NEUROFIBROMATOSIS FACTSHEET

Children's Tumour Foundation
CONQUERING NF

WHAT IS NF?

Neurofibromatosis (NF) is a set of three complex genetic conditions that cause tumours to form on nerve cells throughout the body, including the brain and spine.

- Neurofibromatosis Type 1 (NF1)
- Neurofibromatosis Type 2 (NF2)
- Schwannomatosis

NF can lead to a range of significant health issues including deafness, blindness, paralysis, physical differences, bone abnormalities, cancer, learning difficulties and chronic pain.

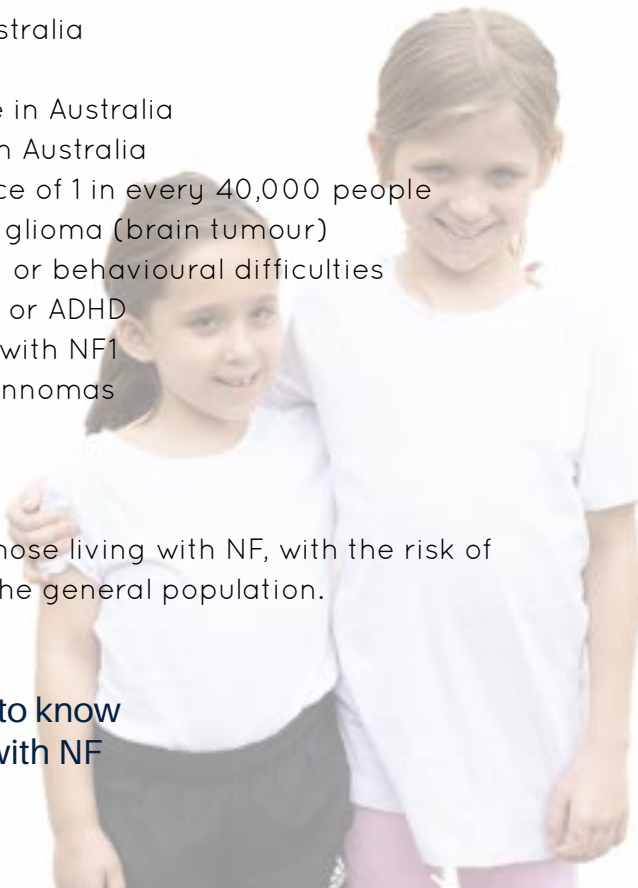
NF can affect anyone regardless of age, ethnicity, gender or family history and causes tumours (known as neurofibromas) to grow around the body's nerve cells, including the spine and brain, under the surface of the skin or deep in the body.

It is impossible to predict how mildly or severely someone with NF will be affected and roughly half of all cases arise in families with no history of NF.

THERE IS NO CURE AND TREATMENT OPTIONS ARE LIMITED.

NF STATISTICS

- There are approximately 10,000 people living with NF in Australia
- Every 3 days a child is born with NF in Australia
- NF1 is the most common and affects 1 in every 2,500 people in Australia
- NF2 is rarer and affects 1 in every 25,000 - 40,000 people in Australia
- Schwannomatosis is the rarest of the three, with an incidence of 1 in every 40,000 people
- Approx 20% of children with NF1 will develop an optic nerve glioma (brain tumour)
- Around 50-80% of children with NF1 will experience learning or behavioural difficulties
- Approx 20% of children with NF1 will be diagnosed with ASD or ADHD
- Incidence of breast cancer increase significantly in women with NF1
- Up to 90% of people with NF2 will develop vestibular schwannomas (benign tumours on the hearing nerves)
- Spinal tumours are seen in 60-80% of people with NF2



Anxiety, depression and social isolation is common amongst those living with NF, with the risk of suicide for people in their 20's being **4x higher** compared to the general population.

> "It's like living with a "ticking time bomb". There is no way to know when, where or how severe it will be. The only constant with NF is it's unpredictability.

DIAGNOSIS

Reaching a diganosis of NF can be a long and painful journey.
For some families a diagnosis comes as a shock, whilst for others, typically those who have been on the diagnostic monitoring path for a while, a confirmed diagnosis can actually be a relief.

The diagnostic criteria is complex and understanding of NF amongst medical professionals is severely lacking, adding to the frustrations of parents or adults seeking solutions.

NF1 is most often diagnosed in childhood and characterised by brown skin spots called café-au-lait marks, freckling in the groin and armpits and benign tumours known as neurofibromas. It is an extremely variable condition and the majority of people with NF1 will never be impacted by major medical complications and will live a long, fulfilling life.

For others the condition can be severe, debilitating and life-threatening.

HEALTH IMPLICATIONS AND TREATMENT

NF is caused by a single gene change, but it can lead to variable signs and symptoms anywhere there are nerves in the body. Currently there is no cure for NF.

The cornerstone of NF management is surveillance. This is because with many of the tumours being non-cancerous, treatments can often be more harmful than the presence of the tumour itself. Doctors need to weigh up the pros and cons of treatment carefully as every person's signs and symptoms are so varied.

There are some ways in which symptoms can be managed with interventions such as pain medication, allied health therapies and surgery, but none of these represent a cure.

Many of the traditional therapies are not as effective for NF-related tumours, such as chemotherapy and it therefore leave people with limited options except to "watch and wait". This leaves both families and individuals living with the condition with an overwhelming sense of uncertainty and fear.

There is some hope with international research into more effective drug therapies underway, but these are still under investigation and not widely available in Australia for those impacted by NF.

ABOUT THE CHILDREN'S TUMOUR FOUNDATION

The Children's Tumour Foundation (CTF) is the peak body in Australia supporting people with Neurofibromatosis (NF).

The CTF exists to provide a pathway from fear to hope for those impacted by NF, empowering individuals and their families with knowledge, connections and support, while investing in promising research leading to more effective treatments.

For us, conquering NF is more than just about finding a cure. The NF journey from diagnosis through to treatment is challenging, and most of what families will experience is unknown. Our role is to be a guide, a friend and an advocate.

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