



Missing M  
Genes



## Teenager/Young Adult Fact Sheet No.1

# It's not fair!

## CGD makes me feel...

### ... tired

Chronic Granulomatous Disorder (CGD) is an unpredictable condition. Sometimes you will feel okay, but at other times there will be symptoms that can get you down and periods of illness when you don't feel like doing anything. Be kind to yourself - if you're having a tired time take a break – let your self have some lazy time watching a video or having a lie in with a magazine. Get a few early night in, do some 'quiet' activities, like listening to music, playing computer games etc with your friends. If schoolwork is a problem have a word with your teachers – they may be able to give you a little more time to get your homework done. If you save up some of your energy when you're having a 'tired time' you'll have more of it later when you feel like being a bit more energetic!

### ... different

There are times when you may feel that having CGD is making you 'different' from all of your friends, and this may make you feel miserable, angry or confused. Sometimes, if you feel like this it helps to do some things you enjoy, wear your favourite clothes, find some small treats like favourite foods or spending your pocket money on a CD or make-up etc. Although these tricks don't stop you feeling tired they can cheer you up and help you feel a bit more ok about yourself.

Children and teenagers with CGD tend to be smaller than their friends. This can be for a number of reasons. The stomach may not digest food and absorb the goodness very effectively, so the body does not get the things it needs to grow. Sometimes all of your energy is used to fight off infection. Puberty can be delayed so that teenagers have the appearance of someone much younger. Don't worry – you may start growing later than your friends and you will probably catch up with them eventually.

### ... fed up with taking pills every day

You may feel fed up to the back teeth with having to take tablets every day. You're probably also fed up with being reminded, questioned and nagged about your medication! None of your friends have to take them, so why should you, especially if you are feeling well? Sometimes people stop taking their tablets, thinking that they don't need them and it will help them to forget all about having CGD. This is not a good idea as taking the medication helps to keep you well. Not taking them means that sooner or later, it will be easy for an infection to occur.





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## It's not fair! CGD makes me feel...

Try to take responsibility for your medicines yourself, and fit them into a daily routine. Take them when you are cleaning your teeth, getting ready for bed or when you get your books to go to school. This way you will feel that you are in control of your treatment and you are keeping yourself well.

### ... I can't join in with my friends

When you cannot join in with activities, like going on school trips that may involve going into dusty buildings, for example, or because you haven't got the energy to do things at the moment, you might feel you are not allowed to do anything. Try and remember all the things that you can do. If you're feeling like this why not plan something nice to do with your friends that you really enjoy. Doing some physical activity (like sports/games, going for a walk with the dog, etc) often helps to make you feel a bit better – it reminds you what you can do, works off a bit of 'steam' and gets the body's natural 'cheering-up chemicals' going, which helps to give you a bit of a 'buzz'!

These are a few of the things you could try: bike rides, micro-scooting, theatre club, youth club, visits to the cinema, ten-pin bowling, fencing, arts and crafts, walks, visits to the play park (as long as it doesn't have a bark chipping surface).

### ... other people don't understand

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?' or say 'I know just how you feel', and so on.

It's hard for friends to imagine being too tired to stay up late and have fun, which can get you down. Sometimes people might seem to be avoiding you. This is possibly because they feel embarrassed themselves and don't know how to act or what to say. It might help to tell your closest friends what things are like for you and ask them to explain to the others that sometimes you feel well and other times you don't – that you might not always be able to join in but that you are always still the same 'you'.





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CGD Family  
Fact Series



## It's not fair! CGD makes me feel...

### ... it might be my fault

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. You might secretly wonder if you are somehow to blame for having CGD. **You are not. Nothing anyone does, or did not do, gives them CGD.**

If you would like to know about how you got CGD – take a look at 'What is CGD'.

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

- Coping with...
- 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

**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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