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## Teenager/Young Adult Fact Sheet No.5

# How to stay well

**You can help to keep yourself well! Keeping yourself generally as fit and well as you can also helps you feel good about yourself, gives you energy and helps avoid infection and get better more quickly if you are unwell.**

Here are a few other things that you can do for yourself that will help to keep you at your best.

## Exercise

Take regular exercise. This helps to keep you fit, boosts your immune system and releases the body's natural 'feel good' chemicals. Exercise doesn't mean you have to do anything heroic!

Activities to consider are:

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

Make sure you build up your exercise gradually and that you do something that you enjoy and suits you. Don't try and do too much too often or you will feel exhausted and fed up! A short walk each day or a gentle exercise or yoga video at home may be for you. Many people who have CGD find that they get tired a bit more easily than their friends. 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.

Check out your local health centre, library and sports centres – they should have information on what is available in your area. Many local council-run 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.

Don't forget to enjoy all the activities that you like most and if you can't do one thing, find an alternative. For example, as an alternative to contact sports, you could take up cycling, badminton, ten-pin bowling, etc.





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## How to stay well

### Diet

Eating regularly and having a balanced diet is the best way to maintain your weight and ensure that your body has the fuel it needs. Having a good, nutritious diet is important to keep your immune system and help you fight off infection. A balanced diet doesn't have to mean that burgers and pizzas are out – just remember not to have too many and to have some 'healthy food' too!

Don't skip meals – try for three small, manageable meals a day and snacks at breaktime, after school and before bed, such as plain biscuits, milky drinks, cereal, fruit or yoghurt.

### I don't want to get fat!

People with CGD tend to use up their energy quicker than other people and so need a bit more 'fuel'. If you eat a balanced diet with lots of different foods and fruit and vegetables it's very unlikely that you would put on too much weight. It's definitely not a good idea to go on a diet, without the help of a doctor, nurse or dietician (a specialist in food and nutrition). You can ask your doctor to refer you to a dietician at your local clinic or hospital.

If you have worries about your weight or about food, talk to someone who can help such as your school nurse, doctor, or the CGD nurse.

### Vitamins

You might like to take a standard vitamin and mineral supplement as it can be harder for someone with CGD to absorb all the nutrients from their diet. (It may be best to take one that doesn't have iron in – 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 all you will need – it's not a good idea to take large amounts of any vitamin or mineral supplement, as they can be harmful. Ask your doctor or pharmacist.

Flu vaccine – sometimes Influenza can cause a nasty chest infection. So make sure you ask your GP for a flu vaccine in the autumn every year.





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## How to stay well

### Rest

Don't forget to take plenty of rest to build up your reserves. Letting yourself get tired and run down won't help you stay well! You may find there are days where 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 to do. But every now and again you might need to have a lazy day or an early night or do something relaxing just to re-charge. It's ok to feel tired – watch a favourite video, read a magazine, eat some favourite food – in other words enjoy being lazy! Then it doesn't feel as if it's a bore to take some rest. You will feel better for it.

### Preventing infection

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

- *You feel fit and ok and are able to go about your daily life and do what you want*
- *It keeps you out of hospital*

However it is also important because what happens now can make a difference to how well you are when you are older. You need to look after yourself now to make sure that you look after your health for the future. For instance, if you have lots of chest infections your lungs get scarred (a bit like when you cut yourself and you get left with a scar), which can lead to breathing problems later on.

### Look after your teeth

People with CGD do sometimes get sore gums and mouth ulcers. Also, having bad teeth makes it really easy for bugs to get into the blood and cause an infection. So make sure you remember to brush your teeth in the morning after breakfast and before you go to bed. If you like you can use a mouthwash – this can help to keep sore gums and mouth ulcers away. Sugary drinks and sweets can cause a lot of damage to your teeth, This doesn't mean you can't have them but try to keep them as treats and have them at mealtimes rather than on and off during the day. (This way they cause less damage to teeth.)





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It is important to see the dentist regularly (about every 6 months). Make sure you tell your dentist you have CGD and that if you have to have a tooth out (or other dental work which might make your gums bleed) then you will need to take extra antibiotics just before and after your trip to the dentist. (Ask your doctor or the CGD nurse about this.) This is to make sure you don't get an infection.

