NEUROFIBROMATOSIS TYPE 1 (NF1) A GUIDE FOR ADULTS AND FAMILIES

Introduction

Neurofibromatosis (NF) is a collective name for a group of genetic conditions that affect the nervous system. NF causes benign (non cancerous) lumps to grow on nerves. These lumps can grow on nerve endings in the skin where they can be seen clearly; the lumps can also grow on deeper nerves within the body.

Neurofibromatosis occurs all over the world in all races.
It affects men and women equally.

There are two main types of Neurofibromatosis: Neurofibromatosis type 1 (NF1) and Neurofibromatosis type 2 (NF2).
They are **two completely different and separate conditions.** People who have NF will have one type or the other.
NF1 cannot change into NF2.

THIS INFORMATION IS ABOUT NF1 ONLY

NEUROFIBROMATOSIS TYPE 1 (NF1) is a common genetic condition.
A genetic condition is one that can be passed on in families.
Approximately 1 in every 2,500/3000 people is born with NF1.
In the UK, every day a child is born with NF1.
There are about 25000 people in the UK with a diagnosis of NF1.

NF1 varies widely in how it affects people. Many people with NF1 will be affected very mildly and may have nothing more than skin changes.

A minority of people (about a third) who have NF1 will have health problems linked to the diagnosis at some time in their life. Some of these problems will be mild and easily treated, others will be more severe.

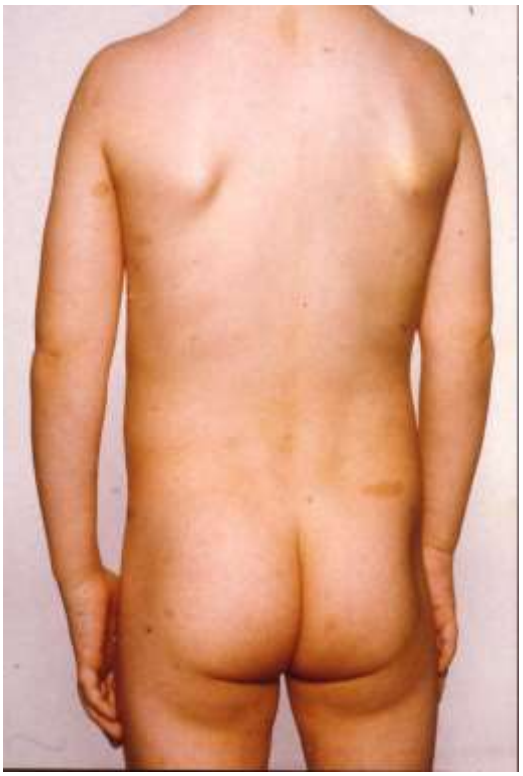
At present, doctors cannot predict who is going to develop health problems linked to having a diagnosis of NF1. Research is helping to identify some individuals at greater risk of developing health complications. Until this is clearer, it is helpful for people to learn more about NF1 to understand what this diagnosis means and to know when to seek medical help.

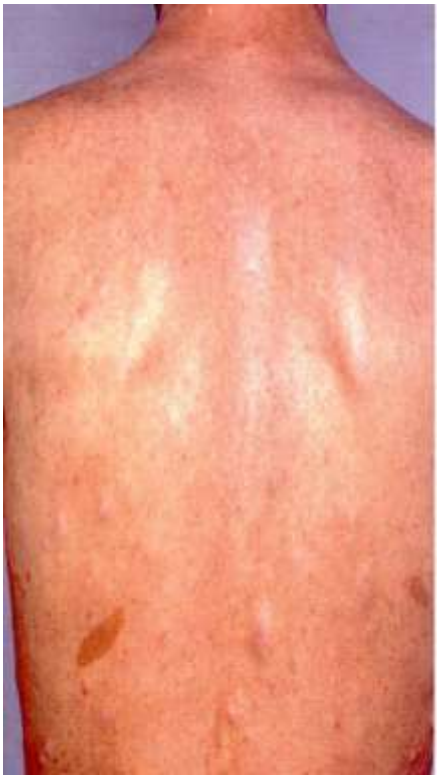
The kind of things that should prompt you to seek advice from your doctor are discussed later in this guide.

How is NF1 diagnosed?

