptoms i.e. eating more in response to previous poor nutrient absorption (and consequent increase in appetite following recovery), or reducing the amount eaten to avoid bowel-related symptoms.
- Maintenance or reduction in the level of physical activity due to symptoms may affect nutritional intake and status.

Unintentional weight loss, despite having a healthy appetite, is an indicator of undernutrition. Normally weight loss in coeliac disease is temporary and, after following a gluten-free diet, customers regain their fat and muscle reserves and weight returns to normal. Some customers may not experience any loss of body weight and some may be overweight at diagnosis and weight should be monitored[20].

A recent study found that almost half of newly diagnosed coeliac patients were overweight or obese at diagnosis[21] .

This learning unit has broadly discussed the rationale for following a gluten-free diet. There is another medical condition whose treatment necessitates a gluten free diet for life - Dermatitis Herpetiformis. This disease presents as a patchy itchy blistering skin rash and usually occurs on the knees, elbows, buttocks and back but can affect any area of skin. Jejunal villous atrophy is present in about 80% of cases but these abnormalities tend to be milder than with coeliac disease. The condition is managed by a gluten-free diet and proprietary gluten-free foods are ACBS prescribable for dermatitis herpetiformis too.

This section will focus on what it means for your customers to follow a gluten-free diet. Perhaps the best way to find this out is to spend a few minutes talking with a customer who follows a gluten-free diet.

Activity 5

If possible we would like you to conduct a short interview with a customer who follows a gluten-free diet. If they are agreeable ask the customer some of these questions.

a. How long have you followed a gluten-free diet?

years

b. What gluten containing foods do you miss most?

c. What gluten-free items do you regularly order on prescription? (tick boxes)

Bread and rolls ☐ Bread mixes ☐ Flour ☐ Pastas ☐

Sweet biscuits ☐ Savoury crackers ☐ Pizza bases ☐

d. Do you buy non-presribable gluten-free items?

Regularly ☐ Occasionally ☐ Special occasions only ☐ Never ☐

b. What other problems do you still experience?

What is Gluten?

The dough-forming proteins found in cereals such as wheat, barley and rye are collectively known as 'gluten' and are known to be harmful to people with coeliac disease. These proteins are high in the amino acids proline and glutamine and these are collectively called the prolamins. The prolamins in various cereals are known by different names e.g. hordein in barley, secalin in rye, gliadin in wheat and avenin in oats. Gliadin is the most toxic and accounts for fifty percent of wheat proteins. As the protein fraction of wheat flour can be separated out, the remaining wheat starch can be used to make gluten-free breads and flour mixes. (see section below regarding codex wheat starch).

Gluten-free foods

Since many staple foods are excluded, some find it harder than others to adapt to their new diet. The gluten-free and nutrient-enriched products available act as substitutes for those containing gluten. Products for coeliac patients are available through the pharmacy and range from those on prescription such as fresh and part-baked breads and rolls, pasta, flour mixes and crackers to those not available on prescription such as luxury biscuits, cakes and seasonal items e.g. Christmas pudding or mince pies.

What is gluten free?

Individuals with coeliac disease are advised to strictly adhere to a gluten-free diet and, as a result, gluten-containing cereals such as wheat, rye, barley and possibly oats, have to be avoided. Naturally gluten-free cereals such as rice and maize can be included and there is a wide range of specially-manufactured gluten-free foods, some available on prescription, to replace many of the gluten-containing cereal foods that have to be excluded such as bread, pasta and biscuits. The Codex Alimentarius Commission, an international standard setting body in food and related areas, has a standard for gluten-free foods, which is looked at in more detail now. A knowledge of this standard is essential to any healthcare professional with an interest in coeliac disease.

Codex Alimentarius Standard for Gluten-Free Foods

Whilst the term 'gluten free' implies no gluten, in practice a zero level does not exist.

In 1981, the first useful standard for gluten-free foods came into force and outlined a threshold level of gluten which would be allowed in foods labelled as 'gluten free'[22]. Since then the standard has been revised as a knowledge of gluten intolerance and testing methods has improved. Around 1998 a threshold level of 200 parts per million (ppm) of gluten was introduced for foods labelled as 'gluten free'.

