



Missing Mitochondrial Genes



Teenager/Young Adult Fact Sheet No.3

Eating and diet

The best diet for anyone (whether you've got CGD or not) is a healthy diet. That means including lots of different types of food in our diets, including five portions of fruit and vegetables each day! This doesn't mean that burgers and pizzas are out – just remember to have some 'healthy food' too!

Some young people with CGD will find that it is difficult for them to maintain their weight and this can mean that they grow more slowly than their friends. It can help to have a few more calories. 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 that usually come in the form of milkshake type drinks (and some fruit flavour drink). These have to be prescribed by a doctor or dietician.

Maybe you feel that you know you need to eat more but find that you don't really feel hungry or can only manage small amounts? Don't worry – try to eat small frequent meals rather than persuade yourself to try and eat one large meal. (It will just put you off!) 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 – your school nurse, doctor, or the CGD nurse.

Growth

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 catch up with them eventually.





Missing M
Genes



Eating and diet

Steroids which are used to calm inflammatory infections can also slow down growth, if taken over a long time. (In other words if you're only having a few days on steroids, this won't affect your growth.) When your doctor reduces or stops your course of steroids, normal development and growth can get going again. If you are anxious because you are not growing, talk to your doctor about it, or ring the CGD nurse. They will be able to reassure you and to tell you about possible future options if they think that a 'kick start' for growth is necessary. They may recommend you see a growth specialist (called an 'endocrinologist').

Some people do find it difficult to keep up their weight when they are ill and are conscious about how thin they are. It is possible to have a short period of being fed by NG tube, whether you are in hospital or at home. A fine tube goes through the nose into the stomach and a special high calorie liquid food containing all of the necessary nutrients can be given to you easily through a pump overnight.

An NG tube - Alex's View

`When I was told that I was going to have an NG Tube put in I was not very pleased. The nurse put the tube in, and for about a week it felt strange, the first couple of days were the worst (it felt like raw spaghetti in my throat) but I soon got used to it.

The thing I was mostly worried about was my appearance and what people would think of me, but sometimes I forgot it was there. For the first month of the tube being in I felt out of place. I remembered me covering my face with my hands and making it look as if I was coughing, soon though I decided to forget about hiding away so I went out more and I did not cover my face as much.

Every month I had to have a new NG tube put in, and the first time this was done I was very worried. I expected the worst but because I had got used to the old tube it did not feel like raw spaghetti, the only thing that was unusual was the tube going into my nose, it made my eyes water. It works much better if you drink some water when they put the tube in.

The reason the tube is in though is to feed me overnight with a high calorie fluid. There is a tube which is attached to a pump and then the pump pumps the fluid through the tube and into my stomach. It is a bit uncomfortable and you can only really lie on one side, but you just have to cope.





Missing M
Genes



CGD Family
Fact Series



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When I started the NG tube feeding I weighed 25 kg and after 5 months approximately of being fed on the tube I am now 35.5 kg. The best thing about the tube though is it takes off the pressure of having to eat lots, but you still must eat. One last thing is that when you have had an overnight feed you will probably not be hungry in the morning so don't worry about that.'

Written by Alex, age 12

Alex's NG tip: Make sure that the tube is long enough so that the end can be taped behind your ear. It's much more comfortable.

There are also some special tubes which can be inserted directly into the stomach wall through a tiny hole (called a 'gastrostomy'). This tube can stay in place for a long time without being changed and can be kept hidden under clothes.

At first the idea is a bit off-putting, but people get used to it quickly and usually it makes you feel much better and more energetic. Once you put on some weight and your body is getting better nourishment, your growth will probably start to improve too. There are some liquid diets being made now that taste much better and can be drunk without a need for a tube.

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

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

Also see the Orange Series:

- Food for Thought.

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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