



Easy reader

# **Neurofibromatosis, type 1**

For adults



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# Neurofibromatosis, type 1

People are alike and different.

Everybody has some things that work well and some things that do not. In this information material, things that do not work so well are called symptoms.



Some illnesses may include a number of **symptoms**. A group of **symptoms**, taken together, is known as a **syndrome**.

Neurofibromatosis, type 1 (NF), is one example of an illness that includes a number of symptoms.

It is good to have a name for the symptoms. Then the medical services can give you better treatment. You can also get help and support from your community. So says Doctor Barbro Westerberg and she knows lots about NF.

## What is Neurofibromatosis, type 1?

People with NF may have many different symptoms.

Some people have a lot of symptoms. Others only have a few. It is unusual for one person to have all the known symptoms of NF. How severe the symptoms are also differs from one person to another.



NF affects both the skin and the nerves.

Here are the **most common symptoms** people with NF can have.

In order to be diagnosed with NF the person must have at least two of these symptoms:

- A number of light brown skin spots (café-au-lait-spots)
- A large number of small bumps on the skin
- Growths developing around the nerves inside the body (plexiform neurofibromas)
- Bumps on the iris of the eye (Lisch-nodules)
- Tumors in the optic nerve
- Freckling in the armpits or groin area
- Skeletal changes, such as deformed vertebrae

## **Skin problems in NF**

The **light brown spots**,  
can be found in almost everyone with NF (95%).  
These spots almost always appear  
during the first few years of life.

The **little bumps on the skin**,  
neurofibromas,  
look like flesh-colored warts.  
These, too, can be found in  
many people with NF.

These bumps appear during childhood,  
but seldom before the age of about 10.  
More tend to appear in the teen years.

They are harmless  
but may cause discomfort.  
They may hurt or be in the way  
depending on where on the body  
they are located.

Adults with NF sometimes have  
these bumps removed.  
For instance,  
bumps on the eyelids,  
which may impair vision.

Some **neurofibromas**,  
may grow not only in the skin,  
but also inside the body  
(plexi-forma neurofibromas).

These are soft, insensitive, and they branch out.  
They may grow around nerves and vessels.

Whether they are a bother depends on where and how they grow.  
Sometimes they can be removed.  
They also tend to appear early, often before the child is 2.

**Freckling** in the groin and armpits is also common in people with NF (approximately 80%).

### **Vision problems**

Bumps on the eyelids can disturb vision.  
Sometimes these bumps can be removed.

Tumors on the optic nerve can impair vision.  
Sometimes these tumors have to be removed or treated with chemotherapy.

Pigment bumps in the iris of the eye are tiny.  
They are only visible using special instruments  
They do not affect vision.

Astigmatism is common.  
Many people with NF wear eyeglasses.

### **Learning difficulties**

About half of all children with NF  
have learning problems.

These children may find it difficult to

- learn new things
- learn to read and write
- concentrate
- be attentive

Some children with NF are also overactive.

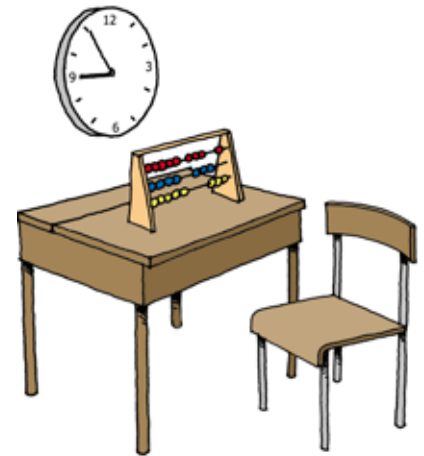
Some are diagnosed with ADHD.  
They are both overactive and  
have trouble concentrating.

Some may find it difficult to  
cooperate with others.  
They may also have trouble understanding  
how others think  
and what they feel.

Some people with NF  
may also have trouble  
interpreting what they see and hear.

### **Motor activity** (movement)

Some children with NF learn to walk,  
jump, run and ride a bike  
later than other children.





Some children may also have problems with small movements.

