Children's Tumour Foundation
CONQUERING NF

TOGETHER WE CAN CONQUER NF

HEALTH AND SOCIAL IMPACT ASSESSMENT IN NEUROFIBROMATOSIS IN AUSTRALIA

JUNE 2024

People living with Neurofibromatosis (NF) face significant challenges that impact their health, wellbeing, and quality of life.

This report examines the health and social impact of NF. The findings emphasise the need for increased awareness, support, and targeted interventions to improve the lives of those affected by NF.

ACKNOWLEDGMENT OF COUNTRY

In the spirit of reconciliation, the Children's Tumour Foundation acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

Cover image, Lyla, aged 6, diagnosed with NF1

FOREWORD

It is with great pleasure and a deep sense of purpose that I introduce the Health and Social Impact Assessment for Australians living with neurofibromatosis (NF). This comprehensive study represents a critical step forward in our collective commitment to understanding and addressing the multifaceted challenges faced by individuals and families affected by all types of NF across Australia.

NF is a complex, genetic condition that not only impacts the physical health of those diagnosed but also extends its influence into the emotional, social, and financial aspects of their lives. As we embarked on this assessment, our primary aim was to gain a comprehensive understanding of holistic impact of all types of NF, including schwannomatosis (SWN), on individuals, families, and the broader community to help build a clear picture of the burden of a condition that is not well known or understood outside of those directly impacted.

By delving into the lived experiences of those affected, we sought to illuminate the daily realities, unmet needs, and systemic challenges that confront individuals living with NF. Through a considered and inclusive approach, we have elevated the voices of patients, caregivers, and healthcare professionals, ensuring that their insights guide our efforts to effect meaningful change.

This assessment is not merely an academic endeavour; it is a call to action. The data and insights gleaned from this study will serve as a catalyst for driving policy reforms, enhancing healthcare delivery, and fostering a more supportive and inclusive environment for those impacted by NF. Our commitment to this cause is unwavering, and our resolve to improve the lives of individuals affected by neurofibromatosis is resolute.

I extend my sincerest gratitude to all those who have contributed to this assessment, including the individuals and families who have generously shared their experiences. It is through our collective dedication and collaboration that we will pave the way for a brighter, more hopeful future for all Australians living with neurofibromatosis.

Thank you for your unwavering support and commitment to this vital endeavour.

Sincerely,

LEANNE DIB
Chief Executive Officer
Children's Tumour Foundation

Grayson, aged 7, diagnosed NF1

NF impacts all organ systems; care access is limited and specialised knowledge is crucial.

EXECUTIVE SUMMARY

Neurofibromatosis (NF) is a group of complex, unpredictable and progressive genetic conditions that can have a profound impact on people's lives. NF causes tumours to form on nerves, under the skin and deep in the body. While NF is a genetic condition, roughly half of all cases arise spontaneously in families with no history of the condition.[1,2] NF collectively refers to neurofibromatosis type 1 (NF1), NF2 related-schwannomatosis (NF2) and schwannomatosis (SWN). Globally, **NF1** occurs in around **1 in 2500**[3] **births, NF2-SWN** is much rarer with a **birth rate of around 1 in 25,000**, while SWN (excluding NF2-SWN) occurs in approximately **1 in 70,000 births.**[4]

NF is a multifaceted condition that can affect all organ systems in the body, leading to a range of clinical symptoms. To effectively manage and treat this condition, a team of specialists from various medical disciplines is required. Unfortunately, **there is currently no cure for NF**.[5] It is a lifelong medical condition that requires ongoing care and management.

Access to care and treatment for people living with NF is limited. **There are only four specialist NF clinics nationally**, based in Sydney, NSW[6,7] and Melbourne, VIC.[8] Additionally, there are only a small number of NF specialists nationally. While awareness and knowledge of NF among clinicians is improving, it is important to note that **NF is a complex condition and expert knowledge in this field is still limited**. These factors combined have a significant impact on the overall health and wellbeing of people living with NF.

ABOUT THIS REPORT

The Children's Tumour Foundation engaged PwC Australia to undertake this study, the first of its kind in Australia, which is intended to raise awareness of the experience of Australians living with or impacted by NF. By identifying gaps and priorities in healthcare, wellbeing and social supports, **this report provides an evidence base of lived experience of those affected by NF**.

The report outlines practical and feasible recommendations that will lead to better outcomes for people living with all types of NF in the years and decades ahead.

