



Missing M
Genes



Teenager/Young Adult Fact Sheet No.4

What helps keep me well if I have CGD?

1. Taking Medicines

Why do I have to take tablets or medicines every day?

Taking daily preventative medication is the best way of making sure that you don't get infections.

Because your white cells don't work properly your body needs extra help to fight off infections. These medicines provide that extra help. Sometimes the medicines won't quite be enough to fight off the infection and even if you've taken your medicines really well, every day, you still get an infection. However because you've been taking your medicines your body has been able to put up a pretty good defence so the infection shouldn't be so serious and you will be back on your feet faster.

Antibiotics (medicine for bacterial infections)

The antibiotic that most people with CGD take **for preventing infection**, is Co-Trimoxazole (also called Septrin). Co-Trimoxazole is used because it provides protection against a number of bugs that can cause problems in CGD and most people find that they can take it ok. A few people find that Septrin doesn't agree with them. This is quite unusual but if this does happen it is possible to use another, similar antibiotic.

Antifungals (medicines for fungal infection)

The antifungal medication **currently recommended to prevent infection** in CGD is Itraconazole (also called Sporonox) as it is good at preventing fungal infections caused by a fungus called Aspergillus, which is the one that people with CGD are more likely to get. Again, most people get on ok with Itraconazole but a few people find that it gives them stomach pain or diarrhoea. If this is a problem it can often be sorted out by changing how the medicine is taken.





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I'm feeling OK - why should I bother with my medication?

Perhaps it is ages since you were ill and you can hardly remember what it felt like. Or perhaps you are feeling fine. Even so, it is important to keep taking your prescribed pills and potions. They are helping to keep you well. (It's worth remembering that you have probably been well because of your medicines!) The problem with CGD is that it is hard to predict when an infection might happen or if it does, how serious it will be. If you stop taking your medicines, sooner or later you will go down with an infection of one sort or another, which will interrupt your plans and stop you enjoying the things you usually do.

2. Preventing infections

Preventing infections in CGD is important for a number of reasons. There are the obvious ones:

- You feel fit and ok and are able to get on with what you want to do
- It keeps you out of hospital!

However it is also important to try and reduce the number of infections you have. Having lots of infections makes it harder to fight them off each time and infections can cause damage that will affect you in the future. For instance, if you have lots of chest infections you can get some scarring in the lungs which can lead to breathing problems in the future.

How do I know if I've got an infection?

Being wise to the signs of infection helps you to recognise it quickly and this means that it can be treated more quickly and easily and you will be back on your feet faster.

So...

There are a few things that you should be on the look-out for:

- Warm, tender or swollen areas
- Hard lumps
- Sores with pus or rashes
- Cough or pain in your chest
- Problems with breathing
- Diarrhoea that doesn't go away after a couple of days





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What helps keep me well if I have CGD?

- Frequent or persistent headaches
- Being very sweaty at night
- Losing your appetite
- Losing weight – sometimes you notice this because your clothes or rings feel suddenly loose on you
- Vomiting shortly after eating on a more or less consistent basis
- Pain or difficulty on passing urine
- Difficulty swallowing food
- A fever :

Having a fever or temperature is a sign that the body is trying to fight off an infection. You have fever if the thermometer says your temperature is 38 degrees or above. (Have you got a thermometer at home? Make sure you know how to use it!) Having a fever generally makes you feel pretty miserable – other signs that you have a fever are feeling as if you are 'burning up', feeling 'shivery' or alternately hot and cold. Taking Paracetamol will help you feel a bit better and will probably take your fever away for a few hours but this doesn't mean that the reason you have a temperature has gone away! So it's ok to take some Paracetamol to make you feel better but make sure you get things checked out too!

If you're not sure if you have any of these symptoms or if you're not sure what they mean ask for help, talk it through with your Mum or Dad, see your doctor or call the CGD Clinical Nurse Specialist. (You can also email the CGD nurse – that's sometimes a bit easier than having to talk on the phone or face to face.)

But it's embarrassing!

It can be embarrassing talking about your body and problems such as difficulty passing urine or diarrhoea but it is important to tell somebody so that it can be sorted out quickly. It's really easy to pretend it's not happening or hope things will go away but remember if you ignore symptoms and put off doing something about them you might be ignoring an infection. That means you might end up a lot more poorly than if you'd sorted it out sooner and you'll be out of action for longer.

Did you know that you can see the doctor or nurse on your own if you prefer to?
See Blue series fact sheet Taking Control - 'I'm here, why don't they speak to me?'





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3. Having regular checks

It's important to see your hospital/CGD doctor regularly. (This doesn't mean you have to go all that often - every 6 months to a year is ok if you are well.) You might feel that you are perfectly well but it is best to get checked out. That way any problems get sorted out early and much more easily. It's important that you keep yourself as well as you can for the future and don't let problems build up. Sometimes the doctors and nurses might pick up on something that you haven't really thought about.

Why do I have to have so many blood tests?

Although nobody likes having blood tests it is important for people with CGD to have to have regular blood tests to make sure that any problems are picked up early and to make sure the medicines are working ok.

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
- 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.

Published by the CGD Research Trust

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Registered Charity No. 1003425