Then, in July 2008, following further debate around the threshold level, testing methods and a review of the scientific evidence, a new dual standard was adopted[6]. Two categories of food now exist which are suitable for people with an intolerance to gluten:

1) Foods containing 20ppm of gluten or less can be labelled as 'gluten free'
2) Foods containing between 21-100ppm gluten can be labelled as 'very low gluten' (in practice this term is rarely used by manufacturers)

Codex wheat starch

Codex wheat starch is a specially manufactured ingredient where the gluten has been removed from the wheat flour to a trace level, leaving behind the wheat starch. Codex wheat starch is used in some of the staple foods available on prescription, such as breads and flour mixes (e.g Glutafin Gluten Free **Select** products). It has been shown to help to improve the quality and texture of the products so that these products more closely resemble gluten-containing products which in turn helps improve adherence to the diet. These products are suitable for the majority of people with coeliac disease[23].

Following the latest change to the Codex standard and subsequent EC legislation, all foods containing Codex wheat starch which contain 20ppm of gluten or less can be labelled as 'gluten free'. At this level gluten-free foods containing Codex wheat starch should no longer cause a problem for patients with coeliac disease. However, sensitivity to gluten will vary and should be assessed on an individual basis.

Gluten-Free and Wheat-Free- what is the difference?

As an alternative to gluten-free foods, gluten-and wheat-free foods may be suitable for those who are not able to tolerate codex wheat starch. Gluten-free, wheat-free foods are made from naturally gluten-free ingredients such as maize and rice.(e.g Glutafin Gluten Free products).

Activity 6

Spend a few moments now to compare the label of a gluten-free food based on wheat starch and one made from naturally gluten-free ingredients such as maize, potato or rice. What clues on the packaging help you to distinguish the two? Next time you have a customer in the pharmacy who is not sure about the difference, it may help to point these features out to them.

Now take a moment to think about what you have eaten so far today. What would you have to exclude if you followed a gluten-free diet? (We will look at this in further detail in Activity 7). It would not just be bread, pastry, pasta, biscuits and cakes. It would also include soups and sauces thickened with flour as well as alcoholic drinks such as beer and lager made with grains that contain gluten. It is difficult to be sure of avoiding all gluten in the diet especially gluten 'hidden' in manufactured foods that is why Evelyn (the lady in our case study) finds 'The Gluten-Free Food and Drink Directory' such a valuable resource and it is one that is available to all members of Coeliac UK.

The table below gives some examples of the foods allowed and those to avoid when adhereing to a gluten-free diet.

	Foods allowed	Foods to avoid
Cereals and flours	Foods and breakfast cereals made from arrowroot, buckwheat, cornflour or maize flour, potato flour, rice and rice flour, sago, soya and soya flour and tapioca	Products containing wheat, whole-wheat and wheatmeal flours, bran, barley, rye,rye flour and pasta. Some vitamins and medicines contain flour as a filler
Baked foods	Gluten-free biscuits, bread, cakes, flour mix, pasta and crackers (manufactured by specialist food companies)	Foods containing wheat, rye, barley, oats, e.g. bread, pastry, cakes, ice cream wafers and cones
Dairy products and eggs	Milk, cream, most yoghurts, natural plain cheeses, eggs	Artificial cream and low-fat cheese spreads may contain gluten
Fats and oils	Butter, margarine, oil	Suet and some very low-fat spreads may contain gluten
Meat, fish and poultry	All fresh meat, fish and poultry	Savoury pies, puddings, stuffing, fish/poultry/other meat in breadcrumbs or batter. Ready-made meat dishes served with sauces, seasonings or marinades may contain gluten
Fruit, vegetables, nuts and pulses	All fruit and vegetables that are fresh, cooked, canned, dried or frozen	Vegetables that are canned in a sauce, e.g. creamed mushrooms may contain gluten

Eating for Health with Coeliac Disease

Once established on a gluten-free diet, a person with coeliac disease will be advised to follow healthy eating principles that are recommended for the UK population as a whole- the 'Eatwell' Plate.

Eatwell Plate

Use the eatwell plate to help you get the balance right. It shows how much of what you eat should come from each food group.