AWARENESS
ACCESS
ACTION

ACKNOWLEDGEMENTS

The Children's Tumour Foundation (CTF) prepared this report to highlight the challenges faced by Australians living with or impacted by NF and to provide some practical solutions to improve their lives. living with or impacted by NF and to provide some practical solutions to improve their lives.

The CTF is grateful to all the interviewees and contributors to this report. Importantly, we would like to thank the NF community who willingly shared their time and information, and most importantly their lived experiences. Without their contribution this report would not have been possible.

We would like to thank CTF's Medical Advisory Panel and Community Advisory Panel who also shared their insights on the barriers facing the NF community as they navigate the health system to access the care and support they need. These insights ultimately helped realise the key findings in this document.

We like to acknowledge Alexion Astra Zeneca Rare Disease for providing grant funding to support the report.

Heartfelt thanks to the NF community, contributors, and advisory panels whose insights and experiences made this report possible.

Shelby and Jackson are siblings who each live with a complex case of NF1.

CONTENTS

SUMMARY OF KEY FINDINGS

People living with NF face considerable challenges that impact on their overall health, wellbeing and quality of life. The following six key themes were identified through data collected from an online survey (a total of 420 respondents completed the survey), stakeholder consultations and desktop research as being the most pressing issues. They are explored in detail in this report.

1. THERE IS A NEED TO CLOSE THE TIME GAP BETWEEN SYMPTOM ONSET AND DIAGNOSIS OF NF, ENSURING ACCESS TO EVIDENCE BASED TREATMENT OPTIONS.

- The 'diagnostic odyssey' or the time between presenting with symptoms to a definitive diagnosis is a long journey for many NF patients.

NEARLY A QUARTER OF SURVEYED NF PATIENTS WAITED OVER 4 YEARS FOR A NF DIAGNOSIS.

FACTORS CONTRIBUTING TO DELAY OR ERROR IN DIAGNOSIS INCLUDE LIMITED KNOWLEDGE BY HEALTHCARE PROFESSIONALS (29%), WAIT TIME TO SEE A SPECIALIST (19%), AND LACK OF ACCESS TO NF SPECIALISTS AND SERVICES DUE TO LOCATION (15%).

- There has been slow progress in understanding NF and its symptoms. Funding in the Medical Research Future Fund (MRFF) was only awarded to NF-specific projects for the first time in 2021.[10] There is an opportunity to boost research and funding to improve access to genetic testing and evidence-based treatments to enable timely diagnosis and appropriate care.

2. NF AFFECTS ALL FACETS OF A PERSON'S LIFE, WITH SIGNIFICANT IMPACTS ON THEIR MENTAL HEALTH, PHYSICAL HEALTH, SOCIAL RELATIONSHIPS, WORK, EDUCATION AND FAMILY PLANNING DECISIONS.

- People living with NF can experience unique circumstances that significantly impact their quality of life and mental health and wellbeing. These include diagnostic delays, uncertainty associated with a rare disease diagnosis, feeling isolated, and prolonged and anticipatory grief attached to not leading the life one had imagined or hoped for.[11]

71% REPORTED A SIGNIFICANT OR MODERATE IMPACT OF NF ON THEIR MENTAL HEALTH.

THE RATES OF DEPRESSION (28%), GENERALISED ANXIETY DISORDER (17%) AND PANIC DISORDER (7%) AMONG SURVEY RESPONDENTS WERE HIGHER THAN AUSTRALIAN GENERAL POPULATION AVERAGES OF 11.7%, 8.2% AND 6.3% RESPECTIVELY.[22]

- NF impacts on people's ability to live a productive life, affecting their participation in education and employment. NF also impacts family planning decisions.

Over 1 in 3 (34%) reported taking time off education and over 1 in 2 (57%) reported taking time off work due to NF.

50%

1 in 2 (50%) reported NF had a moderate or significant impact on family planning decisions.

- NF tumours can cause a range of physical symptoms. Roughly 70% of survey respondents reported a significant or moderate impact of NF on their physical health.

3. THERE IS LIMITED ACCESS TO CARE COORDINATION AND MULTIDISCIPLINARY TEAMS, AND A LACK OF FORMALISED CARE PATHWAYS FOR NF PATIENTS.

