



Missing M
Genes



Teenager/Young Adult Fact Sheet No.2

Coping with...

Parents

You may feel fed up with your parents who seem to worry about you all the time. When you are ill you might want to be comforted and cared for, but when you are well you don't want them to fuss! It is tempting to flare up and accuse them of trying to stop you doing things. Instead try telling them what you feel – 'When I'm well, I really want to make up for the things I've missed and enjoy myself like everyone else'.

They need reassurance; after all, your CGD, through no fault of yours, has caused them a lot of anxiety. They aren't inside your body, so it's understandable that they can't be as sure as you are that you are feeling ok. They used to give you all your medicines when you were little and look after you. Now you are beginning to look after yourself. You can reassure your parents by telling them that you will let them know if you are feeling unwell and show that you can take responsibility for taking your medicines.

Other people

People can be very understanding and supportive, but sometimes they are not. You look well and perfectly normal, so how can you have a rare condition that needs daily medication? Why do you need to take precautions against infection? It is difficult and frustrating trying to explain to them and you might find them infuriating when they ask things like 'Will you grow out of it?' 'I know just how you feel', and so on. Sometimes people simply don't understand – they feel embarrassed themselves and don't know how to act or what to say.

You don't have to tell anyone you have CGD but it helps if a few chosen people know so that they can help you out if you need it. Your teacher at school might need to know, so they understand why you need time off school for hospital visits, why you sometimes can't join in with activities, or why you are a bit low on energy.

Friends

It might help to tell your closest friends what having CGD is like for you. Friends can be a great help but if they are going to help they need to know something about what you're going through. Otherwise, they won't understand why you take medicine regularly or why you get tired easily or can't join in with certain things. Most people genuinely like to help – usually it's not knowing how to help that holds people back. Friends can be there for you when you need someone and keep you up to date with what's going on if you're off school. They will know that despite CGD you are still the same 'you'.





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Of course you won't feel like getting your friends together and holding forth about your problems at school. You'll have your own way of telling them. You may prefer to tell just one or two of your friends and get them to help tell the others. Some of your friends, as well as your teachers, may show their concern for you by being over-protective and they may start telling you what to do and what not to do. You'll have to explain that you are the best person to know what you are capable of doing at any particular time.

Feelings

Even if CGD does not affect you that much, you may still have strong feelings about it. You might feel angry that it is you who has it and it might make you angry with your family and friends. You might feel guilty for causing your family or friends such worry. It's ok to feel afraid, angry, frustrated or fed-up sometimes. Growing up, coping with school, exams, boyfriend or girlfriend trouble and becoming more independent from your parents can all be stressful. CGD can add to this. Even if you feel pretty well most of the time being different from other people, having to take medication everyday, feeling perhaps that you can't do everything you would like to do can all contribute to feeling 'down'.

It often helps to talk to someone about the way you are feeling. It may help to talk to family and friends but sometimes you may be worried about causing them anxiety or you may feel your feelings are too private. Sometimes it can be helpful to talk to someone in a similar situation, and share experiences, discuss problems and possible solutions – often people prefer to chat over the internet/ email or to read other people's experiences.

You might find it helpful to talk to a nurse or doctor with whom you have a good relationship. Sometimes it's helpful to talk to someone who isn't too close to you or who isn't involved in your medical care such as a school counsellor, or social worker and/or the psychologist at the hospital who can offer you some support and help. Whoever you choose – don't be afraid to admit that you are feeling low or that you're finding things tough. It really is good to talk!

If you would like to talk to someone about your feelings, you can book to see the school counsellor (ask your teacher, school nurse or the school office if you don't know how to do this) or ask your GP, hospital doctor, or the CGD nurse to help arrange this (you don't need to tell them what you want to talk about).





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People often think that if they talk to a psychologist or counsellor it means that people will think they are 'mad'. It doesn't mean that – it's about helping you find ways to help you cope with the things you have to cope with and talk through the way you are feeling. You take tablets to look after your body – it's just as important to look after the way you feel!

Doctors and nurses

Going to the doctor can seem a bit of pain. It can feel embarrassing having to talk about yourself and personal things about your body. You may find some of the doctor's questions embarrassing but your answers are very important if the doctor is to make an accurate diagnosis and get you going with the right treatment.

It can feel especially difficult if you see a doctor who doesn't know you or know much about CGD. Some people are tempted not to tell the doctor they have CGD and what it means. You know that having CGD means it is important you get any problems dealt with quickly and get the right treatment. The doctors want to help you but they need some help from you! You need to tell the doctor looking after you that you have CGD. The easiest way may be to take a CGD booklet with you – then you can explain that you have CGD and give them the booklet.

School

Explaining to staff

Ask the CGD nurse for a leaflet that explains CGD and the needs that you might sometimes have. For example, if you have bowel problems then the teachers will need to know that you should be allowed to leave class as quickly when you need to, that you should be able to use the staff toilet if it's nearer etc.

The leaflet will also explain that you may feel better some days than others. If you've not been well, you may feel tired at times and being able to have a quiet period will probably be enough to restore your energy. That's much better than going home and missing two to three periods.

There are other things the staff will need to know. You might need to take medicine at certain times or you might need to eat between meals. It's a good idea to ask if there is one teacher you can go to if you need help at school in coping with CGD and any problems caused by it. Perhaps you hate being singled out at school like this, but it will pay off and avoid more singling out later.





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CGD Family Fact Series



Coping with...

Sport

Maybe you're keen on sport. If you're feeling fit there should be nothing to stop you playing the games you usually play. Think of the months professionals have to take off for injuries and they bounce back again. One famous sportsman has Inflammatory Bowel Disease and it doesn't stop him winning medals. Others have run the London marathon! Your team captain and PE teacher may be afraid of overtaxing your strength. You'll need to talk to them and explain that while you are feeling fit it is perfectly in order to carry on as normal.

Getting back to normal

After a spell of illness or a stay in hospital it may take some time for you to start feeling better and regaining your energy. See if some of your friends can call round so that you have a chance to catch up with everything that has been going on. Try to eat well to build up your strength and persevere with the medicines and various treatments that you need to make you feel better. It is probably a bit of a bore, but it is worth it to get back to normal.

It can sometimes be difficult going back to school after time off, even after only a week or so. You may feel as if you've missed out, or worry that your friends will have been doing things without you. You might find it a bit daunting that you've missed some of the work and will be behind. Talk to your teacher about how best you can catch up. If you have to stay off school for more than a couple of days ask if someone can bring you homework. That way you'll not only keep up in class, you'll keep up on school gossip too, so you won't feel so out of it when you go back.

It might help to go back to school gradually – go in for a few mornings or afternoons only in the first week or so. This helps you to build up your physical stamina for school (it can seem like a long day if you've been off for a while). Also, you get back into things slowly – if you include some of your favourite lessons and things you're good at it will give you a bit of a 'boost' to know that you can cope.

For further information on all aspects of CGD, look at the Blue series, including:

- It's not fair...
- Eating and Diet
- What keeps me well if I have CGD?
- How to stay well
- Taking control
- Taking medicines and how to carry on taking them

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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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