



An easy read guide to NF1.



The doctor says “You have Neurofibromatosis”.

What is that?

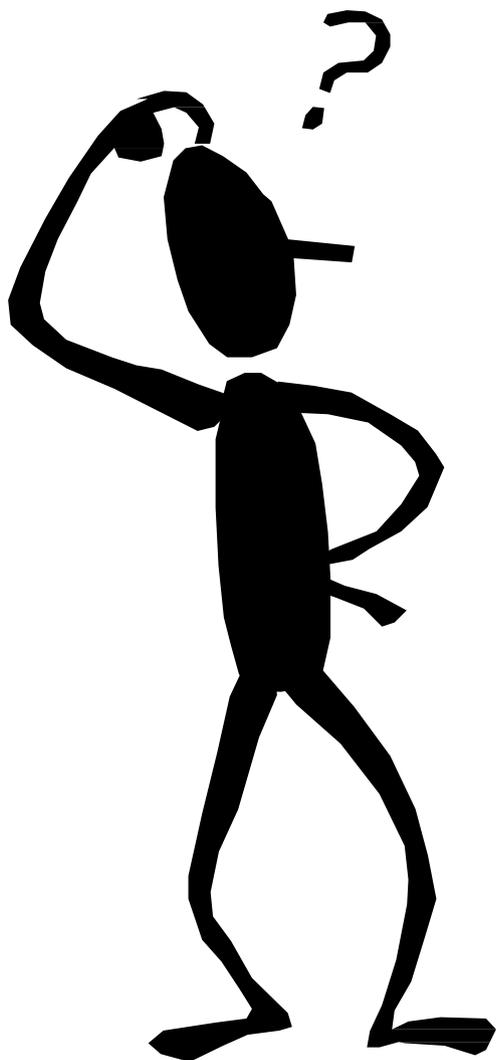
What does it mean for me?



Neurofibromatosis type 1

Neuro...fibro...ma...to...sis
is a long word and difficult to say.

So we call it NF1 which is easy to say.



What is NF1?

NF1 is a medical condition. It affects your health.

NF1 affects people in different ways.

... some people just have signs of NF1 on their skin.

... other people will have more serious health problems.

If you have NF1 it is good to learn more about it.



How does the doctor know I have NF1?

The doctor looks for signs of NF1 on your skin.

The first sign is having lots of birthmarks...more than 6 birthmarks.

The doctor calls these cafe au lait (kaff ay o lay) marks.



Signs of NF1

The doctor looks for other signs of NF1 on your skin.

Freckles in the armpit or groin is another sign of NF1.



Signs of NF1

If you have NF1 you will get lumps and bumps.
You can see these lumps clearly on your skin.
Some people get a few lumps...others get a lot.



Now the doctor is sure you have NF1.

Because you have the 3 main signs of NF1...

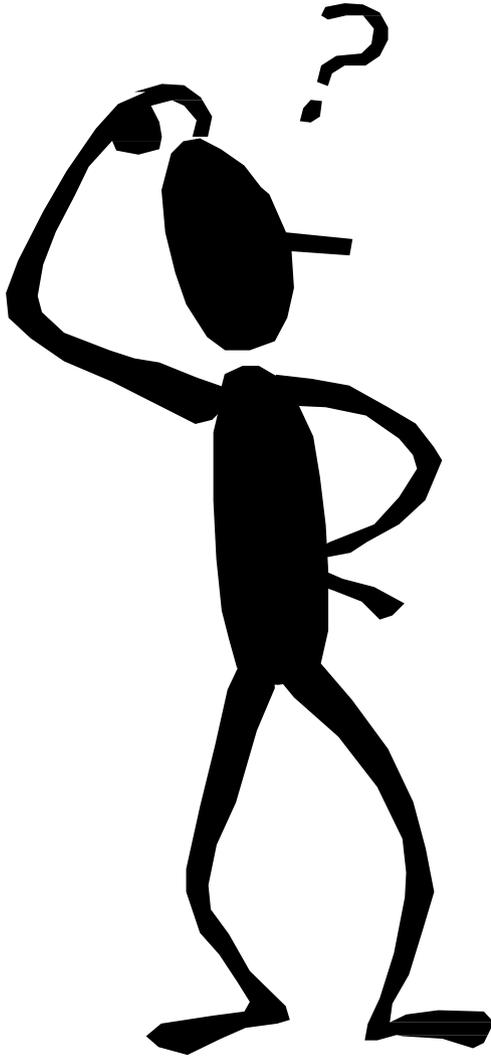
- brown birthmarks
- freckles in unusual places
- lumps and bumps

The doctor asks you lots of questions:



- If your parents, brothers, sisters or your children have signs of NF1.
- If your family want an NF1 health check.
- What you know about NF1...and what you don't know.
- If you are worried about anything to do with your health.

You may want to ask the doctor some questions.



Meeting your doctor is a chance to ask about things you want to know.

Questions that you think are important.

You could make a list of questions to remind you.

Or take someone you trust with you to your appointment.

Why do I need to see a doctor if I have NF1?



If you have NF1 then you need to learn more about it.

Learning about NF1 helps you to take better care of yourself.

And to know when to ask for help.