- While NF clinics that currently exist provide some level of care coordination and access to multidisciplinary teams (MDTs), these clinics do not exist in every jurisdiction and need outweighs capacity.
- There is inconsistency in triaging and referral systems and there is significant variability in how people are connected to needed services.
- There is a lack of formalised care pathways as NF patients transition from paediatric to adult care.
- Many people experience long wait times to see specialists and many need to wait for multiple appointments with different specialists to receive comprehensive care.
- The survey revealed low satisfaction rates relating to health system interactions.

ONLY 15% ARE VERY SATISFIED WITH NF-RELATED CARE COORDINATION, 7% WITH THEIR TRANSITION FROM PAEDIATRIC TO ADULT CARE, AND 20% WITH DISCUSSING CONCERNS OR FEARS REGARDING NF WHEN ACCESSING SERVICES.

NEARLY 1 IN 10 COULD NOT ACCESS A SPECIALIST.

4. EXPERIENCES OF INEQUITY ARE AMPLIFIED FOR PEOPLE WITH NF LIVING IN REGIONAL AND RURAL AREAS.

The four specialist NF clinics in Australia are in two major cities. Access to services for those in regional and remote areas are impacted by the need to travel long distances due to a lack of knowledgeable clinicians.

1 IN 3 RURAL RESPONDENTS AND 1 IN 4 REGIONAL RESPONDENTS NEED TO TRAVEL MORE THAN 400 KILOMETRES TO ACCESS THE NEAREST NF SPECIALIST OR CLINIC, COMPARED TO 7% OF METRO RESPONDENTS.

A FURTHER 54% OF RURAL RESPONDENTS AND 39% OF REGIONAL RESPONDENTS NEED TO TRAVEL BETWEEN 100-400 KILOMETRES TO ACCESS A NF SPECIALIST OR CLINIC, COMPARED TO 5% OF PEOPLE IN METRO AREAS.

- The location-based inequity is also shown through access to specialist care – 13% and 17% of those in regional and rural areas, respectively, said they could not access a specialist, compared to only 5% in metro areas.
- The survey revealed high levels of dissatisfaction with ease of getting appointments among those in rural areas (52%), compared to those in metro and regional (42%).

5. MANY HEALTH PROFESSIONALS ARE NOT FULLY AWARE OF NF. THIS LIMITS THEIR ABILITY TO PROVIDE APPROPRIATE TREATMENT AND ONGOING MANAGEMENT OF NF.

- When asked about the level of understanding and awareness demonstrated by healthcare professionals, **only 12%** of patients said health professionals were very knowledgeable.
- Limited awareness and understanding were more pronounced for SWN, with 56% saying health professionals were unknowledgeable in SWN compared with 40% for NF1 and 33% for NF2.

6. THERE IS A SIGNIFICANT EMOTIONAL AND FINANCIAL BURDEN ON NF CAREGIVERS.

- Caregivers are forced to juggle multiple roles in addition to their unique caring responsibilities, such as acting as an advocate, case manager, and health system navigator.

NEARLY 4 IN 5 CAREGIVERS (77%) REPORTED A SIGNIFICANT OR MODERATE IMPACT ON THEIR MENTAL HEALTH DUE TO CARING FOR A CHILD OR PERSON WITH NF.

NEARLY 3 IN 10 (29%) CAREGIVERS REPORTED TAKING EXTENDED TIME OFF WORK.

- Most NF caregivers are female (90%), meaning that women are disproportionately impacted by the burden of caregiving. This is particularly significant because lost income from taking time off work can have considerable impacts for women. These include reduced opportunities for career advancement and lower lifetime earnings, which impacts on their overall quality of life.

The multifaceted impact of NF: mental, physical, and financial burdens.

Skye, aged 5, diagnosed with NF1

SUMMARY OF RECOMMENDATIONS

Based on the key findings including identified needs and challenges, the following six recommendations were developed to tackle the inequities that people living with or caring for those with NF experience in Australia. These are explored further under ‘detailed recommendations’ on page 46 and 47.

1. DEVELOP AND IMPLEMENT A NATIONAL STRATEGIC APPROACH THAT DRIVES EQUITABLE AND TIMELY CLINICAL CARE FOR NEUROFIBROMATOSIS.