The way a doctor can tell if a person has NF1 is by examining them for signs of this condition. There are specific features that the doctor will look for. Signs of NF1 usually appear in childhood (mostly in the first 3 years of life and almost always before the age of 5). The diagnosis of NF1 is confirmed if two or more of the following signs are present:

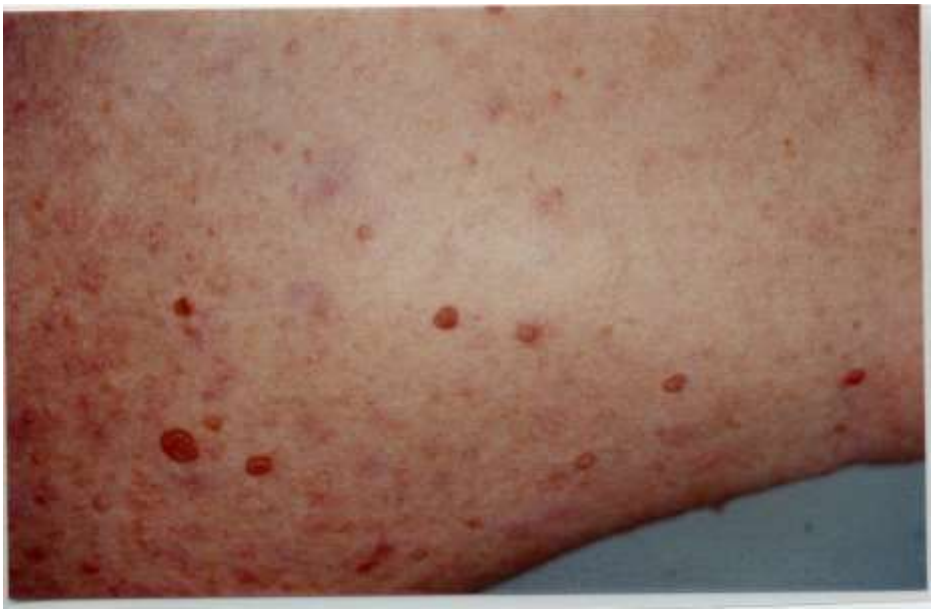
• Six or more flat, **café au lait** patches (brown coffee-coloured skin patches like a birthmark), which are the size of a pencil top or bigger. These usually appear during the first year of life and can increase in size and number. Café au lait patches are generally harmless and there is no connection between the number or size of café au lait patches and the severity of the condition. They sometimes fade later in life.





• **Freckles** in the armpit or in the groin. Again, these are harmless but can be another sign of NF1.

• **Neurofibromas** (small benign pea-sized growths or lumps) on or under the skin. These are a common feature of NF1. They usually appear during adolescence and tend to increase in number throughout life. Sometimes neurofibromas are present in childhood.



• **Plexiform neurofibromas**. These are a particular kind of neurofibroma. In a plexiform neurofibroma a whole section of the nerve or a group of nerves in one area of the body are affected. Sometimes the overlying skin has a large area of café au lait pigmentation. In adults this can become a red-purple colour. The overlying skin can be more hairy.

• **Lisch nodules** – these are small pigmented areas in the iris (coloured part) of the eye. They are often not visible except during examination with an eye microscope called a slit lamp. Lisch nodules are harmless and never cause symptoms. When identified they help confirm the diagnosis.

• A mother, father or child who has NF1.

Summary of how NF1 is diagnosed

Signs of NF1 appear in childhood.
The signs include:
- Café au lait patches (more than 6)
- Freckles in unusual places
- Lumps and bumps on the skin

Another health problem linked to NF1
Mother or father with NF1
A blood test is not normally needed

Why does a person develop NF1?

About half the people who have NF1 are the first person in the family to be affected. The condition has started with them by chance.

Our body is made of thousands of cells. These cells contain sets of instructions in the form of genes. The instructions contain chemical codes that ensure the cell works correctly. A change in a gene means it cannot do its job properly. The change in the gene is called a "mutation". This happens before birth and there is no known reason why it occurs.

Where there are no signs of NF1 in either parent, it means that the gene change (mutation) has occurred for the first time in that individual (child or adult). This is called a 'new mutation'.

The other group of people who have NF1 will have inherited the same condition from a parent who also has NF1.

