



Missing M
Genes



Teenager/Young Adult Fact Sheet No.6

Taking control

Having a medical condition means visits to clinics and sometimes means staying in hospital. It can be frustrating if you have to see lots of different doctors – they all seem to ask the same questions! Remember though, they need to know about you before they can help.

My Mum knows all that stuff...

It is tempting to let Mum or Dad do all of talking for you – after all they know all about the things that happened to you as a child (and this is probably when your CGD was diagnosed). You will need their help (and their memory!) but try to answer as many of the doctor's questions as you can for yourself – ask your parents to fill in the gaps. It's important that you get to know the names of your medicines and how much you take (and what they are for) and that you know about the things that happened to you in your past, as well as how you are at the moment. These are the things doctors will always need to know and you will need to know them to start looking after yourself in the future.

You might want to write down a few facts (maybe in your copy of the CGD booklet) such as which medicines you take (what they are called and how much) and the kind of medical problems you have had – such as chest infections or bowel problems. This saves on some of the explaining and helps you remember.

You might like to carry the details of your doctor and /or the CGD Nurse with you so that the doctor looking after you knows who to contact for more information.

It's my life isn't it?

When you were younger, your parents did all the talking and worrying, and that was fine. But now you might want to remind them that it is time that you have some say in the discussions about problems and possible treatments that the doctors are suggesting. You are the patient and you have a say in the decisions about your treatment.

I'm here - why don't they speak to me?!

Sometimes, because the doctors themselves are adult, they may explain to the adult who is with you what they think is the matter and what is advisable for treatment and why, instead of talking to you. If this happens, chip in politely and ask for a repeat. Sometimes they are very short of time and talk too fast, and then there you are outside the door with a dozen questions you feel you didn't have time to ask. If this happens, don't leave the clinic until you can find a nurse who can answer your questions or arrange another appointment with the doctor. If this is difficult, you can always telephone the CGD nurse and ask her to explain what it all means.





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What if I'd rather see the doctor on my own?

Sometimes, especially when you've had time to get to know and trust your doctor or nurse, you may feel you would like to talk to him or her alone. You have a perfect right to ask for this. Perhaps you'll hesitate to ask because you're afraid that your parents will feel hurt and rejected. After all, they've probably done a lot for you and are certain to have been worried and anxious. If you explain your feelings, they should understand that in future you will have to manage your illness yourself, and this is one way to start. You already live a large part of your life away from your parents at school, although they play an important part helping you through your school life. Perhaps you feel that this part of your life has something in common with this. In any case, it's part of your growing independence and your parents will be proud of you living up to this natural stage of development in spite of your medical condition.

Before any course of treatment the doctor should ask your permission, as well as your parents, if he or she believes that you are old enough to understand what it is all about. In fact, you have a legal right to give consent. Understanding what is happening to you is the first stage of treatment for you.

What if I don't understand what they say?

Always ask the nurses and doctors to explain again – they are there to help you. It is OK to ask to talk to them on your own – it is your symptoms that are being treated and only you know how you feel. You will probably want to be a little independent about looking after yourself and taking your treatments.

How do I cope with my parents - they're driving me nuts!

You may find that your parents continue to worry even when you're feeling well and you'll begin to resent their continuous 'how are you feeling today', 'don't overdo it' and so on and on, and on. After all, your CGD, through no fault of yours, has caused them a lot of anxiety and 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. 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 anything. 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'. Reassure them that you really are feeling ok and that you will let them know if you are feeling unwell.





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

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

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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