

Who is this guide for?

This guide is for people with Neurofibromatosis Type 1 (NF1), especially those with small lumps on their skin called **neurofibromas**. It explains what these are, how they can make people feel, and what treatments might help.

What is NF1?

NF1 is a condition some people are born with. It can cause lumps called neurofibromas to grow in or under the skin. Most people with NF1 have these lumps, and they are usually not dangerous. But they can sometimes be tricky to live with.

What are skin neurofibromas?

Skin neurofibromas are soft, small lumps that appear on the skin. They are very common in people with NF1. These lumps can:

- Be seen easily, especially on the face, arms, or body
- Itch or feel sore
- Be a source of embarrassment or frustration
- Attract unwanted attention or questions from others

Sometimes even small children may touch or ask questions about them, which can be upsetting or uncomfortable.

When do neurofibromas need extra help?

While most neurofibromas are not dangerous, some may:

- Grow very large
- Become twisted or red
- Get infected

If this happens, they may hurt or look unpleasant. In some cases, you may need to visit the doctor, take antibiotics, or have surgery to remove the lump.

Who can help with treatment?

There are two special clinics for people with complex NF1 in **London** and **Manchester**. These clinics help people from all over England who have more difficult cases of NF1.

But most people with NF1 are not complex. They have common problems, like skin neurofibromas, which can be treated by doctors in plastic surgery units in **England, Scotland, Wales, and Northern Ireland.**

How are neurofibromas treated?

There are different ways to treat neurofibromas:

1. Cutting them out (excision)

- Good for larger lumps
- Done using a small operation

2. Punch removal

- Uses a small circular tool
- Best for smaller lumps

3. Burning with heat (cautery)

- Uses a special machine
- Can treat many small lumps at once
- Healing takes time but can be very effective

4. Laser treatment

- Used by some dermatologists
- Works in a similar way to cautery

Your doctor will help choose the best treatment for you. All of these treatments take time, and healing may take a few weeks.

How can I cope with people's reactions?

It can be hard when people ask about your lumps. Everyone reacts differently. You might choose to:

- Explain what they are
- Change the subject
- Walk away

There is no right or wrong way to respond. What matters is that you feel safe and confident.

Remember: You are not alone. Many people with NF1 have the same feelings and experiences. If you have questions or worries, talk to your doctor or someone at your clinic. Help is available.

Please call the Nerve Tumours UK Helpline if you need further advice. The Helpline is available on Monday, Wednesday and Friday 9am-5pm. Call 07939 046 030/ Freephone 0300 102 17 22 or email helpline@nervetumours.org.uk