An experienced doctor can diagnose NF1 by a careful physical examination. Sometimes the signs of NF1 take time to appear and therefore it may not be possible to make an immediate diagnosis of NF1. You (or your child) may be asked to come back to see the doctor on another occasion for a second examination. This can be a frustrating and anxious time for parents (or adults) who are under investigation; however, your doctor will want to be sure that the diagnosis of NF1 is correct.

Sometimes a doctor will offer to test for NF1. The genetic blood test for NF1 is getting better all the time but still does not pick up 100% of gene changes – only around 95%. The blood tests are being used more and more to aid diagnosis, particularly where neither parent is affected.

NF1 does not skip generations. There are two ways in which NF1 occurs: it crops up out of the blue as a first event in an individual or it is inherited from an affected parent.

Summary of how NF1 occurs

Our body is made up of thousands of cells. Each cell contains a set of genes. Genes carry instructions that make the cell work correctly. NF1 is caused by a misprint or miscopy in these instructions.
Half of people with NF1 have inherited it from a parent who also has NF1.
Half of people with NF1 are the first person in the family with NF1.
NF1 is a dominant condition. Everyone who has NF1 will have some signs of the condition.
If a parent has NF1, there is a 1 in 2 chance of passing it on to each child they have.

How does NF1 affect the body and what can be done about this?

If someone has NF1, he or she will have it for life. There is as yet no

specific medical treatment or gene therapy to cure, prevent or reverse the features of NF1. Many people who have been diagnosed with NF1 never experience health problems. However, some people who have NF1 can develop some of the complications that are known to be linked to the condition.

The development of some of these features is related to age and some complications can first appear in childhood. Specific complications can be treated medically or surgically depending on the problem. Research may lead to new treatments in the future.

NF1 is complicated. It varies from one person to another, even within members of the same family. It is also unpredictable.

At present there is no way to predict how mildly or severely any individual will be affected. Expert NF1 doctors recognise that some groups of NF1 patients need more specialist care than most. To address their needs, there are now 2 nationally funded Neurofibromatosis Centres in England. These Centres care for patients with the most complex NF1. They are located at Guy's Hospital in London and St Mary's Hospital in Manchester. Patients can be referred to these centres by their own doctor. There are national guidelines as to which patients are eligible for this service.

It is important to remember that many people have still not heard of NF1.This suggests that in spite of the many thousands of people who have NF1, it is not necessarily a problem. About two thirds of people with NF1 will be mildly affected and lead a normal healthy life.

If there is a TV programme or magazine article about NF1, it is inevitably described as a severe and frightening condition. It is important to get a balanced view. The vast majority of complications associated with NF1 are not life threatening.

Summary
NF1 is variable and unpredictable.
Even in the same family people can be affected in different ways: some very mildly others with more problems.
The majority of people with NF1 are well and lead normal lives.
There is a specialist service in England to care for patients with the most complex NF1.

Some specific complications that occur in NF1

(This is not a complete list of all complications that can occur in NF1. Nor is it a substitute for advice from your own doctor)

Ophthalmology (Eyes)

NF1 can cause problems at the back of the eye in the form of lump or tumour. This lump is called an optic nerve tumour or an optic pathway glioma. This is most likely to occur in early childhood, up to about the age of 7. An optic glioma is a non-cancerous growth that involves the cells of the optic nerve, the nerve that connects the eye to the brain. Many optic gliomas in NF1 never cause any symptoms. They can be found coincidentally when a scan is done for something else. When they do cause problems it is usually a decrease in vision, the eye bulging forward (proptosis) or, in a small percentage of cases it can cause early puberty.

Where this complication is diagnosed during childhood, it rarely progresses in adulthood. However people with this problem need careful monitoring by an ophthalmologist (specialist eye doctor).

All children under the age of 7 years will have hospital eye checks as part of their NF1 health check. Once discharged from the hospital eye service, children and adults should have annual vision checks, reminding their optician they have NF1.

If someone with NF1 develops unusual changes in vision, blurred or double vision, they need to seek medical advice quickly. If parents notice young children bumping into things or a sudden onset of squint, they should ask for an urgent eye check.

