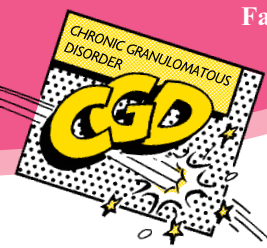




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Fact Sheet No.4

Coping with Bowel Problems in CGD

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Many people with CGD find that they have problems with their bowels, from time to time. This can range from the occasional episode of loose bowel motions (often called ‘stools’ by doctors and nurses) to more troublesome problems associated with inflammation of the bowel. It is very common for people with CGD to find that their bowel function is varied. Some days they may have what they feel are ‘normal’ bowel motions and other days will have to go to the toilet much more often and pass looser bowel motions.

Constipation is also a potential problem although this is very common in the general population as well as in people who have CGD. Everybody’s bowel habit is different and responds differently to aspects such as diet and stress. So it is important to get to know your own bowel habit and identify changes that are significant for you. Some people only ever have their bowels open once a day or once every two days and for some people it is entirely normal to go three times a day. The important thing is when what is normal for you changes, particularly if the changes occur over a period of time.





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Coping with Bowel Problems in CGD

It can sometimes be quite difficult to assess bowel habit. It's difficult to remember the changes that have occurred, all the things that you have tried and how successful they have been when you come to tell the nurse or doctor. You may find it easier to keep a stool chart from time to time which records the number of bowel actions per day and other things, such as diet or medicines which may have affected the way your bowels behave. Again, your doctor or nurse would be able to provide you with a stool chart. Children may well like to draw their own stool chart from basic guidelines or make a stool chart on the computer that is personalised to them.

If it's quite common to have some loose bowel motions in CGD how do I know if I need to tell someone about my symptoms?

You should tell your nurse or doctor if:

- You have had diarrhoea for more than just a few days
- If your bowel habit has changed i.e. if you are opening your bowels more often, much less often, if the stools have changed – are more watery, are a different colour
- If you find yourself having to run to the toilet
- If your bowel motions are very offensive smelling
- If you have slime (mucous) in your bowel motions
- If you have blood in your motions
- If you are having a lot of stomach ache
- If you have a sore bottom
- If you feel you have lost weight, (or if a child has failed to gain weight)
- If you feel generally unwell & run down

Everybody finds talking about their bowels embarrassing but it is important to tell someone about your symptoms and seek help early.

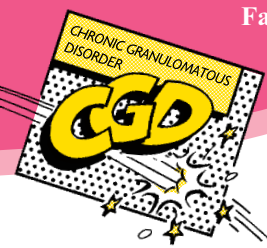
Constipation

Constipation occurs when there is delay and difficulty in passing bowel motions. The motions themselves can be of a much firmer or hard consistency and therefore can be quite difficult and painful to pass. Particularly in children, the fact that stools are difficult and painful to pass can lead to avoiding the need to go to the toilet and that means that stool continues to build up in the bowel and becomes more and more difficult to pass. This can cause problems such as abdominal pain, bloating and discomfort.





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Coping with Bowel Problems in CGD

It can be quite difficult to distinguish between constipation and diarrhoea as, in constipation, it is also possible to pass very loose stool. This is because as the stool builds up and hardens in the bowel it becomes more and more difficult to pass a motion. However, liquid stool can seep through around the hardened stool and so it seems as if you have diarrhoea. This is often called ‘constipation with overflow’.

Constipation is a very common problem in lots of people with or without CGD and is something which your GP or local doctor will be very used to dealing with. It can be treated in the same way in someone who has CGD as in anyone else.

There are a number of laxative medications available which will help with constipation. There are several different sorts, which work in different ways: to help to make motions softer and easier to pass, to encourage fluid into the bowel which helps to passing a stool easier, or to stimulate the bowel to expel bowel motions. Laxative medications are generally best used in combination with each other and taken over a longer period of time. Medicines which work to soften stool need to be used before any other type of laxative in order to help soften stool before it is expelled. Equally, when constipation is under control, it is sensible to carry on using stool softeners for some period of time in order for the problem not to build up again. These medicines should only be used on the advice of your doctor. However, once you get used to taking the medications and assessing your own bowel habit, constipation can be managed, with support from your GP, local doctor and nurses.

As well as using medications there are a number of strategies which you can undertake at home which may well help with constipation.

Diet

A diet that is low in fibre certainly won't help with constipation so it helps to try and increase the fibre intake in your diet. Foods such as fruit and vegetables, wholemeal breads, pastas and rice, and breakfast cereals all help to increase the amount of fibre in the diet. If you are not used to a lot of fibre in your diet it would be sensible to increase your dietary fibre gradually by adding in one food at a time. Again, it is sensible to seek advice from your GP, nurse or a dietician.

