



Missing Mitochondrial Genes



Fact Sheet No.5

# Keeping Myself Well

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We live in a health conscious age, and everyone wants to know how they can maintain stable health. This is especially important if you have CGD and there are things that you can do to help yourself stay well. You might have questions about how best to look after yourself, so that you can enjoy all the things that you like doing and help safeguard your health for the future. This information sheet should help you.

Taking your preventative medication regularly every day is the single most important factor in keeping you well. However keeping your self generally as fit and well as you can also helps you avoid infection and get better more quickly when you are unwell. There are a few things that you can do for yourself that will help to keep you at your best.





## Keeping Myself Well

### Exercise

Take regular exercise. This helps to keep you fit, boosts your immune system and release natural ‘endorphins’ chemicals in the brain that increase your sense of well-being. Exercise doesn’t mean you have to do anything heroic and needn’t involve expensive gym fees.

#### Activities to consider are:

- Basket ball/volley ball/netball
- Swimming (in clean, chlorinated swimming pools)
- Badminton/tennis
- Dance/yoga/‘keep-fit’
- Pilates
- Cycling
- Walking – just down the road, to the shops or taking the dog for a walk is exercise!

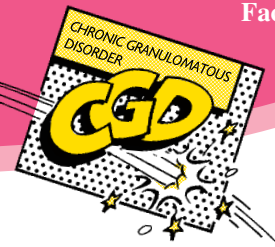
Exercise should be built up regularly and adjusted to suit you. Don’t aim to do too much too often or you will either feel exhausted or find that you can’t keep up with your exercise plan. This will not help your motivation! A short walk each day or a gentle exercise or yoga video at home may be for you. Many people with CGD will tire more easily and have lower energy levels than other people. So you may need to take exercise more gently and do a ‘little and often’. A few minutes of exercise that speeds up your heart rate is good for you – but if you have breathing or heart problems take advice from your nurse or doctor first.

People with breathing problems, or who are generally unwell, may benefit from seeing a physiotherapist who can develop an appropriate exercise regime to target specific problems and benefit general health. Talk to your GP about this.

Your local health centre, library and sports centres should have information on what is available in your area. Many local authority sports centres have a gym and offer classes for different age groups and abilities/levels of fitness. They often have a discount card scheme and concessions rates.

### Diet

The best diet for anyone, regardless of whether you have CGD or not, is a healthy diet. We all know that that means including lots of different types of food in our diets, including five portions of fruit and vegetables each day!



## Keeping Myself Well

Some children and adults with CGD will find that it is difficult for them to maintain their weight and for children this can mean that they are slow to grow. For these people a few additional calories are required. Adding high calorie foods to the diet, such as butter or cheese, can be sufficient but some people may need a little extra help from dietary supplements. These usually come in the form of milkshake type drinks (and some fruit flavour drinks) and must be prescribed by a doctor or dietician.

It may sometimes be the case that while you know you (or your child) need to eat more you find that that you have only a small appetite. In this instance it is probably better to eat small, frequent meals rather than try and persuade yourself to eat one large meal. Don't skip meals – try to have three small, manageable meals a day and snacks, such as plain biscuits, milky drinks, fruit or yoghurt at 'coffee time', 'teatime' and bedtime.

Making meals presentable and not overloading the plate makes them much more appealing. Children may need some praise for what they do manage to eat. As a parent it can be very worrying when your child doesn't eat as well or as much as you feel they should. It is worth remembering that children with CGD may have small appetites and may feel that they are eating as much as they can. Extra calories may need to be disguised to encourage their intake and little 'treats' can be useful sources of extra calories.

*If you have concerns about your/your child's diet or weight talk to your doctor or nurse. You can ask to be referred to a dietician – there are specialist dietician's for children.*

For more detail, see Information Sheet: Food for Thought.

## Vitamins

Both adults and children with CGD are likely to benefit from a standard vitamin and mineral supplement as it may be harder for them to absorb all the nutrients from their diet, although it may be best to avoid supplements containing iron (as some people find that iron doesn't agree with them – you can take extra iron medication if your doctor thinks it's necessary). A one-a-day vitamin/mineral supplement is adequate and it is not advisable to take large amounts of any vitamin or mineral supplement. Take advice from your doctor or pharmacist.

## Immunisations

Children should be fully immunised, just as any other child would be. The only immunisation adults and children with CGD should not have is BCG, the vaccination against tuberculosis (T.B.) – occasionally given to new babies, otherwise given at school



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## Keeping Myself Well

at around 13-14 years of age. All other immunisations including polio, Hib, MMR and Meningitis C are OK.

As for the general public, Tetanus and polio vaccines should be kept up-to-date for all people (adults and children) with CGD. For children this is done automatically through school. Adults can make sure they are up-to-date by talking with the nurse at their GP practice, who can then administer the immunisations as necessary.