Orthopaedic (bones)

In NF1 bones are affected in two main ways: there are some problems that affect a specific part of the body (for example a curve developing in the spine). The second way is there is increasing evidence that some people with NF1 can have a general decrease in bone strength (decreased bone mineral density).

Specific localised bone problems arise during childhood. For example NF1 can affect the growth and development of long bones, particularly the tibia (front lower leg bone or shinbone) causing them to bow. Rarely the bones that create the eye socket may not form properly causing problems with the position of the eye. Both of these problems are likely to be identified during infancy and will not develop out of the blue in later years.

Children can develop curvature of the spine (scoliosis) in NF1. This complication can occur up until a child is fully grown. If the spine is straight on reaching the final height (at 17/18 years), it will remain straight.

Complications affecting bones in NF1 are referred to a bone specialist (orthopaedic surgeon).

Decreased bone density or osteopaenia is found more frequently in NF1. This can lead to osteoporosis in adults. Adults with NF1 may also have

lower levels of vitamin D than normal. The NF1 clinic doctors are trying to work out whether all NF1 patients should therefore have bone checks as part of their routine healthcare. How best to manage this risk should be discussed with your doctor or NF1 specialist.

Dermatology (skin)

Neurofibromas are benign (non cancerous) tumours/growths that develop on or under the skin or along a nerve. They can occur anywhere on the body where there are nerves. They may look and feel like small pea-sized lumps or nodules under the skin. Skin neurofibromas are usually soft and painless. Those that are under the skin may be firmer to touch but are normally painless. Other neurofibromas may be located deep in the body and cannot be felt from the outside. They do not usually cause health problems although some may press on a nerve causing symptoms such as pain or numbness. In this case further medical advice is needed.

Many adults feel embarrassed and self-conscious about their neurofibromas. There is no way to predict how many neurofibromas a person with NF1 will have, or when or where on the body they will develop. However, almost all people with NF1 will have some neurofibromas. Some people will have very few; others will have many. At present there is no treatment that can prevent or slow the growth of neurofibromas. Research into preventative treatment for neurofibromas is continuing in the UK and internationally.

Sometimes a neurofibroma grows in an awkward place and may catch on clothing. It may be possible to remove it. This should always be undertaken by a doctor who has experience of NF1. This doctor will be a dermatologist or a plastic surgeon. There are at present 2 main ways that neurofibromas can be removed: one is by surgery and the other by laser treatment. To access this service you should ask your GP or NF doctor to refer you to the nearest specialist.

Many people with NF1 tend to tan easily without sunburn. Café au lait patches are not at risk of turning into a skin cancer. However, like everyone else, people with NF1 should take the usual steps to avoid too much sun exposure and sunburn.

Plexiform neurofibromas

Some neurofibromas can grow in a wide, spreading fashion around large nerves and may feel like a bunch of knots or cords beneath the skin. These types of growths are called plexiform neurofibromas. About a third of people will have one or more of this type of lump. Sometimes they will be obvious in early life as an area of swelling or fullness but other times they can lie deeper in the body and are harder to detect. They can grow anywhere on the body and, more rarely, on the face.

When they are present near the surface plexiform neurofibromas sometimes grow to a large size. If this is going to happen, it usually does so within the first few years of life. These tumours can be painful if knocked and can be disfiguring depending on their size and shape. Less

commonly, a plexiform can become cancerous (more on this follows). Any unusual pain in a plexiform neurofibroma should be checked by a doctor. **If a plexiform neurofibroma is painful all the time, grows very rapidly or feels hard rather than soft, medical advice is needed without delay.**

Removal of plexiform neurofibromas is difficult and needs the specialist skills of experienced plastic surgeons, orthopaedic or neurosurgeons who specialise in peripheral nerve surgery.

Tumours and cancer

Everyone, whether they have NF1 or not, has a risk of about 1 in 3 of developing cancer during their lifetime. People with NF1 have about a 1 in 10 (or 10%) chance of developing a specific cancer related to NF1. Putting this another way, there is a 90% chance of someone NOT developing an NF1 related cancer. Research in this area is continually being updated.

People generally are aware of what is their "normal" state of health whether they have NF1 or not. Having NF1 means it is important to be aware of unusual health changes or symptoms. You should seek medical advice if you experience any new, significant or unusual changes in body habits which do not go away, just as you would if you did not have NF1. This could include a new or persistent pain, or a change in physical activities.