## Look after your skin

You may find that your skin is a bit extra sensitive. You can try using soap free body wash or fragrance-free cleansers and skin care products and plenty of moisturiser

See also the Pink Series: Looking after Your Skin.

## Sun care

Some people with 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 can also make some people more sun sensitive. (Septrin can do this.) 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.

### Enjoy safe sun!

- 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!
- Try not to be in the full 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 your 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 so you don't get dehydrated.





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## How to stay well

### Emotional health

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 think 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.

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).

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 body – it's just as important to look after the way you feel!

Physical symptoms aren't generally caused by stress but it is true that stress and anxiety can make things worse – we all know how being nervous about an exam 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. So be nice to your self! If you're feeling low – do something you enjoy, spend some time with your friends, put on your favourite video or CD. The better you feel in yourself the better you will be able to cope.





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## How to stay well

### 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 break a bone even from only a minor accident 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.)

Bone thickness (or density) gradually increases during childhood and early adult life until it reaches its peak at around 30 years of age. After this age the bones begin to get thinner. Things we do in everyday life can affect how much bone we can store in the 'bone bank' when we're 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 – not having periods or stopping periods earlier in life
- not enough physical activity
- being underweight
- diet (if your diet is low in calcium and vitamin D).

So some even quite young people with CGD may be at risk of developing thin bones if they are very underweight, don't get any exercise or have a poor diet (low in calcium).

If you have bowel inflammation or take steroids for any length of time this too can cause thinning of the bones.

The good news is – 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. You especially need to ensure that you get enough calcium. The best sources of calcium are milk and dairy products such as cheese and yoghurt. It's also found in green leafy vegetables, baked beans, bony fish and dried fruit.

**Take exercise** – like muscles and other parts of the body, bones suffer if they are not used. They need regular weight-bearing exercise. (That means exercise on your legs and feet!) So, do things like running, walking, playing tennis/badminton/basketball etc. (Dancing counts too!) These types of exercise stimulate bones to get stronger.





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## How to stay well

### And finally!

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 and could develop long-term problems with your chest and breathing.

If you suffer from bowel inflammation and you smoke, you are more likely to be more unwell, have more flare-ups and will need more medicines to treat your symptoms. Smoking also causes thinning of the bones.

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

To sum up, you might find like to adopt one young person's view of CGD, who manages to live to the full! His creed is 'Don't let CGD stop you do anything – you can usually find your way around a problem.'

He says that the important things in life are:

- Eating well.
- Having fun!
- Having an education – getting through it, although it may take longer than it does for other people.
- Having strategies for coping with being ill. He suggests you:
  1. keep in contact with friends, so that you don't lose touch and you don't feel as though you've been in prison!
  2. try to have an aim everyday, like going for a walk.
  3. speak to the CGD nurse if you have any worries. She is a great help!

He also has tips for staying well. He feels it is helpful to:

- Keep fit – physically and mentally. This helps you to recover faster, if you do get ill.
- Take vitamins. (See Diet.)
- **Don't smoke!** Smoking weakens the lungs and makes it more difficult for your body to fight off infection. It is especially important not to smoke when you have a lung infection.
- Don't drink alcohol too much or too often.
- If you've got a temperature or you are feeling unwell – see a doctor or phone the CGD Nurse!





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*Drinking alcohol regularly when you are too young can cause long term damage to your liver. So it's generally not a good idea. Drinking too much means that you lose control over what you are doing and what is happening to you which can get you in to tricky and potentially dangerous situations,*

*Drinking too much can interfere with your CGD medicines and make you feel horrible. Even worse, you also might forget to take them.*

Of course, you will probably have a drink every now and again at home or with friends and that's fine. Learning to enjoy having a social drink but not to drink too much is part of growing up.

### For more information see:

#### The Pink series, including:

- Food for Thought
- Immunisations

#### 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?
- Taking control
- Taking medicines and how to carry on taking them!

#### Websites:

- [www.givingupsmoking.co.uk](http://www.givingupsmoking.co.uk)  
If you have started smoking and want help to stop
- [www.nos.org.uk](http://www.nos.org.uk)  
For information on osteoporosis, see the sections 'What is osteoporosis';  
Prevention; Treatment

**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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