

IS THERE ANY TREATMENT FOR NF2?

While there is currently no cure for NF2, there are several options that may be considered in managing NF2 tumours.

Surveillance: many people with NF2 will be closely monitored by specialists and may have regular imaging, but no treatments will be offered.

Surgery is still the most commonly used treatment for NF2 tumours. This is often a last resort as hearing is often compromised during the operation.

Radiosurgery (Gamma Knife) is a *single* high dose of targeted radiation directed at the tumour(s).

Radiotherapy is a *series* of high dose of targeted radiation.

Medication/Drug Therapies are limited. One medication is Bevacizumab (Avastin), which has shrunk vestibular schwannomas and preserved hearing in some cases overseas.

Bevacizumab is not routinely available in Australia. However, you can ask your Specialist or contact the CTF for more information.

Hearing rehabilitation aids are also sometimes used to manage hearing loss caused by NF2 tumours. These include hearing aids and cochlear implants.

As the size, location and symptoms of tumours effect which treatments may be offered impact upon which treatments are available, it is always best to consult with a specialist healthcare provider for more information about the options.

ABOUT US

The Children's Tumour Foundation (CTF) is the only support service for families living with Neurofibromatosis (NF) in Australia.

NF is a life-long genetic condition with few treatment options and no cure.

The CTF exists to provide a pathway from fear to hope by investing in promising research, advocating for better resources and empowering individuals and their families with knowledge, connections and support needed at every stage of their journey.



CONTACT US

National Support: (02) 9713 6111
Email: support@ctf.org.au
Website: www.ctf.org.au
Social Media: @ctfaustralia



UNDERSTANDING
NEUROFIBROMATOSIS TYPE 2
(NF2)

CTF.ORG.AU

WHAT IS NEUROFIBROMATOSIS?

Neurofibromatosis (NF) is a set of three complex genetic conditions that cause tumours to form on nerves throughout the body.

NF affects more than 10,000 Australians.

While the signs and symptoms of each condition are distinct, the way they present and impact upon someone's life is variable. There is no way to predict how mildly or severely someone will be affected.

NF can affect anyone regardless of gender, ethnicity or family history.

NF2 is the second most common form of NF affecting 1 in every 25,000 – 40,000 people worldwide.

WHAT CAUSES NF2?

NF2 is a genetic condition caused by an alteration to the NF2 gene found on Chromosome 22.

The NF2 gene is responsible for protecting cells from developing tumours, and as it is not functioning correctly, tumours can form and grow in the Central Nervous System.

The most common type of tumours in people with NF2 are called Vestibular Schwannomas (formerly called Acoustic Neuromas).

These tumours are benign (not cancerous) and grow on the hearing and balance nerves.

They can cause damage by pressing on important structures in the brain and generally occur bilaterally (both sides of the brain).

Around half of the people impacted by NF2 will be the first in their family to have the gene change, meaning it is 'spontaneous' in them.

The other half of people will have inherited the condition from one of their parents.

When a person with NF2 has children there is a 1 in 2 (or 50%) chance that they will pass on the condition to any of their children.

Monitoring is vital for people with a diagnosis of NF2.

Each person's condition will develop differently and may change quickly so prompt review and appropriate action, based on observed changes over time, is very important in managing the condition.

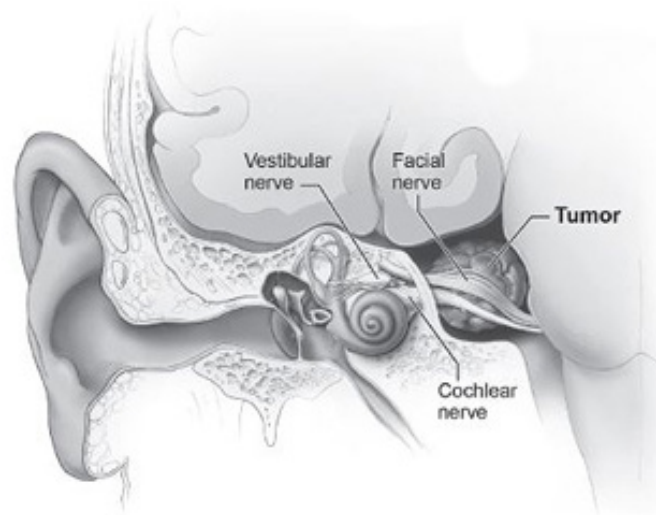


Image: Inner ear with vestibular schwannoma
Source: www.nidcd.nih.gov

WHAT ARE THE SYMPTOMS OF NF2?

The first signs and symptoms of NF2 often develop during adolescence or early adulthood; however, symptoms can appear in younger children too.

Symptoms may include:

- Hearing Loss
- Headaches
- Ringing in the ears (tinnitus)
- Balance problems and seizures
- Swallowing and voice difficulties
- Vision loss
- Muscle weakness
- Difficulty moving around
- Nerve damage and pain



These signs and symptoms appear as a result of the presence of non-cancerous tumours on the nerves throughout the body.

Vestibular Schwannomas are the standout symptom for this condition, but there are four types of non-cancerous tumours that are seen:

Schwannomas – develop on the hearing nerves and within the brain, but can also form and along the spine, as well as on peripheral nerves

Meningiomas – develop on the membranes that surround the brain and spine.

Gliomas – develop in the structures that support nerves in the brain and the spine.

Ependymomas – develop on the lining of areas of the brain and spinal cord where spinal fluid is produced.