The small skin neurofibromas never become cancerous.

Plexiform neurofibromas are more at risk of turning into nasty lumps (becoming malignant). When this happens the tumour is called a malignant peripheral nerve sheath tumour or MPNST.

The signs to be concerned about if you have a plexiform neurofibroma are: **sudden rapid growth where there was previously slow growth; change in texture and the development of unexplained pain, for example where the plexiform neurofibroma was not bumped or knocked. If the pain appears for no apparent reason and does not go away, this should be checked out with your doctor.**

MPNSTs can also develop out of the blue. So if anyone with NF1 notices a lump under the skin growing rapidly or that has become painful, they should get it checked by their doctor urgently. Also if they develop unexplained persistent pain, this could be a sign of an internal MPNST. Again this needs urgent advice from the doctor.

People with NF1 have a slightly increased chance of developing a brain tumour compared to the general population.

Adults who experience persistent new headaches or a change in their usual physical abilities or activities (weakness, numbness, tingling in arms or legs,) or a change in personality or memory

should seek medical advice.

Children with NF1 are at risk of two very rare childhood cancers (a rare form of leukaemia and a tumour called a rhabdomyosarcoma that usually grow near the bladder). These are so rare that even in the Specialist NF clinics, doctors rarely see these developing. The important thing for parents to know is that if their child is "just not right" they should be asking their doctors if it could be linked to their diagnosis of NF1.

For adults, understanding what is "normal" for you is helpful. If you have symptoms that are unusual for you it is sensible to seek advice and remind your doctors that you have NF1.

If you think that your doctor is not getting to the bottom of things, then it can be helpful to ring Nerve Tumours UK for advice. The charity has a Helpline service for patients. Alternatively you can ring one of the two national NF1 centres: either Guys hospital, London or in St Mary's hospital, Manchester.

Breast cancer

Research shows that women who have NF1 have a slightly higher chance of developing breast cancer during their lifetime. Their breast cancer risk is described as "moderate" and therefore screening should follow national guidelines. At present this means having a breast x-ray (mammogram) each year from the age of 40 years. Your GP can arrange this.

Hypertension (high blood pressure)

Occasionally NF1 can cause high blood pressure. **It is recommended that everyone with NF1 should have their blood pressure checked once a year throughout life**. Sometimes high blood pressure may not be related to NF1 and it is a **common** and **treatable** condition in adults who do not have NF1.

The specific reasons for raised blood pressure linked to NF1 include a lump growing on or near the kidney (phaeochromocytoma) or a narrowing of the artery to the kidney (renal artery stenosis). These can be treated.

Glomus tumour

This is a small benign lump that grows in the nail bed of one or more fingernails and toenails. It is rare. It causes severe pain in the affected finger/toe which is often worse in the cold. Sometimes doctors get confused and think the pain is coming from a nerve tumour elsewhere. Doctors in specialist NF clinics sometimes see patients referred with unexplained hand or foot pain who have undergone lots of scans of the spine and nerves supplying hands and feet which all turn out to be normal. The diagnosis of glomus tumour is made in the clinic by simple means: the doctor presses on the nail bed and the pain is excruciating. Once diagnosed, the tumour can be easily removed, fully relieving the symptoms.

Epilepsy

Everyone is at risk of developing epilepsy during their lifetime. In people with NF1 that risk is slightly increased. Symptoms suggestive of epilepsy should be investigated and treated in the usual way. This will usually involve referral to a neurologist who will be able to diagnose and treat the symptoms.

Young children with NF1, usually before the age of 2, have a very small risk of developing a specific kind of seizure called infantile spasm or hypsarrythmia. This should be suspected if the child develops sudden jerking movements of the arms and legs.

Self image

Most people with NF1 have some signs of the condition visible on their skin. Some individuals have more obvious signs of NF1 than others and they can find the outward signs of the condition an extremely distressing burden to live with. There is no easy way to deal with this medically. Café au lait patches may increase as a child gets older but may fade in adulthood. They can be covered with clothes or make-up.