Source: Department of Health in association with the Welsh Government, the Scottish Government and the Food Standards Agency in Northern Ireland.

The 'Eatwell Plate' applies to patients with coeliac disease except that gluten-free alternatives are substituted for gluten containing staples.

Bread, pasta, rice, potatoes and other cereals	**This group forms the major source of starchy carbohydrate needed by the body to supply energy. It is important that a selection of food from this group is eaten and where possible high-fibre alternatives.**
Fruit and vegetables	**Five portions a day are recommended to optimise the intake of fibre, vitamins and minerals. A portion may be one piece of fruit e.g. an apple or banana, a small glass of unsweetened fruit juice or a small bowl of salad.**
Milk and dairy foods	**Three portions of milk or dairy foods daily (e.g. cheese or yoghurt) will contribute towards an adequate calcium intake. Remember people with coeliac disease may need extra calcium due to the risk of osteoporosis. If an adequate calcium intake cannot be achieved a calcium supplement may be considered. Low fat dairy foods are useful in weight control and are still good sources of calcium.**
Meat, fish and alternatives	**This group of foods contributes protein, iron and other minerals to the diet. Two or three portions a day of lean meat, skinless poultry and pulses are recommended.**
Foods containing fat, foods containing sugar	**These foods should be eaten in moderation i.e. chocolate, cream and butter.**

Oats in a gluten-free diet

There has been a long-term debate on the safety of inclusion of oats within a gluten-free diet, as mentioned earlier in this unit. To review why this has been the case it is useful to think about the difference between avenin, the prolamin found in oats, and the prolamins found in other gluten-containing cereals. Avenin has been shown to comprise a much smaller proportion of protein in oats than the prolamins in wheat, rye and barley[24]. Recent evidence from clinical studies has shown pure, uncontaminated oats may safely be included in a gluten-free diet for the majority[25,26]. Research has been undertaken in adult and paediatric individuals with coeliac disease, and those with dermatitis herpetiformis, to demonstrate the toxicity of oats to these patient groups. Results have indicated that the consumption of oats does not have an immunogenic or toxic effects on the small bowel mucosa[27,28]. Serological markers of coeliac disease (as a marker of compliance) have also been shown not to be affected by the inclusion of oats in an otherwise strict gluten-free diet[29].

There are a number of potential benefits of including oats in an otherwise cereal-restricted diet, particularly in countries in which many of the staple foods are based on gluten-containing foods, such as the UK.
Possible benefits include:

- Increase an individual's iron, soluble fibre, thiamin and zinc intake (intake of some of these nutrients may be restricted by a gluten-free diet)
- Increased palatability of a gluten-free diet
- Inclusion of oats would increase the variety of foods in a gluten-free diet, aiding compliance

The British Society of Gastroenterology makes the following recommendations regarding the inclusion of oats[13]:

- It may be helpful to exclude oats in the first six to twelve months of a gluten-free diet. Pure, uncontaminated oats (labelled as gluten free) may then be gradually introduced at a later stage.
- Monitoring patients who have introduced oats in to their diet (by repeating blood tests/ biopsies) is recommended, where symptoms appear to be exacerbated.

Patients should always discuss this issue with their gastroenterologist and dietitian before changing their diet.

As the customer with coeliac disease moves from being newly diagnosed to someone who has become more confident about their diet, many are keen to try out new foods and experiment with recipes. Baking cakes, biscuits and breads is popular but it should be remembered that handling and cooking with gluten-free foods is quite different from regular baking. Many manufacturers produce an extensive range of recipes including tips on bread making, cake making and pastry making. The availability and accessibility of proprietary food information and support groups means that patients with coeliac disease can live a normal life and ostensibly eat a ‘normal’ diet.

For our last activity we return to you recalling what you eat but this time the activity is a little more formalised. It will allow you to see what changes you would make to your diet if you had to follow a gluten-free regimen (the table shown on page 26 will be helpful).

Activity 7

Fill in the following food diary for a whole day. Enter the details of everything you eat or drink in the first column. After you have completed the food diary, identify all gluten containing foods or drinks by highlighting them. In the second column enter a gluten-free alternative.