Flu vaccine – sometimes Influenza can be complicated by bacterial infection (which can cause a nasty chest infection) and so it is advisable for people with CGD to have the flu vaccine each year (if over 6 months of age).

For further information, see Fact Sheet: Immunisations

## Rest

Don't forget to take plenty of rest to build up your reserves. Letting yourself get tired and run down will not help you fight off infection. You may find there are days when you feel generally 'weary' and some people find that they have 'achey' legs or joints from time to time. If you find yourself feeling very tired it's your body's way of telling you to take a break. So listen to it!

No one wants to go to bed early every night and you don't have to miss out on going out and doing the things you want and need to do. But every now and again you might need to have a lazy day or an early night or do something restful and relaxing just to re-charge. It's okay to feel tired – if you feel like taking to the sofa for a day, let yourself do it. Watch a favourite video, read magazines, eat some favourite food – in other words enjoy being lazy! Then it doesn't feel as if it's a chore to take some rest. You will feel better for it.

## Preventing infection

Preventing infection in CGD is important for a number of reasons.

There are the obvious ones:

You feel fit and ok and are able to go about your daily life

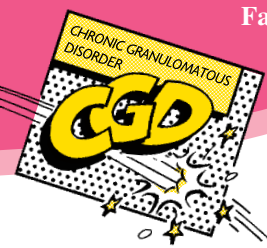
It keeps you out of hospital

However it is also important to try and reduce the number and severity of infections in order to reduce the potential consequences of infection and to look after your health for the future. For instance, having repeated chest infections can lead to scarring in the lungs, which can lead to breathing problems in the future.





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## Keeping Myself Well

Taking daily preventative medication is the best way of minimising the number of infections you might get and the severity of the infection when it does happen. Also, being wise to the signs of infection helps you to recognise it quickly. This means that it can be treated more quickly and easily, which in turn means that you will be back on your feet quicker.

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 have been really well for a long time it is easy to think that you don't need your medicines - **BUT** it is worth remembering that you have probably been well **because** of your medicines! Just because you feel OK and haven't had an infection for a long time doesn't mean that you won't get one. The chances are that without preventative medicines you will get an infection sooner or later and it could well be a serious one.

So...there are a few things that you should be on the look-out for:

- A fever of 38°C or above
- Warm, tender or swollen areas
- Hard lumps
- Sores with pus or rashes
- Persistent cough or chest pain
- Persistent diarrhoea
- Frequent or persistent headaches
- Night sweats
- Loss of appetite
- Weight loss
- Vomiting shortly after eating on a more or less consistent basis
- Pain or difficulty on urinating
- Difficulty swallowing food

People with CGD will suffer colds and other viral infections like any other person and this part of their immune system will respond normally. Consequently it can be difficult to identify those infections that are 'normal' from those that are due to CGD. It can be very hard to determine what is a cause for concern and what is not. This is particularly difficult for parents when their child is first diagnosed with CGD. So if you're not sure about any of the above symptoms or if you're not sure what they mean, ask for help – see your doctor or call the CGD Clinical Nurse Specialist.





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## Keeping Myself Well

### Precautions for CGD patients

- To avoid inhaling high levels of fungi, do not work with or around mulch, hay, wood chips, grass clippings, other garden waste or firewood that has dry rot or old fungi on it
- Stay out of barns, caves and other dusty or damp areas because of the danger of disturbing harmful fungal spores
- Keep all recommended immunisations up to date to prevent major illnesses
- Be careful with personal hygiene; use mild moisturising soap; brush teeth twice daily; use mouthwash to reduce occurrence of gingivitis
- Take additional antibiotics before and after dental work to attack harmful bacteria that may invade the body during treatment
- Wash all cuts and scrapes thoroughly with soap and water and observe for signs of infection.
- Do not drink to excess as this interferes with your medication
- Don't smoke as this weakens the lungs and reduces the body's ability to fight off infection
- Don't smoke marijuana as you may inhale fungal spores
- Avoid swimming in lakes, rivers and canals because harmful bacteria live in the water which may cause stomach upset or infect a wound
- It is inadvisable to go barefoot outside
- Do not use playgrounds with wood chips under play areas as this can contain fungal spores. Choose playgrounds with plain dirt or gravel
- If you must garden, try to wear a surgical mask to filter the air
- Avoid re-potting houseplants – mould frequently grows in the soil
- If you have fresh flowers, add a teaspoon of bleach to the water to prevent mould and algae
- Do not renovate old buildings or go inside a newly renovated building until it has been thoroughly cleaned as the dust may irritate the lung and can contain fine spores of aspergillus
- Avoid a newly constructed or renovated building until it has been thoroughly cleaned
- Do not rip up or replace carpets or tiles. Have rooms cleaned thoroughly with disinfectant (normal household cleaner) before living in them. Do not sleep in the building until this has been done
- Pets are fine, but do not use wood shavings, hay, straw or sawdust as bedding as this can harbour fungus and bacteria; make sure pets are up to date on all recommended immunisations; keep water dishes and bedding clean to prevent mould growth
- If you use a vaporiser, empty it daily and wash it with bleach to prevent mould
- Fever, especially if accompanied by a cough, should always be reported immediately to your doctor as this may be the first sign of infection