Skin neurofibromas can cause more obvious cosmetic effects. They can be removed by a plastic surgeon but there will be some scarring. They may or may not grow back and it would be impossible to remove all neurofibromas in someone who has a lot of them. Laser treatment can be used but, again, it is difficult if someone has a lot of neurofibromas. You need to ask your doctor for a referral to a specialist plastic surgeon or dermatologist to discuss what is possible for you.

Camouflage make-up can sometimes help. This is a hospital-based service offered by the charity Changing Faces and you can be referred by your GP. Many people find it helpful to talk through these sorts of issues with a skilled counsellor. It is important to know that you do not have to feel alone with these difficulties and that there is support available.

Pain and itching in NF1

For most people neurofibromas do not cause any problems. However, some individuals can experience pain and/or itching. Some adults with NF1 complain of chronic pain and this should be investigated medically. Back pain is sometimes related to a neurofibroma growing near the spine and it might not be possible to remove this neurofibroma surgically. For an adult in whom chronic pain has been fully investigated, a referral to a specialist pain clinic may be useful (ask your GP about this).

Pain-relieving medication can sometimes help in the management of this type of pain. Some pain relief medications are very helpful, including a type of anti depressant that is effective in relieving nerve pain. If you find the medication unsuitable either because it does not seem to work or you have unpleasant side effects, return to your doctor to seek further advice.
(For more information about pain relief please look at our information sheet on pain management).

Headaches can be a problem for some people with NF1. Again, medication may help. Headache should be investigated particularly to work out if it is a migraine type headache that will respond to medication. If headache gets worse or occurs in the morning on waking or wakens you from sleep, medical advice is necessary.

Itching sometimes happens in NF1. This seems to be worse when exposed to heat (e.g. when taking a hot bath). Avoiding situations that you know will make matters worse is helpful. Medication such as antihistamines or a simple emollient can sometimes help – ask your GP for guidance.

Learning and behaviour problems

Most people with NF1 have normal intelligence, but around two thirds of people who have the condition will experience some problems with learning. It is the most common "complication" of NF1. The majority of children who have NF1 are educated in mainstream schools and do not require special education, although they may benefit from extra help.

Children and adults who have NF1 and who have learning problems may have difficulty reading and writing, they may find it hard to concentrate, have memory difficulties or have poor co-ordination. Where someone with NF1 has learning problems, this is often evident from their earliest years at school and, as children, they may underachieve at school and have difficulties establishing and maintaining peer friendships.

Research has demonstrated that there is an increased incidence of Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD) in NF1. There is also an increased incidence of mild autism (sometimes called Aspergers). These conditions should be assessed, diagnosed and supported in the same way as any other individual where this is suspected.

There can sometimes be behaviour difficulties at home and at school. These difficulties can be similar to the difficulties found in children who do not have NF1, where there are conditions such as dyslexia, dyspraxia (clumsiness) and attention difficulties. It is important that these problems are recognised as early as possible so that teachers are aware of how NF1 can affect school performance. It is useful to have a frank discussion with teachers so that common misconceptions about NF1 can be dispelled and the child can get help in school if he or she needs it.

Learning and behaviour problems in NF1 are not progressive, that is they do not get worse over time. In fact, they can usually be improved with appropriate help.

The Nerve Tumours UK website (www.nervetumours.org.uk) has a number of Information Sheets about learning problems in NF1

Deciding to have children if you have NF1

NF1 is caused by a change in the structure of a gene. Each person has about 30,000 genes in their body. Genes are the set of instructions within cells that tell the body how to grow, develop and function.

Genes come in pairs, so we all have two copies of the NF1 gene. If a person has NF1, one of these copies will have an alteration or miscopy. When someone with NF1 has a child, he or she passes on one of their two copies

of the gene: either the normal one or the copy with the NF1 alteration. If the normal copy of the gene is passed on, the child is very unlikely to have NF1. If the altered NF1 gene is passed on, the child will have NF1.

Therefore, every person with NF1 has a 50:50 or 1 in 2 chance of passing the condition on to each of their children, boys or girls.
For adults with NF1 who are planning their family, there is no way to predict how mildly or severely a child who inherits NF1 will be affected. The decision whether or not to have children is a very personal one for a couple and may depend on personal experience of NF1.