They will learn, for instance, to draw, cut with scissors and tie their shoes later than other children.



### **How common is NF?**

In Sweden about 30 children a year are born with NF.

NF is just as common in boys as in girls.

### **What causes NF?**

The human body is made up of millions of cells.

Different cells have different functions.

Some cells develop into the heart, for example, and make it work well.

Other cells develop, for instance, into the kidneys, the skin or the brain.

Each cell is so tiny it can barely be seen.

Yet each cell is fully programmed.

This is called our genetic make-up.

The program determines what each cell will become and do.

Sometimes the programming goes wrong.

When that happens, the person may have a sickness or a syndrome.

**Can children inherit NF?**

If one of a child's parents has NF  
the child can inherit it.

If one of the parents has NF  
there is always a 50% risk  
that the child will have it.

Half of all children with NF  
have inherited it  
from one of the parents.

Children can be born with NF  
even if neither parent has it.  
About half of all children  
born with NF  
have two parents who do not have NF.

Something went wrong  
with those children's  
genetic make-up  
when they were conceived.

**When can the doctors suspect  
that a child has NF?**

Children with NF are often  
born with lots of light brown spots.

Skin growths often appear  
before the child is 2.



Pigment bumps in the eye usually appear when the child is over 4.

There are people with NF who live their whole lives and never know they have NF. That is because they have so few symptoms.

### **How is the diagnosis made?**

In order to be diagnosed with NF the child must have a number of symptoms.

If one of the parents or the child's brother or sister has NF it is easier to make the diagnosis.

### **Other symptoms**

About one third of adults with NF are somewhat short.

Lots of adults must have skin growths removed. The growths sometimes itch, hurt, or rub against clothing.

The soft growths, inside the body, surrounding nerves and vessels, sometimes put pressure on the nerves.



This may cause problems including less ability to feel or difficulty moving some part of the body.

People with NF are at somewhat greater risk than others of developing epilepsy.

They are also at slightly greater risk of developing other tumors in their bodies.

Most of these tumors are harmless.

Some people may feel worried or depressed.

Some people with NF may have sleep problems.

Some have pauses in breathing at night, (sleep apnea).

This disturbs sleep.

### **Adults with NF should have regular medical checkups**

It is important for adults with NF to have regular medical checkups once every year or two.

The doctor should check your

- blood pressure
- skin
- heart and lungs
- reflexes
- vision and hearing



At these checkups  
the doctor can also tell you  
if any of the skin growths  
need to be removed.

These checkups are also important  
for finding tumors early.

It is important to tell the doctor  
if you are feeling depressed.  
There is good medication  
to treat depression.

### **Physical exercise**

Exercise is good for your health.

It is a good idea to work on your

- strength
- mobility
- balance
- fitness
- relaxation

A physiotherapist can help you  
develop an exercise program  
suited to your needs.

It is important to have good posture  
when you work.

Physiotherapists and occupational therapists  
can help you find good positions  
for sitting and standing at work.



They can check  
 that your chairs and tables are good  
 for your needs.  
 They can also help you find  
 useful assistive devices.

### **Dental care is important**

It is important to brush your teeth  
 both morning and evening.  
 Always use fluoridated toothpaste.  
 The dentist can give you good advice  
 about how to keep  
 your teeth clean and healthy.



Children with NF  
 often get their teeth earlier  
 than other children.  
 Sometimes braces may be needed.

Adults with NF may have  
 bumps in their mouths.  
 These bumps can be removed  
 if they are bothersome.

### **Support and help in the community**

People with illnesses and syndromes  
 may need help and support  
 from community services.

You may need help in finding a job  
 or some other occupation.





If you are living on your own,  
you may also need help  
to manage things like  
shopping and cleaning.

There are laws  
regulating the rights of people  
with an illness or a syndrome  
to support and help.

For instance,  
some help is available  
under the **Social Services Act (SoL)**.

What determines  
your right to support  
is the extent of  
your difficulties and needs.

### **The Health and Medical Care Act (HSL)**

may entitle you to

- health care
- habilitation
- personal aids
- transportation to and  
from the hospital or health centre

You can get help  
from the habilitation centre  
in applying for  
medical and transportation services.