Fluid intake

A lot of people find that they don't drink very much during the day if they are busy and it is easy to forget. However, a poor fluid intake will certainly contribute to constipation and drinking more water is a relatively simple thing that you can do for yourself. Ideally, an adult should be aiming to drink about 2 litres of water a day. Children obviously require smaller volumes – your doctor or nurse will be able to advise you.





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Coping with Bowel Problems in CGD

Exercise

It is not too surprising to think that if you are a little slow and sluggish and not taking much exercise that your bowels will also be quite slow and sluggish. A little bit of gentle exercise, as much as you can tolerate, will certainly help your bowel function. Even a gentle walk each day will help.

Although all these things seem quite simple to do it is always difficult introducing new things into day-to-day life. It is always much better to do one thing at a time so that you can see how the change affects you. Also, if you try and make too many changes at once it's almost certain that you won't manage it, which doesn't help to keep you motivated!

Constipation in children can be made worse if children fear going to the toilet in an unknown environment because they are embarrassed or because there is no parent available to help or because of inadequate the toilet facilities at school. If your child is suffering from constipation it is worth investigating the toilet facilities at school to see whether these may be contributing to the problem.

Bowel inflammation

People with CGD have problems with inflammation (soreness) which can occur in various parts of the body. The swollen gums that many people experience is a sign of chronic inflammation. When inflammation occurs in the bowels this can result in problems with constipation, diarrhoea, abdominal pain or weight loss and for children, problems with putting on weight and growing appropriately.

The symptoms associated with bowel inflammation in CGD can be very similar to other types of inflammatory bowel disease known as Ulcerative Colitis and Crohn's disease. Some people with CGD may even have been told that they have one of these disorders, or been diagnosed as having Crohn's disease, and then later found out that they have CGD. Although the bowel problems in CGD are very similar to Ulcerative Colitis and Crohn's disease, it is important to understand that the bowel inflammation is caused by CGD and is part of the overall condition.

Inflammation can occur in any part of the gastrointestinal tract but most commonly affects the large bowel. Inflammation in the large bowel is called colitis, as 'colon' is another name for the large bowel. In colitis the lining of the large bowel is inflamed and may show some ulcers very similar to the types of ulcers that people with CGD can get in their mouths. Colitis can occur throughout the large bowel or may well be confined to just a small area, often the very last part of the bowel before the anus. Occasionally bowel inflammation is associated with strictures. A stricture is an area of narrowing in the bowel. This is caused by the bowel wall getting thicker or scarred as a result of the inflammation.





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Coping with Bowel Problems in CGD

Bowel inflammation causes symptoms such as diarrhoea, needing to get to the toilet quickly and stomach pain. Often stomach pain is associated with needing to go to the toilet and is relieved on having passed a bowel motion. Colitis can also cause bowel motions to be slimy (called mucous) or to contain blood. People with bowel problems will often find that it makes them feel very low in energy, can affect their appetite and may cause them to lose weight. Particularly when inflammation occurs in the stomach and upper part of the bowel it can be more difficult to absorb nutrients from the diet. Also inflammation itself uses up a lot of calories as the body needs energy to heal itself.

Many people with bowel inflammation get harmless bits of extra skin around the anus. These are called 'skin tags' and should not cause any difficulty and are not associated with any particular worrying symptoms. People with CGD may also have problems with a sore bottom. Small cracks (called fissures) can occur in the skin surrounding the anus which can be very painful, particularly when passing a bowel motion but tend to heal up on their own. Using a barrier cream may help - you can buy these over the counter at your local chemists. Sometimes abscesses can occur around the bottom area - these usually start as small hard, sore lumps - later they can begin to fill with pus. Often these clear up with antibiotics but occasionally a small operation is needed to help the abscess drain.

Occasionally, as a result of inflammation, a small hole can appear around the edge of the anus. This is called a fistula. A fistula can leak fluid and pus and occasionally small amounts of stool as there is a little opening between the outside of the skin around the anus and the bowel. These fistulas can be quite difficult to treat often requiring long courses of antibiotics. Sometimes it is necessary to have a minor operation to help let some of the fluid or pus out and to help the fistula heal.

Growth problems

An important symptom of bowel inflammation in children and young people is a delay in growth. This means that growth slows down for a while and that children and young people with CGD may be a little behind their peers in terms of growth - amongst the smaller people in the class or year group. We don't yet know quite why and how growth is affected by CGD. Although bowel problems do contribute to delayed growth in CGD they are probably not the only cause. If growth is a bit behind then it is possible that sexual development may be a bit delayed too - girls may menstruate (have periods) later than other girls do and boys' testicular development slows down. With treatment and time, most people catch up with their friends.