	Food diary	Gluten-free alternative
Breakfast		
Mid-morning		
Lunch		
Mid-afternoon		
Evening meal		
Before bed		

Now we would advise you to taste some gluten-free foods in order to provide a more informed service for your customers.

Please tick the box under the face that best describes how you feel about the taste and texture of each gluten-free food. You can request product samples from the Glutafin Helpline 0800 988 2470 or email: glutenfree@glutafin.co.uk

Product:

Taste

Texture

Product:

Taste

Texture

Product:

Taste

Texture

Points to Remember

Customers who have been newly diagnosed with coeliac disease will be hungry for information.

- Customers should be encouraged to speak freely with their doctor, dietitian and pharmacist.
- They should be provided with information on the range of gluten-free foods that are available on prescription and non-prescribable foods.
- Those who are suspected of having a gluten intolerance should be encouraged to consume a gluten-containing diet for at least 6 weeks prior to diagnostic testing for coeliac disease
- Customers should have access to appropriate sources of support and information e.g. Coeliac UK, manufacturer's starter packs and websites. Such information may be paper based or electronic.
- Patients are likely to require regular support in maintaining dietary adherence, the pharmacist is ideally placed to provide this.
- Recipes, information leaflets and product samples can be obtained from the gluten-free food manufactures directly.

In addition the nutritional requirements of a child and adult will be different. The child will require sufficient nourishment to sustain normal growth and the adult a well-balanced diet to maintain health.

This is recognised in 'Gluten-Free Foods: a revised prescribing guide' which outlines monthly quantities of prescribable gluten-free foods for different age groups, available on from: https://www.coeliac.org.uk/healthcare-professionals/resources/guidance-documents/

Notes

Section 4

Frequently asked questions

This learning unit has been developed to allow you to understand the needs of customers with coeliac disease. To help you respond to customers questions we have compiled a list of frequently asked questions and of course the answers. Additional space has been left for you to add any other questions you're asked about on a gluten-free diet. It can provide a useful ***aide memoir.***

Q ***I thought coeliac disease only presented in childhood.***

A Not true, the highest prevalence of coeliac disease is now found in the 40-60 year age group.

Q ***Do all patients with coeliac disease respond to a gluten-free diet?***

A A small proportion of patients with coeliac disease may not respond to a gluten-free diet. This may be 'primary' where the patient does not improve on a gluten-free diet following initial diagnosis or 'secondary' where they have previously responded but now experience symptoms or show a flat or severely damaged mucosa. Voluntary or inadvertent ingestion of gluten is often cited as the most common cause. However, other factors should be considered such as food intolerance, pancreatic insufficiency, malignancy, ulcerative jejunitis or presence of another condition e.g. Crohn's disease, IBS, collagenous colitis or ulcerative colitis. Confirmation of the diagnosis of coeliac disease, exclusion of lymphoma and establishing the cause of the non-responsiveness are key issues.

Q ***When can gluten be introduced into the diet of a baby with a family history of coeliac disease?***

A Children of parents with coeliac disease have a higher risk of developing the condition. However, it is not possible to predict those who will or will not develop it. Current guidelines state that where there is a family history of coeliac disease breastfeeding should be encouraged for the first 6 months of life. weaning should commence at around 6 months, but no earlier than 4 months, and all gluten- containing cereals should be avoided until six months there is no advantage to delaying their introduction beyond this point.

Q ***Do patients with Dermatitis Herpetiformis always have gut involvement?***

A Up to 90% of patients with dermatitis herpetiformis do not complain of gastrointestinal symptoms, although villious atrophy may be present in 80% of cases. The lack of symptoms may be explained in part by the fact that gut changes may be patchy. In addition changes may be very subtle e.g. raised intraepithelial lymphocyte count in an otherwise normal-looking mucosa. All patients, however, are gluten intolerant and therefore should follow a strict life-long gluten-free diet to avoid complications.

Q ***Are all medicines gluten-free?***

A Some medicines contain flour as a filler and this should always be checked with the manufacturer. This also applies to over-the-counter vitamin and mineral supplements.