## **The National Insurance Office (Försäkringskassan)**

works with  
benefits and support for  
people with illnesses or a disability.

Below are a few examples of benefits  
you can apply for  
from the National Insurance Office.

### **Activity compensation**

is for people  
between the ages of 19 and 29  
who have an illness or a disability.

You are eligible for activity compensation  
if you have been unable to work  
for at least a year  
because of a disability.

The size of your activity compensation  
will depend on  
how much you are able to work.

You are also eligible  
for activity compensation  
if you have to extend your schooling  
for extra years  
because of a disability.  
This applies both to  
secondary and upper secondary school.





**Sickness compensation**

is for people  
between 30 and 64  
who have an illness or a disability.

If you will probably never  
be able to work full time  
you may be eligible for  
sickness compensation.

The size of your sickness compensation  
will depend on  
how much you are able to work.

**Automobile compensation**

People with a disability  
may be eligible for automobile compensation.  
For example,  
if you must have a car  
in order to  
be able to work or study.

You can get automobile compensation,  
for instance to

- buy a car
- have a car adapted to your needs
- take driving lessons

You might need to have your car adapted  
if you are particularly short,  
for example.

**Occupational aids**

Your employer is responsible for adapting the workplace to the people who work there.

An employer can receive support for aids or for adapting the workplace so it is well suited.

If you need aids for your life outside the workplace, you can get help from the health and medical care services.

**Housing supplement**

If you are receiving activity or sickness compensation you will also be eligible for a housing supplement.

How much supplement you receive depends on how much money you earn and how high your rent is.

**Children with disabilities**

Parents taking care of a child with a disability can get a childcare allowance if the child needs special care or looking after for at least six months.

You can also get a childcare allowance to cover additional costs.

Additional costs may be,  
for instance,  
if the child needs special food  
or wears out his or her clothes  
very fast.

## Interview

### **Eva has NF**

Eva is 45.  
Here she talks about  
what it is like  
to be an adult with NF.

### **What is it like to be an adult with NF?**

I have a good job.  
My work is not affected by my NF.

I was diagnosed  
at the age of 28.  
Before that nobody understood  
the cause of my problems.

Since then  
a lot of my questions  
about NF  
have been answered.

I wish I had regular contact  
with a good doctor.  
That would be a doctor  
who knows a lot  
about NF.



More than I know.  
That doctor would help me  
to get regular checkups.

One problem I have  
is that my eyesight  
in my right eye  
is getting worse.  
I can hardly see anything at all  
in that eye.  
I have an appointment  
to have my vision checked.

My fibromas (growths) have not been a  
problem for me.  
They have not bothered me or rubbed  
against my clothes.

But now something is changing.  
I am developing  
more and more growths.  
I do not know why.

### **What was your childhood like?**

At school I was  
in a special class.  
I had trouble concentrating  
and sitting still.

I did all kinds of things.  
The teachers were not happy about that.

I thought the teaching was good.  
There is not much

to complain about.  
The problem was  
that I was bullied.  
The special class was  
in a regular school.  
At recess the other children  
made life difficult  
for my classmates and me.

### **Do you have vocational training and a job?**

After leaving school  
I went to see  
the employment service.  
They told me  
no one who had been  
in a special class  
ever got a job.  
That destroyed my  
self-confidence.

I moved to a different city.  
That changed everything.  
After only one week  
the employment service called.  
I was offered a job.  
Ever since then  
I have had a job  
or studied.  
I finished compulsory school.



Then I studied  
first to become a nurses' aide  
and then an assistant nurse.  
Since then I have had work  
in the healthcare sector.

Studying and working helped me  
grow as a person.  
I now have good self-confidence  
and self-esteem.

### **What are things like today?**

Now I have a daughter.  
She has NF too.  
Her problems are  
much more serious  
than mine.  
So I try to help her  
as much as I can.

### **What are your wishes for the future?**

I would like a referral  
to the adult habilitation services.  
I have got so many questions  
about NF.

I also hope  
they will not make too many changes  
at my workplace.  
I have trouble with changes.





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