You may have heard that taking steroids can slow growth down a bit too. This can happen and it's one of the reasons why the doctor keeps a careful check on physical development. Most people catch up with growth later on.





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Coping with Bowel Problems in CGD

How will my bowel problem be diagnosed?

You will probably be diagnosed by your GP or CGD doctor who will probably refer you to a doctor specialising in gastro-intestinal illnesses (disorders of the stomach and bowels). This doctor will start by giving you a very thorough physical examination, including feeling your stomach and maybe examining your bottom. You'll also be asked a lot of questions. You may find some of them embarrassing, but your answers are very important if the doctor is to make an accurate diagnosis and get you going with the right treatment.

Then there will be several tests, which may include:

Blood tests

You will need to have a few blood tests done to help the doctor decide what the problem is. Some of the tests will continue to be done regularly to monitor your treatment and progress. These tests include looking for changes in the blood called 'inflammatory markers', which indicate whether inflammation is still present.

A barium meal and follow-through

(This test will take some time, so take a book, magazine or Walkman along with you). Your stomach will have to be empty for this test and so you'll be asked not to eat or drink anything for a few hours beforehand. At the test, you'll be asked to drink a special liquid called barium which shows up on X-ray as it passes through your stomach and bowels. (It is a thick, white chalky liquid so it can be a bit difficult to drink.) As the barium goes down the radiologist will take several X-ray pictures, so that your doctor will be able to see quite clearly what your bowel looks like and what is happening inside.

You may have to wait for some time between each picture while the barium moves on through your gut. In fact, the whole test can take two to three hours... so you really do need your book.

(For further information, visit The Royal College of Radiologists website at www.goingfora.com This explains various X-ray procedures, and helps give an idea about what to expect.)

Colonoscopy and endoscopy

These are ways of seeing right inside your bowel with the aid of a light at the end of a very flexible tube, which goes in either through your anus (colonoscopy) or your mouth (called endoscopy or gastroscopy). Don't worry, different tubes are used! These instruments can also, without you feeling it, take a biopsy. That is a tiny snippet from





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the lining of your bowel, which the doctor will send to the lab to be examined under a microscope. This sounds rather nasty, but you will be given some sedative medication to make you feel very drowsy and so that you won't feel too much discomfort. Some people may need to have a light anaesthetic for this test. You can take someone along with you for all of these tests if you want to have them there. You can talk to the doctors and nurses about this.

Every hospital that carries out these tests should have an information leaflet about them for you to read. If in doubt – ask the doctor or nurse, or contact the CGD Nurse.

After the test

The doctors may not be able to tell you what the problem is immediately after the test but they will tell you what they think is likely to be the problem. They will be able to give you a more definite diagnosis after a week or so when the results of the biopsy are known.

As well as regular blood tests, you'll probably need another colonoscopy later to check on the effect of your treatment.

What kind of treatments are there?

Bowel inflammation in CGD is generally treated with medication. Occasionally surgery is required but this needs to be considered carefully in CGD and should be discussed with your CGD doctor. Do remember that just as CGD affects people differently, bowel inflammation will be different for each person too. You will probably have a treatment plan designed especially for you, which takes into account your daily medication for CGD.

Diet

There is no particular dietary recommendation for people with bowel inflammation but it is possible that some dietary changes may help.

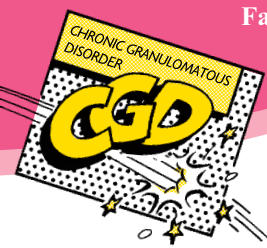
Different people find that different foods may affect their bowel habit. If you do know of a particular food that affects you then it is probably sensible to avoid it (but do check with your doctor or nurse first). Some people with colitis may be advised by their doctor to adopt a 'low residue' diet – this is usually a diet that is low in fibre and fat and is easier for the gut to tolerate. This diet should only be undertaken with advice from a dietician.

Special milk-shake type drinks (or fruit-flavour drinks) can be very helpful to supplement your diet if you are not able to maintain your weight or have lost your appetite. These drinks can be used to add extra calories to the diet. They can also be





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used to replace food, providing all the nutrients you need. This is useful when the bowel is very inflamed and not able to do the work required of it to digest a normal diet. This kind of 'special milk-only' diet is only needed very occasionally and usually for short periods. It should only be undertaken on advice from a doctor and dietician.