Most people with NF1 are well. You need to have a health check every year. This can be with your GP (family doctor) or NF1 doctor.

Some people with NF1 have problems with their health. If you are worried about your health, talk to your doctor.



At your NF1 appointment the doctor will check:

- your eyes
- your skin
- your blood pressure

The doctor will ask lots of questions.

This helps the doctor to work out if you are keeping well, or if you have any health changes that need more checks.

Lumps and bumps are part of NF1

Some lumps are small. Some lumps are big. The lumps grow on nerves.

Nerves are like the wires in an electric cable. They carry messages for feeling.

Nerves tell us if something is hot or cold, sharp or smooth when we touch it.

Nerves tell our muscles when to work so we can move our arms and legs.

Some lumps grow on nerves inside the body. You might be able to feel them under the skin.

It is important you know where your lumps are and what is normal for you.

Most NF1 lumps are not cancer.





Lumps that must be checked by a doctor.

Having lumps is part of NF1. Some lumps can cause a problem. You should tell your doctor if you notice

- a lump that grows very fast
- a lump that hurts all the time
- a lump under the skin that changes from feeling soft to feeling hard

Remind your doctor you have NF1

I don't like the lumps. What can I do?

Some people want their lumps removed. Talk to your GP. Your GP can send you to a specialist doctor.

A specialist doctor called a plastic surgeon can remove lumps. They can cut the lumps out. This can leave a scar. Sometimes the lump grows back again.

Some skin doctors use a laser to burn the lumps off. This can also leave a scar.

Big lumps or lumps deep inside the body can be very difficult to remove.

The specialist doctor will explain what they can do. And what they can't.



What do I need to check?

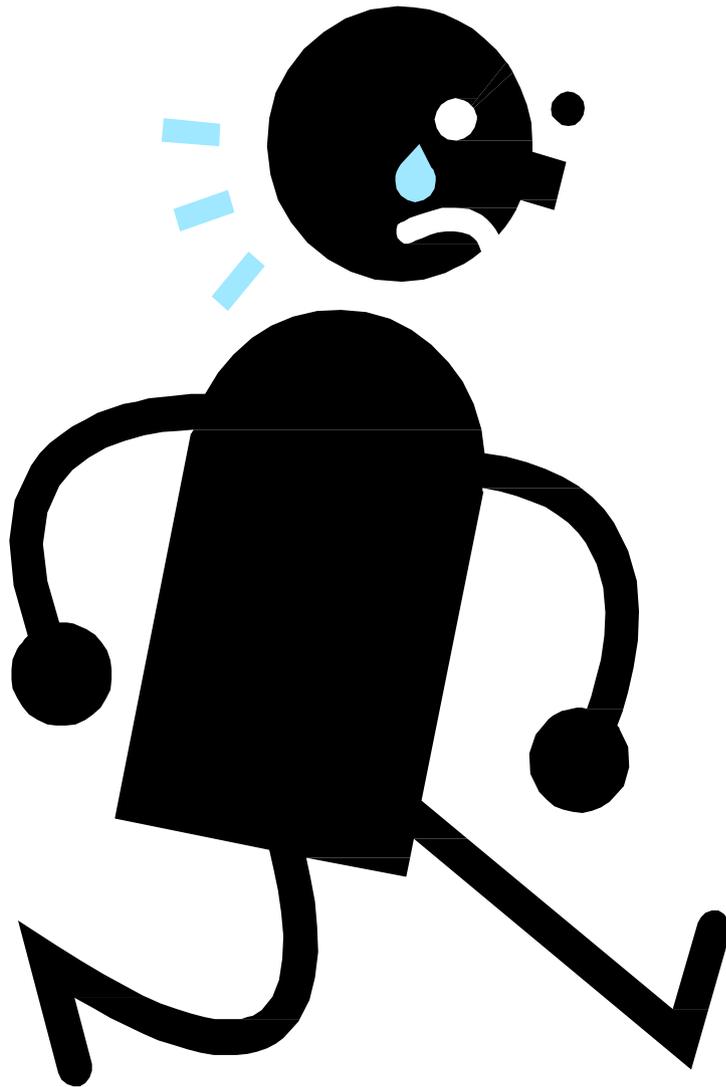
Tell your doctor if you have

- headaches that are getting worse, that make you sick, or wake you in the night
- if your eyes are blurry or you see double
- your arms or legs feel numb, have pins and needles or if your legs give way so you fall down
- any unusual pain that lasts more than a few days

Remind your doctor you have NF1.

Ask your doctor “Can this be to do with my NF1?”





Sometimes I feel sad because I have NF1.

Everyone feels sad from time to time. If you feel sad, it is important to talk to someone like

- a friend
- a family member
- someone you can trust

But if you are feeling sad most of the time it is important to tell your doctor so they can help you.



Remember...

Lots of people have NF1.

Not everyone has problems because they have NF1.

There is help for you if you ask.

Make sure you talk to your doctor if you are worried.

Helpline Team
Nerve Tumours UK Helpline

helpline@nervetumours.org.uk
07939 046 030

Nerve Tumours UK
44 Coombe Lane, London SW20 0LA

nervetumours.org.uk



Please seek further information from www.nervetumours.org.uk, or contact our helpline on the details above.

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