Prenatal diagnosis (testing an unborn baby in the womb) and pre-implantation genetic diagnosis (PGD) techniques are now available to couples planning a family. Couples wishing to find out more about these choices need to ask for referral to their regional genetics department **at a very early stage of their planning.**

NF1 and pregnancy

If you are generally in good health, there are no specific concerns about pregnancy and NF1. If you are pregnant and you have NF1, you should let the maternity unit know that you have NF1 at the first antenatal visit. Some women report an increase in the number of neurofibromas and an increase in size of existing neurofibromas. When your baby arrives, they should be checked for features of NF1 from the first months of life by a community or hospital paediatrician, geneticist or clinic specialising in NF1.

There is no reason why a mother with NF1 should not be able to breastfeed. Occasionally the presence of neurofibroma(s) around the nipple can create difficulties for the baby to "latch on".

What do I need to do to look after myself or my family if we have NF1?

If you have NF1, you should expect to live a long life in good health. Most people who have NF1 go through life with relatively few medical problems. NF1 can cause life-threatening problems but these are rare. It is important to have regular medical follow-up so that any complications can be identified early.

If you notice unusual health changes or symptoms it is important to seek medical advice sooner rather than later.

When to seek advice from your doctor

It is important to seek advice from your doctor if you have any of the following symptoms:

- **headaches that are getting worse**
- **double vision or blurred vision**
- **numbness, tingling or weakness in your arms or legs, or your legs give way**
- **a lump that grows fast and is painful all the time, even when it has not been knocked**
- **a lump under the skin that was soft but now feels hard**
- **any pain that persists or wakes you from sleep at night**
- **any unexplained worrying health change that goes on for more than a few days**

Remind your doctor that you have NF1 and ask the question "Could this be linked to my NF1?"

If the problem does not go away or is getting worse, return to your doctor for further advice or ask to be referred to a specialist

Professionals important to your care if you or your child has NF1 are:

Family doctor (GP)

It is important to note that your GP may not see many people with NF1 and for this reason they may not know how variable NF1 can be from person to person. Medical guidelines can be sent from Nerve Tumours UK to your GP to give more information.

If you are an adult, it is a good idea to see your GP once a year for a general health check up and to have your blood pressure checked. It is also a good idea to have regular eye checks with your optician. See your doctor if you have any new or unexplained symptoms, just as you would if you did not have NF1.

Hospital or community paediatrician (children's doctor)

If you have a child with NF1, it is advisable that their growth, development and general health is monitored by a Community or Hospital Paediatrician from diagnosis until adulthood. The paediatrician will advise you how frequently your child needs to be reviewed.

There are a number of specialist paediatric NF1 clinics in some areas of the UK.

Brain scans are not routinely performed in NF1 unless there are specific reasons to do this, for example unusual symptoms. If you notice any changes in your health (as described earlier) outside of routine review appointments, it is sensible to seek medical advice. If symptoms do not go away, then it is important to return to your doctor for further advice because if you do not, the doctor will assume that you have recovered from the problem.

Complex NF1 service

This is a specialist nationally funded service to look after the healthcare needs of the most complex NF1 patients in England. There are clear criteria to assess which patients are eligible.

Referral from your doctor is needed to access a Neurofibromatosis Centre.

The 2 centres are:

Department of Genetic Medicine, St Mary's Hospital, Oxford Road, Manchester M13 9WL
Department of Neurology, 1st Floor, Thomas Guy House, Guy's Hospital, Great Maze Pond, London SE1 9RT

NF Specialist Advisor

Nerve Tumours UK funds jointly with the NHS a small number of NF Specialist Advisor posts. **The NF Specialist Advisor service offers support and information which is available to families and individuals who have NF1.** The NF Specialist Advisor can speak with you by phone or can visit you at home. The service also has links with many other health and education professionals. The Specialist Advisor can visit your child's school to give information to teachers on learning and NF1 or contact other health professionals who are working with you to give them information about NF1.

The charity also has a Helpline service for advice and information. For information about the Helpline please contact the charity.

Conclusion

We hope you have found this information useful. **It is important to remember that this is an introduction to NF1 and not all of the information will apply to everyone who has NF1.** For specific information, it is advisable to seek advice from the doctor who is treating you or your child.

This booklet has been written as a general guide to NF1 and tries to address some of the questions and concerns that people have when an adult or child has been diagnosed with NF1.

It has been updated in 2012.

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