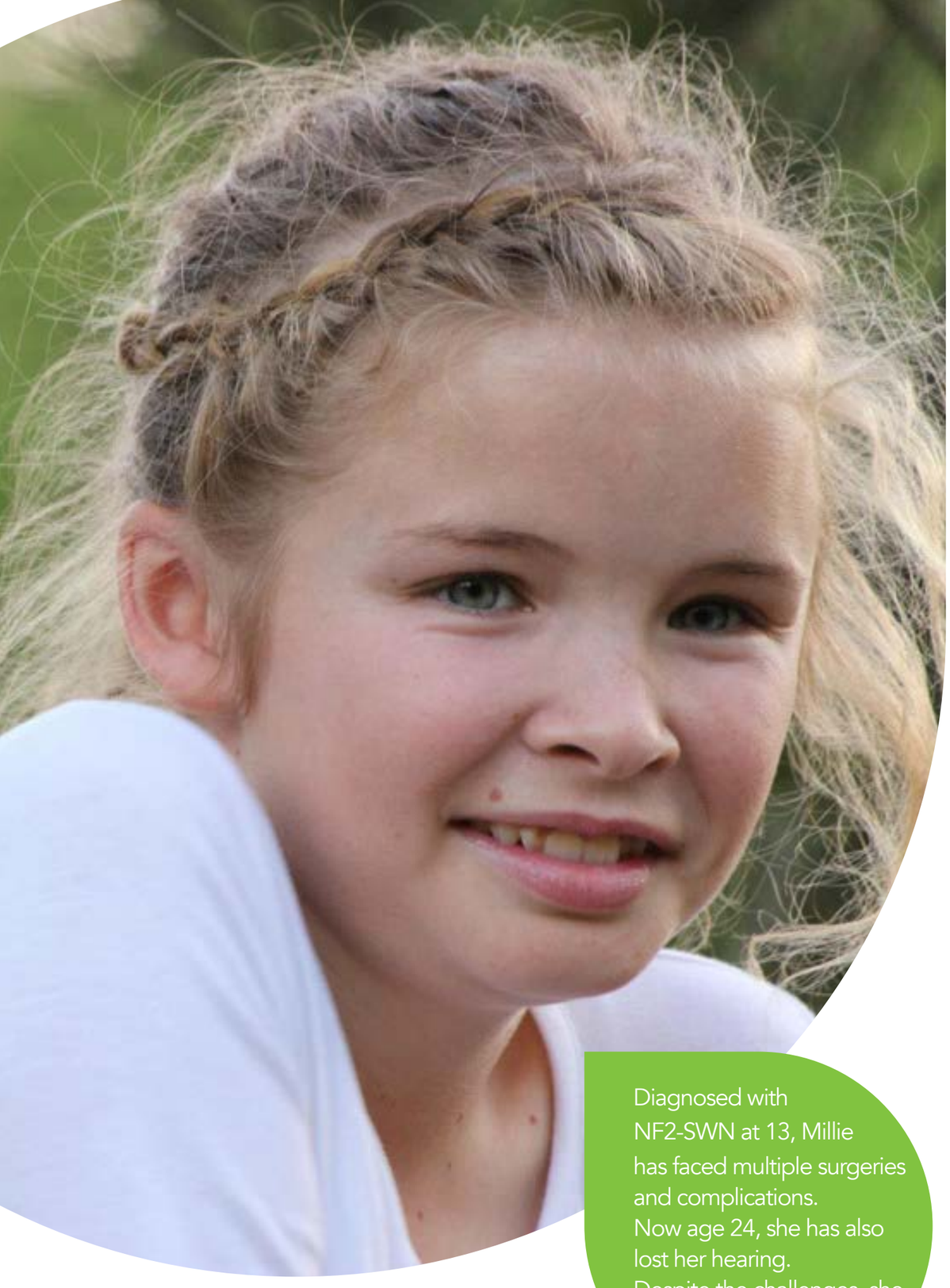
2. ENSURE DELIVERY OF COORDINATED CARE ACROSS A PERSON’S NF LIFESPAN AS PEOPLE WITH NF REQUIRE ACCESS TO A RANGE OF MEDICAL AND SOCIAL SUPPORT SERVICES.

3. DELIVER TARGETED SUPPORTS FOR THE MENTAL HEALTH AND WELLBEING NEEDS OF NF PATIENTS AND THEIR CAREGIVERS.

4. INCREASE NATIONAL AWARENESS AND EDUCATION OF NF TO ELEVATE KNOWLEDGE OF CONDITION IMPACT, AND VARIABLE HEALTH AND SUPPORT NEEDS OF THE NF COMMUNITY.