Q ***How many items can I get on each prescription?***

A Monthly gluten-free food revised prescription guidelines exist indicating appropriate quantities for different age groups (Gluten-free foods: a prescribing guide, 2011). The prescription may alter due to factors like weight loss, illness and pregnancy. It is up to the customer to discuss this with their doctor.

At diagnosis patients should always be referred to a state registered dietitian for individual advice on a gluten-free diet. During this consultation the dietitian will assess dietary requirements, usual intake of gluten-containing staples and likes and dislikes. This will enable him or her to advise on suitable gluten-free alternatives in suitable quantities. Patients should be offered review appointments, on an annual basis at least.

Q ***What if I want other items not available on prescription?***

A If they are not already available for sale in the pharmacy, non-prescription items can be ordered by the pharmacist direct from the manufacturers or from a wholesaler. Seasonal items may only be available at certain times of the year.

Q ***What is the difference between gluten-free and wheat-free foods?***

A Some gluten-free foods contain an ingredient called wheat starch from which the gluten has been removed. Other foods are made from naturally gluten-free grains and flours. Both types of foods are suitable for people with coeliac disease, however if your customer is intolerant to the entire wheat grain, they should use gluten-free and wheat-free foods (see section 3).

Q ***I am going on holiday, what arrangements should I make about my diet?***

A Many hotels and airlines offer to cater for special dietary requirements if they are given adequate notice. Customers should check with the tour operator, airline or hotel direct. It is often prudent to take some staple gluten-free items such as a few loaves of gluten-free bread and a packet of biscuits. Some countries may require a note from their doctor to allow such food items to be brought into the country.

Q ***I have been following my gluten-free diet for almost a year and I still have some symptoms, what should I do?***

A It is important that **all** sources of gluten are removed from the diet for the complete relief of symptoms. This may take up to a year. Some people are particularly sensitive and if symptoms persist they should be referred to their doctor.

Q ***Can I replace ordinary flour in a recipe with gluten-free flour?***

A As you may have already noticed, gluten-free flour is textually different and it cannot generally replace standard flour in a recipe. Manufacturers of gluten-free foods have a lot of expertise in baking with gluten-free flour and produce recipes which have been thoroughly tried and tested by home economists. Contact the manufacturers if you need any additional recipes or practical advice.

Q ***Where can I get more information or contact other people with coeliac disease?***

A Join Coeliac UK, the patient association for people with coeliac disease for more information and to obtain a copy of the Gluten-Free Food and Drink Directory.

Website : www.coeliac.org.uk

Answers to activities

Activity 1

All ACBS approved gluten-free foods are listed in the BNF and MIMS. In recent years this list has significantly increased. Manufacturers can provide an up-to-date list of their foods available on prescription.

As it is imperative to avoid all sources of gluten in the diet, customers must be confident that a food they are eating is gluten- free. Specialist prescription brands, e.g Glutafin offer guaranteed gluten free versions of staple food products such as breads, rolls, flour mixes and crackers. DS Gluten Free, Glutafin's sister brand is available in supermarkets and health food stores and offers a range of staple and more 'luxury' gluten free products. From the list of ingredients you may be able to spot if an ordinary food contains any obvious sources of gluten, however not all sources are clearly indicated. If unsure, check in 'The Gluten-Free Food & Drink Directory', which is updated regularly and includes a list of all everyday foods guaranteed to be gluten-free

Activity 2

It is unlikely that you are seeing all cases in your area. Although the incidence of the disease may not be uniformly distributed, especially as it does run in families, it is those individuals who have no overt symptoms of this disease who are particularly at risk of being undiagnosed.

Activity 3

Steatorrhoea is a result of the **malabsorption** of fat in the small intestine. General **malabsorptio**n of food can result in inadequate calorie intake and subsequent weight loss. This **weight loss** will be reflected in a loss of fat and muscle mass. In children long term malabsorption means there is insufficient nourishment available for normal growth and development. Children with coeliac disease may be shorter in stature than their normally nourished counterparts.

A decrease in the absorption of calcium, which is absorbed in the small intestine, can lead to the development of **osteoporosis** in later life.