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## Keeping Myself Well

### Smoking

There is one very important contribution you can make towards helping yourself to stay well:

**Don't smoke!**

Smoking lowers your immunity and damages your lungs – so if you smoke you are likely to get more infections, particularly chest infections. You could develop long-term problems with your chest and breathing.

If you suffer from bowel inflammation and you smoke, you are likely to be more unwell, have more flare-ups and will need more medicines to treat your symptoms.

Smoking is also harmful to bones too, which could lead to weak bones later in life (see Healthy Bones - page 10).

It's particularly important not to smoke 'dope' (marijuana) – it actually contains fungus which is inhaled straight into the lungs when you smoke it.

For help with giving up smoking, log on to the NHS website: [www.givingupsmoking.co.uk](http://www.givingupsmoking.co.uk), or phone NHS Smoking Helpline **0800 169 0 169**, or talk to your GP.

### Dental care

Dental hygiene is very important in CGD as it is easy for infection to enter through the mouth. Teeth should be brushed thoroughly twice a day with a standard commercial toothpaste. Some patients may also find that using a mouthwash (containing chlorhexidine gluconate) regularly helps to keep gum inflammation at bay. Sugary drinks and sweets can cause a lot of damage to teeth, particularly in children and if taken throughout the day. It is much better for teeth to keep sweets and sugary drinks to be enjoyed occasionally and are best kept to mealtimes.

It is important to get a frequent dental check-up (every 6 months). People with CGD should take anti-biotic cover for all dental procedures which are likely to cause bleeding as this can allow bacteria to enter the blood stream. CGD patients should take a course of anti-biotics before and after such work so make sure you discuss this with your dentist and doctor before going ahead with dental treatment.

(For more detail, see Information Sheet: 'Mouth Matters'.)





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### Skin care

People with CGD need to be a bit careful in their personal hygiene to help prevent minor skin infections and often find that their skin is quite sensitive. It may help to use mild soap or fragrance-free cleansers and skin care products and plenty of moisturiser (see Fact Sheet: Looking After Your Skin).

### Sun care

People with CGD (and some carriers of X-linked CGD) find that they are extra-sensitive to the sun. This means that they may burn more easily, develop skin rashes or that their skin blisters in the sun. Some medications are also associated with skin sensitivity - colouring or burning more easily in the sun, or developing a rash. Taking Septrin may make some people more sun sensitive and the new antifungal medication, Voriconazole, which a few people with CGD take, does seem to cause increased sun sensitivity/sun rash in some people. Also, if you are taking steroids for any reason you might find you are more sun sensitive/develop a skin rash in the sun – so you might want to be extra careful.

The following precautions will help you or your child enjoy the sun safely:

- Wear a high factor sun cream (SPF 15-30) or sun block. Make sure you re-apply it every couple of hours.
- Wear a hat, sunglasses and a T-shirt. Don't forget to protect the back of your neck!
- Remember sun can get through clothes - dark clothes protect the skin better than lighter colours.
- Hands, feet, faces and ears need sunscreen too!
- Avoid exposure to the sun during the hours of 12-3pm.
- Remember - it's particularly easy to burn when swimming or on a boat trip – the light reflects off the water and it's easy to pass a lot of time in the sun without realising.
- When you've been out in the sun make sure skin gets plenty of moisturiser – you don't need to spend money on expensive 'after-sun' products – a good 'ordinary' moisturiser will do just as well.
- Make sure you drink plenty in order not to get dehydrated.





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## Keeping Myself Well

### Emotional health

It is not unusual for people with CGD and their families to find themselves feeling afraid, angry, frustrated or depressed. Frequent episodes of being unwell, serious infections, and long stays in hospital are stressful for everyone. 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. **(If you would like the charity to put you in touch with someone, contact the CGD Research Trust office on telephone: 01725 517 977.)**

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 counsellor, social worker and /or a clinical psychologist who can offer you some support. 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!

People often think that if they talk to a psychologist or counsellor it means that they are 'mad' or that they will be 'labelled'. 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 physical health – it's just as important to look after your emotional health!

Whilst physical symptoms aren't generally caused by stress it is true that stress and anxiety can make things worse – we all know how being anxious about an exam or job interview gives you 'butterflies in the stomach' and makes you run to the toilet! If you are feeling low it makes even little 'upsets' more difficult to deal with. The better you feel in yourself the better you will be able to cope.

