



Missing Mitochondrial Genes



Fact Sheet No.2

Dealing with a liver abscess

One family's experience:

Christopher was born in 1992, one month after his older brother Steven died, aged three. Doctors had been unable to find a cause for Steven's illness and tragically CGD was not confirmed until the day before he died from an infection he was unable to fight.

Christopher was diagnosed early. His mother, Tracey, wanted to share Chris' experience of a liver abscess:

'Christopher did well for the first few years, only suffering with mild infections and nose infections but until now no major problems. He's nine now, but recently he has been poorly. There was nothing obvious at first – tiredness, off his food, and feeling generally run down. The doctors said there was nothing wrong.

A few weeks later he seemed no different but began complaining of pains in his shoulder and stomach. I called out the doctor who admitted him to hospital. After an X-ray CAT scan it was confirmed he had three liver abscesses.

Christopher had trouble with the canulas. They didn't last very long and all in all he has had 15 canulas in five weeks. He was allergic to three of his antibiotics – he has quite bad reactions. There were times when we thought he would never get better.

For five weeks he had a constant temperature, usually as high as 40.7C. One abscess was drained but doctors couldn't get to the other ones. A neck line and a nasogastric tube were fitted. He was started on interferon three times a week but still he wasn't fighting the infection.

Finally, he was put on Vancymycin which started to work but then the line in his neck became infected. This was taken out and a new line was put in just under his shoulder. So far so good. The antibiotics are now working and temperatures have been normal for just over a week. The abscesses have shrunk and Christopher is a lot better. When he does come home he will still be on antibiotics for the foreseeable future.'

What are liver abscesses?

An abscess is a localised collection of pus in the tissues of the body, usually caused by bacterial infection. An abscess can occur anywhere in the body, including the liver. Abscesses can occur in individuals with a healthy immune system but a liver abscess is uncommon. People with CGD are prone to getting abscesses in lots of places and a liver abscess may be the feature that leads to a diagnosis of CGD.





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What causes the abscess?

A bacterium called staphylococcus aureus is the most likely cause, although other bacteria or even fungi may be responsible.

What should I look out for?

Liver abscesses can be quite hard to detect as they don't give out very clear signs that they are there.

Some of the things to look out for are:

- Feeling generally unwell
- Feeling very tired and 'floppy'
- Loss of appetite
- Loss of weight
- Tummy pain or back pain
- A fever (perhaps low to start with (37.5 – 37.9) and then higher (38-40).)

Many of these symptoms also accompany other more minor conditions and infections in other parts of the body, so the presence of one or more of these symptoms does not mean that you/your child has a liver abscess but it could be a **possible** cause.

How is it diagnosed?

When a doctor examines the abdomen they may be able to feel that the liver is enlarged and harder than normal. It may also feel very tender when they press over the liver.

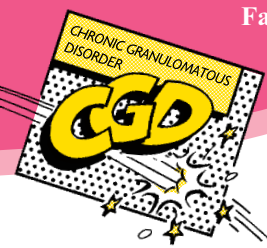
The doctor will then request an ultrasound scan of the abdomen and liver. This is a very simple and quick way to look for abscesses in the liver and can show where they are and what size they are. It is not unusual to have one larger abscess together with some smaller ones. Sometimes two small abscesses will join together to form a larger abscess. Further scans, such as a CT scan, may be needed to get more detailed information about the abscess.

It is also important to try and confirm which bug is causing the abscess. To do this, some of the pus from the abscess is removed and sent to the lab for analysis. This is done by inserting a fine needle into the centre of the abscess through the outside wall of the abdomen. The doctor may use a scan during the procedure to help them insert the needle into the abscess. You/your child will be given appropriate sedation, local anaesthetic or general anaesthetic for this procedure.





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How serious is it?

Liver abscesses can be serious and can make you/your child feel very unwell so they do need to be treated promptly and effectively. Liver abscesses can take quite a long time to get better but with the appropriate treatment you / your child should make a complete recovery.

How are they treated?

Treatment for liver abscesses usually requires a lengthy stay in hospital while investigations, drainage etc is carried out and to have intravenous medication. Once well it is often possible to return home and have the medicines given by a community nurse at home, or, where this is not possible, by attending hospital only for medication and going home in between. Some people may be able to learn how to give antibiotics themselves at home.

Liver abscesses are treated with antibiotics and occasionally antifungal medication. Usually a combination of antibiotics is used. These will need to be given intravenously over a long period of time, often several months, to ensure that all the bugs are killed. To make giving the antibiotics easier, a special tube may be needed, which is inserted into the arm, neck or chest (often called a 'central line') and can stay in place for several months and allows medication to be given directly into a vein. These tubes can also be used for the frequent blood tests that will be required. Central lines are removed as soon as they are no longer needed. After some time, it will be possible to change on to antibiotics taken by mouth, but these too may need to be taken over several months.

It is also quite common to use Interferon Gamma for treatment of liver abscesses, in combination with anti-biotics/anti-fungal medicines. This is given as an injection, just under the skin, three times each week. For many people, Interferon Gamma can cause flu-like symptoms and 'chills' during the twenty four hours following treatment. These can usually be managed with Paracetamol. Interferon Gamma can also be given at home by community nurses, although some people learn to give it themselves.

Getting better from liver abscesses takes time and it may take a while to feel fit and well and get back to normal levels of activity. This is quite normal for someone recovering from liver abscesses. You or your child may need to take things slowly and get back to school or work gradually a few hours at a time.





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Liver abscesses can be very slow to get better. The fever that accompanies the abscess can take a long time to reduce. The temperatures should begin to be a bit less frequent, and perhaps not so high, once treatment is underway but you or your child may still have a high temperature once or twice a day for some time. This does not necessarily mean that you/are not on the right treatment or that it is not working. It simply takes a long time for treatment to be fully effective.

Sometimes it is helpful to put a drain (narrow plastic tube attached to a collection bag) in to the abscess to drain out the pus, which may need to be left in place for several days. Draining the abscess may make it easier for the antibiotic treatment to work. However it is not always possible to drain abscesses, either because they haven't any liquid pus inside or because they are in a place that is difficult to get to. Occasionally an abscess will need to be drained on more than one occasion.

It is sometimes helpful to have an operation to remove the bulk of the abscess. Again this leaves less work for the antibiotic treatment to do but antibiotics are still needed in order to clear the bug completely or deal with other smaller abscesses.

Nutrition

Many people find that they lose their appetite during long-term treatment and stays in hospital. This sometimes means that they need extra nutrition, which can be taken in the form of milkshake drinks, or given via a special feeding tube in the nose or stomach. Very occasionally patients may need to be fed for a short time intravenously through a central line.

Do liver abscesses cause any long-term problems?

The presence of the abscesses can cause some 'upset' to the liver. This usually shows itself in changes in the blood tests that are used to assess how well the liver is working (called 'liver function tests or 'LFT's'). Some people will find that they get 'jaundice', a yellowish colouring of the skin or whites of the eyes, caused by a build up of bilirubin, a waste product of the liver. Liver function tests usually settle back to normal once the abscesses are better and the liver becomes softer and smaller. The scars left by the abscesses are likely to remain visible on x-rays or scans for some time (even years). There is rarely any long-term damage to the liver.

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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