



## IS THERE ANY TREATMENT FOR NF2?

While there is no simple cure for the issues that having NF2 causes, there is a great deal known about how to manage and treat them when they are identified. Most importantly, even if a person with NF2 seems to have little or no symptoms, it is important that there are a team of health professionals monitoring so as to ensure prompt treatment should it become necessary. Monitoring may include having specialised imaging such as an MRI. If tumours cause severe symptoms or threaten function, there may be options for medications, surgical and non-surgical treatments. These will depend on the tumour location, size and what the managing specialist and the person with NF2 feel are the best options. There is often not a "one size fits all" treatment even for different tumours affecting the same person with NF2.

Hearing loss and/or visual problems associated with NF2 can be treated in the same way as for people who not have NF2, e.g. hearing aids, Cochlear implants and visual aids.

### WHERE CAN I FIND OUT MORE?

For information and support you can contact the Children's Tumour Foundation (see back of this brochure).



## ABOUT THE CHILDREN'S TUMOUR FOUNDATION

The Children's Tumour Foundation of Australia (CTF) provides information and support to individuals and families impacted by all forms of NF. We have a dedicated support team who are here to answer your questions, provide reliable information and help strengthen the NF community in Australia.

### FIND OUT MORE HERE:

The Children's Tumour foundation (CTF) website [www.ctf.org.au](http://www.ctf.org.au) or contact your health professional.

## ONLINE SUPPORTS



There are some online support groups for those impacted by NF.

CTF Public Facebook Group:  
<https://www.facebook.com/CTFAus/>

CTF Closed Facebook Group:  
<https://bit.ly/2wgroA9>



## CONTACT US

National Support:  
02 9713 6111

VIC/TAS Support:  
03 9936 6268

QLD/NT Support:  
07 3646 1262

Email: [info@ctf.org.au](mailto:info@ctf.org.au)

# NEUROFIBROMATOSIS TYPE 2

## ( NF2 )



## NERVE TUMOURS

A *vestibular schwannoma* is usually benign and develops on the nerves associated with hearing. *Bilateral vestibular schwannomas* refers to tumours which are present on both the left and right hearing nerves. While most vestibular schwannomas are benign, they can cause difficulties for those affected which can include hearing loss, balance problems and tinnitus (ringing in the ears).

Other nerves can also develop schwannomas such as those in the brain, the spine and the skin.

In addition, *meningiomas* (tumours of the lining of the skull) and *ependymomas* (tumours in the brain or spine) can develop in some people with NF2.

## WHAT CAUSES NF2?

NF2 is a genetic condition which means that it comes about due to a genetic change (mutation) in an important gene which is needed for tumour protection. The gene involved in NF2 is located on chromosome number 22 and is called *merlin*. Some people with NF2 (about 50%) will be the first in their family to have this gene change. This means it is not inherited but caused by a “new mutation” in the *merlin* gene.

For the other 50% of people with NF2, the gene change will be inherited from one of their parents who may or may not have a milder form of NF2. When a person with NF2 has children, there is a 1 in 2 chance that they will pass on the NF2 causing gene.

## SKIN CHANGES

People with NF2 can develop some tumours under their skin and may also have changes in skin pigmentation called café-au-lait spots. These do not usually cause problems and are much fewer in number than people with NF1 who can develop many of these skin changes.

## EYE CHANGES

Some people with NF2 will develop cataracts (clouding of the inner lens of the eye) however these do not always affect a person's ability to see. Other eye problems can develop due to the fact that NF2 often has tumour involvement in the brain which can lead to decreased vision.



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## WHAT IS NEUROFIBROMATOSIS?

Neurofibromatosis or NF refers to several variable conditions which cause tumours to grow on nerves in the body. NF can affect both males and females and is diagnosed in people from all ethnicities and backgrounds.

NF type 1 (NF1) is quite common and is thought to affect around 1 in every 2,500 people. NF type 2 or NF2 is much less common and affects around 1 in 35,000.

Schwannomatosis is also a type of NF which is rare in the community.

**This brochure provides an overview of NF2 only.**

## WHAT ARE THE SYMPTOMS OF NF2?

NF2 is a condition which is variable, and no two people will have the same number of symptoms or experience. Most people with NF2 are diagnosed as young adults following investigations for unexplained headaches, dizziness, balance problems, ringing in the ears or hearing loss.

NF2 causes tumours to develop on certain nerves in the body, particularly the nerves related to hearing. The way in which a tumour will affect a person always depends on its location, size and whether it interrupts the function of the nerve/s. For this reason, a small tumour interrupting an important nerve may cause more functional problems for a person with NF2 than a larger tumour which is not interfering with nerve function at all.



#ConquerNF