Anaemia, resulting from inadequate absorption of iron, reduces the body's ability to transport oxygen around the body. This can cause the symptoms of **fatigue** and **breathlessness.**

Activity 4 - Case study

It may be comforting for Evelyn to know that 100 people in the UK may have coeliac disease. Explaining that the disease can be controlled by diet and a person with coeliac disease can continue to lead a full and active life may also provide reassurance. Evelyn should also be made aware that Coeliac UK, the patient association for coeliac disease, offers further information and support. In addition some manufacturers of gluten-free foods run information days and cooking demonstrations.

As a post-menopausal woman, Evelyn is already at an increased risk of developing osteoporosis. During the early stages of coeliac disease, particularly before diagnosis, there may be long term malabsorption of calcium.
Even by following a strict gluten-free diet, it may take up to a year for the gastrointestinal mucosa to normalise.
It is therefore important that Evelyn has a good intake of calcium and adheres to her gluten-free diet to optimise calcium absorption and prevent any increased risk of osteoporosis. Some gluten-free foods are rich in calcium.

Activity 5
Interview with a customer

If your selected customer was diagnosed with coeliac disease as an infant or in childhood they will have probably tried very few, if any, gluten-containing foods. If they have followed the diet for a long time, they may like to stick with the foods they are used to. As the prescribable and non-prescribable range of gluten-free foods available is continually being expanded these customers should be informed about new additions and encouraged to try them.

For a customer diagnosed in later years gluten-containing foods will be greatly missed. The apparent loss of freedom of dietary choice can be hard particularly when the dietary pattern may be set. Your customer may welcome a brief chat about gluten-free alternatives which in effect mean little change to their dietary habits for this reason it is helpful to encourage the patient to try a wide variety of gluten-free alternatives early on.

Activity 6

First look at a product based on gluten-free wheat starch. The packaging will say ‘gluten-free’ and may be accompanied by a symbol. Look at the ingredients list. Usually the wheat starch is first or second in the list of ingredients and therefore easy to find. A statement indicating that this ingredient complies with the Codex Alimentarius standard for gluten-free foods can be found close by. Check on your computer to see how these foods are listed.

Now look at the gluten-free food made from naturally gluten-free ingredients. The packaging may say gluten-free and wheat-free. The ingredients list will tell you which gluten-free cereals have been used in this product. Check on your computer to see how these foods are listed. NB, legislation regarding allergen labelling on gluten free products is changing so the claim 'wheat free' may not be visible on pack, check the ingredients list to ascertain the type of starch used.

Activity 7
Food Diary

Are you confident that you identified **all** the gluten in your diet ?

Hopefully you will have been able to find suitable gluten-free alternatives and your diet will not have been changed too much.

After tasting some of the foods you should have an appreciation and rating of their taste and texture.

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Useful Contacts

Coeliac UK

Coeliac UK, 3rd Floor, Apollo Centre,
Desborough Road, High Wycombe, Bucks HP11 2QW

Coeliac UK Helpline: 0845 305 2060

www.coeliac.org.uk

Dr Schär; our brands and services.

Dr Schär UK is the leading European manufacturer of gluten and wheat free foods. Our brands Glutafin (available on prescription) and DS Gluten Free (available in retail outlets) offers patients a combination of choice, quality and superior taste.

The Dr Schär Institute is a dedicated healthcare professional resource specialising in coeliac disease and gluten sensitivity. Our online and written resources, produced in collaboration with leading experts in the field, provide the latest information and training on the diagnosis and management of gluten related disorders.

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For product information, technical advice, recipes and patient support relating to our retail brand, visit:
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email: info@dsglutenfree.co.uk
Tel: 0800 954 1981

My local Dr Schär UK contact is:

Name:

Contact Number

Assessment

Coeliac UK is producing an information leaflet on 'Living with Coeliac Disease- How your Pharmacist can help' and they have asked for your input.

What topics would you suggest they include and what information would you find beneficial to pass onto your patients? Please list your suggestions in the comment box below.

Please return this completed module by email to professionals@drschaer.com or print and post to the Dr Schar Institute, Dr Schär UK, Units 1-2 Station Court, 442 Stockport Road, Thelwall WA4 2GW

A certificate of completion can then be issued to you.

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