You may find you lose your appetite or that food doesn't taste like it should. So a bit of willpower is called for. This is the time to indulge in all of your favourite meals and try to eat what you can. You may find you can't eat big meals and that it is off-putting to have large amounts of food on a plate. Aim to have small meals, attractively arranged on the plate. It is a good idea to eat little and often.

Diet and growth

Sometimes, in children and young people, if growth is slowing down a lot, the doctor may recommend drinking 'special milk-shake type drinks', in addition to a normal diet in order to give extra calories to help promote growth. Sometimes it is difficult for children (and occasionally adults) to drink enough of these supplements to provide the calories they need. In this instance the 'special milk' can be given via a tube passed through the nose into the stomach. This tube comes out easily when no longer needed.

It is important not to make major changes to your diet and particularly that of a child without making sure you have the proper advice from a dietician. You can ask your GP to refer you to a dietician in your area.

Medicines

Anti-inflammatory medication

There are a group of special anti-inflammatory medicines used to treat bowel inflammation (often medicines called Sulphasalazine, or Mesalazine). These are usually taken by mouth but some of them can also be given via the rectum (see below). These medicines are very useful in CGD and are often the first medicines to try. For many people with milder inflammation these may be the only bowel medicines they need. They are also very useful in keeping inflammation at bay – often after a course of steroid has been used. These medicines have very few side effects and can be taken safely for long periods of time.

Steroids

Steroids are anti-inflammatory medicines that are very useful in treating the inflammation associated with CGD. However they also have the effect of 'damping down' your body's response to infection. So you can see why doctors will be cautious about using steroids in CGD and only recommend them when they are really necessary.





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Your doctor will monitor you carefully while you are on steroids and advise you how to spot early signs of infection.

Steroids act quite quickly so that you will soon begin to feel better but they do have some side effects and different people react in different ways. Some people do find they feel hungrier when taking steroids (this can be quite a good thing for some people). It's quite common to put on weight too but not all the weight is about you eating more. So, if this happens to you, you should eat what you feel like eating and not worry about putting on weight as this will soon disappear once the steroids have been stopped. You may get a round face (moon face) or become a bit pimply, and girls sometimes get a few coarser hairs on their face. Steroids can make you moody and restless, too. Some people who have had long or frequent courses of steroids may develop thinning of the bones. Thinning of the bones, called 'osteoporosis', is usually found in older people but can occur in younger people who take steroids at high doses or for a long time. There are ways of minimising this effect – you should talk to your doctor or nurse about this. (See 'Fact Sheet 5 - Keeping Myself Well').

It can be tough dealing with these side effects, but you have to weigh the disadvantages against the advantage of feeling much better and being able to get back to normal life. If things get very tough don't hesitate to talk to the doctor or a nurse about how you feel. It is important never to just stop taking steroids without talking to your doctor as this could make you quite unwell. Steroids usually need to be reduced gradually over time so that your body gets used to managing without the extra steroids. Your doctor will prescribe the lowest possible dose for the shortest possible time and when you come off the steroids most of the side effects will disappear. By the way, the steroids that you would be given aren't at all like the steroids taken illegally by some athletes.

Other medicines

There are other medicines which are sometimes used in more severe bowel inflammation, that work in a similar way to steroids (one of the more common ones is called 'Azathioprine'). They are often used to 'take over' from steroids if you have been on them for a long time. These medicines, like steroids, can 'damp down' the body's response to infection. So you will have regular blood tests and be carefully monitored by your doctors if you need to take these medicines.

Taking the medicines

Some medicines may be given through your anus up into your rectum in order to reduce any inflammation in your bowel. This sounds a bit unpleasant but it isn't difficult to do and the nurse will show you how. Some people even prefer this to taking lots of tablets.





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Coping with Bowel Problems in CGD

Because some of the medicines taken for bowel inflammation are quite powerful, it is very important that you take them exactly as the doctor has prescribed. The hospital pharmacy or the pharmacist at your local chemist will write instructions on the bottle or package and if you don't understand them you should ask there and then for an explanation.

With any medicines, always read the information leaflet in the medicine packet and tell your doctor right away if you find you are getting any unusual symptoms. If you are on steroids or Azathioprine you may find you are more likely to pick up infections. If you have a temperature or a sore throat it is important to tell the CGD nurse or your doctor.

Surgery

This is not often needed. If your doctor thinks it might be necessary, he/she will talk to you about the different types of surgery. You should seek the advice of your CGD doctor and you can contact the CGD nurse to ask more about it and talk it through.

What can I do to help look after myself?