Relaxation techniques, such as medication, visual imagery and therapeutic massage can reduce physical and mental stress and help people to think positively.

Parents of children with CGD may feel guilty about passing on the disorder, or blame themselves for the infections the child has. Parents are also often torn between the needs of their child with CGD and the needs of their other children or the demands of their jobs. All these feelings can cause stress and are absolutely normal.





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## Keeping Myself Well

Brothers and sisters of children with CGD may become jealous of the attention given to the sick child. They may feel resentful, and become increasingly demanding and dependent. They should be encouraged to talk about their feelings and worries – family counselling can help sort out these and other problems within the family. Clinical psychologists who are used to working with children and families can help to suggest ways of talking with children about their illness, or that of their sibling, and strategies that parents can use to address difficulties such as problems taking medicine or demanding behaviour.

## Healthy bones

Thinning of the bones, or 'Osteoporosis', is quite common in the general population, particularly in later life. Having thin bones means you are more likely to experience a fracture from even a minor injury and that important bones in joints such as hips and knees can 'wear-out'. (If this happens an operation is required to replace the worn out joint with an artificial one).

During childhood and early adult life our bone mass (thickness or density of the bones) increases, reaching a peak by around 30 years of age. Following this, the bone mass generally declines. Lifestyle factors can affect how much bone each of us invests in our 'bone bank' when young and how much we hold on to later in life. For this reason it is really important to start looking after your bones early on!

Some of the risk factors for developing thin bones are things such as:

- smoking
- for women - absence of menstrual periods or stopping periods earlier in life
- lack of physical activity
- being underweight
- diet (if low in calcium and vitamin D).

So some even quite young people with CGD may be at risk of developing osteoporosis if they are significantly underweight, get very little exercise or have a poor diet (low in calcium).





## Keeping Myself Well

### Other risk factors are:

**Taking steroids** (unless for very short periods of time) – there are ways of minimising the effects of steroids by reducing the dose as quickly as possible, giving different forms of steroid medication, or giving it on alternate days (ask your doctor or nurse about this).

**Bowel inflammation** – this is related to the inflammation itself and the effect it has on the body, poor absorption of nutrients because of bowel inflammation, and the need for steroid treatment. (However it is important to note that steroids are still a good treatment for severe bowel inflammation and that the inflammation, if not controlled, can also contribute to thinning of the bones).

There are a number of simple things that you can do to protect your bones:

**Follow a bone-healthy diet** - healthy bones need a well-balanced diet, incorporating minerals and vitamins from different food groups.

You especially need to ensure that your diet is rich in calcium. The best sources of calcium are milk and dairy products such as cheese and yoghurt. Non-dairy sources of calcium include green leafy vegetables, baked beans, bony fish and dried fruit. (If you are concerned that you are not getting enough calcium you might like to see a dietician. A doctor or dietician can also prescribe an appropriate calcium supplement for you to take if necessary)

**Take regular, weight-bearing exercise** - like muscles and other parts of the body, bones suffer if they are not used. They need regular weight-bearing exercise which stimulates bone to strengthen. Good bone-building exercises include running, skipping, tennis, even brisk walking. (See exercise)

**Don't smoke!**

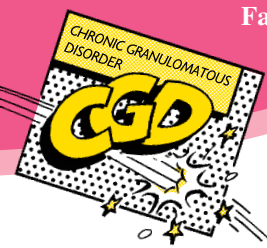
**Watch what you drink!** Drinking too much alcohol is damaging to bone.

(see CGD precautions - page 6)

For more information about osteoporosis, contact the National Osteoporosis Society on [www.nos.org.uk](http://www.nos.org.uk), or telephone their helpline on **0845 4500 230**. If you are worried that you might be at risk talk to your doctor or nurse.



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## Keeping Myself Well

### Alternative therapies

Many people may be interested in exploring complementary therapies in addition to conventional treatments. Treatments such as aromatherapy, reflexology, massage and homeopathy 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. These types of problems respond well to special relaxation techniques and even hypnotherapy.

Many people find the use of complementary therapies helpful but it's worth remembering that there is only limited scientific evidence available about the effects of complementary treatments and so it is important to think about the following:

- Always tell your doctor if you are thinking about starting another course of treatment, since it is possible for certain treatments/medicines to interact.
- Remember that because a medicine is described as natural or herbal, it does not mean that it is guaranteed to be safe (always check the contents of any homeopathic/herbal treatments with your doctor – some treatments will not be suitable for people with CGD).
- Never stop your CGD medications (Septrin and Itraconazole)
- Do not stop any other conventional treatments without consulting your doctor.
- Ensure that the practitioner of a complementary therapy is properly qualified and that they are registered with the appropriate regulatory body.
- Something that works well for one person will not necessarily suit another.

**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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