The medications that your doctor has prescribed for you are very important as they are the best way of clearing up the bowel inflammation.

However keeping yourself as fit and well as you can certainly helps (see 'Keeping Myself Well'). It's important to get to know what triggers bowel problems in you – it might be getting very tired, or eating food that normally 'upsets' your bowel. Sometimes if you get another infection, sometimes even a cold or flu, this can make your bowel problems flare-up for a short period. So generally looking after yourself is the key!

Finally there is one very important contribution you can make towards helping yourself to stay well. If you suffer from bowel problems, you should STOP SMOKING. Smokers are more likely to have a worse course of illness and will need more medicines to treat their symptoms.

How will I cope with bowel problems at home?

It is pretty miserable when you are having these problems. Bowel symptoms have a tendency to come and go. This means you may have a patch where the bowel is very inflamed and you are having problems with diarrhoea and stomach ache. But it's also likely that in time your symptoms will disappear for months or even years at a time. Remember, and remind everyone else, that even when you having trouble with your bowels you are not an invalid. It's still important to do the things that you enjoy with your friends and family.





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Coping with Bowel Problems in CGD

Can I go on holiday?

There's nothing to stop you going on holiday, although it's best to avoid places renowned for stomach upsets as these can sometimes trigger bowel problems. Your doctor may recommend taking a supply of antibiotics with you to take if you become unwell. Make sure you discuss this with your doctor in plenty of time BEFORE you go away.

But there will be some problems, won't there?

Yes, probably there will be. You may be back at school or at work and trying to cope with your bowel problems at the same time. You'll need to take some precautions.

What makes people with bowel problems most fed up is having to go to the toilet so often and the embarrassing things that happen there. It's a good idea to check out the quickest route to the toilet when you visit somewhere new. Some people carry sheets of toilet paper and spare underwear when they go out. They say this gives them confidence, even when they don't use them. If you are worried about not making it to the toilet in time and the possibility of an 'accident' you may want to carry some pads that can be worn in your underwear. Wearing a pad may not seem like a great idea and something you want to do but it can help you feel more confident – pads keep you clean and dry and can be changed more easily and discreetly than underwear. You can buy these at the chemists. Your doctor and nurse will be able to advise you.

A good tip for blocking out sound effects is to flush the toilet just before you use it. You can also buy very small canisters of air freshener (often the 'neutraliser' ones have very little smell to them) to use.

There are medicines that you can take which slow down your bowel movements and so make diarrhoea and the need to hurry to the toilet less of a problem. For some people antispasmodic medications (medicines that work to help 'relax' the bowel) may also help. However it is important that these medicines are only taken on the advice of your doctor.

Get some allies

Everyone finds bowel problems embarrassing and some people avoid things like parties and going out in case they have an emergency. But these are activities that will cheer you up and make you feel more like you and one of your group of friends. If you miss out, you may feel very lonely. It helps if you have one or two people with you who know about your situation and can help you cope if you do hit a bad patch.





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Alternative therapies

Many people may be interested in exploring complementary therapies in addition to conventional treatments. Treatments such as aromatherapy, reflexology, relaxation and massage are readily available and may prove helpful. Therapies which cause deep relaxation can be particularly useful for people with day-to-day pain and are often useful in managing bowel problems. Bowel problems, particularly where you have to rush to the toilet in a hurry or find that things get much worse when you are worried or anxious, often respond well to special relaxation techniques that you can learn to help you get a little control over your bowel symptoms. Some people have found hypnotherapy particularly helpful for these types of problems. For more information, see 'Fact Sheet 5 - Keeping Myself Well'.

And Finally ...

Sometimes, things may begin to get you down. Don't forget that you can always contact the CGD specialist nurse for advice and moral support.

Glossary

Anus – the opening of the back passage through which stools are passed.

Biopsy – a tiny piece of tissue removed from the body that can then be examined under a microscope in the laboratory – taking a biopsy from the gut doesn't hurt and helps the doctors to work out what's causing the problem.

Colon – otherwise called the 'large bowel' or 'large intestine'. This is the lower part of your bowel where stools are made solid.

Fissure – a small crack in the skin, sometimes found around the anus.

Fistula – a small, sore opening sometimes found around the anus in people with CGD / bowel inflammation.

Rectum – the last part of the large bowel just inside the anus.

Skin tags – small bits or tags of skin that are sometimes found around the anus.

Stricture – a narrowing of the bowel.

Important Note: The information contained in this document is intended only as a guideline, not as a substitute for medical advice. Always consult your doctor if you or your child has any CGD symptoms or concerns.

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