5. ADDRESS KNOWLEDGE GAPS AMONG HEALTHCARE PROFESSIONALS OF NF TO IMPROVE DIAGNOSIS, TESTING AND TREATMENT, AND FURTHER ENABLE HEALTHCARE PROFESSIONALS TO MEET THE HEALTH AND SUPPORT NEEDS OF THOSE DIAGNOSED WITH NF.

6. INCREASE DATA COLLECTION, INVESTMENT IN GENOMICS AND RESEARCH INTO NF, AND ACCESS TO CLINICAL TRIALS TO DRIVE INNOVATION AND NF INTERVENTIONS AND CARE.



Diagnosed with NF2-SWN at 13, Millie has faced multiple surgeries and complications. Now age 24, she has also lost her hearing. Despite the challenges, she remains hopeful.

BACKGROUND

WHAT IS NEUROFIBROMATOSIS?

Neurofibromatosis (NF) is a group of complex, unpredictable and progressive genetic conditions that cause tumours to form on nerves, under the skin and deep in the body. NF includes neurofibromatosis type 1 (NF1) and all types of schwannomatosis (SWN), including NF2-related schwannomatosis (NF2-SWN), formerly known as neurofibromatosis type 2. Globally, NF1 occurs in around 1 in 2500[3] births, NF2-SWN is much rarer with a birth rate of around 1 in 25,000, while SWN (excluding NF2-SWN) occurs in approximately 1 in 70,000 births.[4]

An estimated 50% of people affected by NF inherit it from a parent. The other 50% is caused by a spontaneous change in a specific gene and can affect anyone regardless of ethnicity, race, gender, or family history.[1,2] The impact that NF can have on organs and other body parts can be debilitating and even life-threatening. Many tumours are inoperable and there is limited access to treatments.[12] NF can lead to significant health issues including blindness, deafness, bone abnormalities, disfigurement, chronic pain, learning difficulties and cancer.

MAIN TYPES OF NF AS DESCRIBED IN TABLE I BELOW.

Table 1: Types of NF

	Neurofibromatosis type 1 (NF1)	NF2-related schwannomatosis (NF2-SWN)	All other types of Schwannomatosis (SWN)
Birth Rates	1 in 2500[3] people	1 in 25,000[3] people	1 in 70,000[4] people
Common symptoms	Café au lait spots Freckling in armpits or groin area, Lisch nodules and tumours.[13]	Tumours in the ears, spinal cord and brain.	Tumours / schwannomas in the brain, spine and on peripheral nerves.
Age at diagnosis	Generally diagnosed in childhood[5], but can also be diagnosed at any age.	Late teens/early adulthood, but can occur at any age.[13]	30-60 years, but can occur at any age.[13]
Common impacts	Learning and behavioural difficulties, bone softening or curving, scoliosis, tumours on nerves in the brain and along the spinal cord.[14]	Partial or complete hearing loss, spinal tumours, balance problems and vision loss.[5]	Chronic pain, numbness, tingling, weakness, headaches, vision changes, swollen areas under skin.[13]

MANAGEMENT OF NF

Currently, there is no cure for NF.[5] It is a lifelong medical condition. However, NF symptoms can be monitored and managed to help people lead normal lives. The management of NF requires multiple doctors and specialists, including oncologists, neurologists, geneticists, cardiologists, dermatologists, neurosurgeons, ophthalmologists, orthopaedic surgeons, plastic surgeons, and endocrinologists, among others.

With NF often diagnosed in childhood, the requirement for testing and monitoring is required from diagnosis into adulthood. Most children with NF are advised to have a comprehensive examination each year. This may include:[15]

- a detailed skin examination to check for new plexiform neurofibromas – older children may also be monitored for neurofibromas,
- a vision test and an examination of both eyes,
- hearing tests,
- a bone assessment to check for problems such as curvature of the spine (scoliosis) or poorly healed bone fractures,
- behavioural assessments,
- blood pressure measurement,
- measuring their physical development,
- assessing their progress at school – particularly abilities in activities such as reading, writing, problem solving and comprehension.

Adults also need regular monitoring.

SERVICES AND SUPPORTS AVAILABLE TO NF PATIENTS

NF CLINICS

There are four specialised NF clinics nationally that provide care for people with NF. These clinics are located within the following hospitals:

Table 2: NF Clinics in Australia

Children's Hospital Westmead (NSW)[6]	Royal North Shore Hospital (NSW)[7]	The Royal Children's Hospital Melbourne (VIC)[8]	Royal Hospital Melbourne (VIC)[9]
Only patients under 18-years-old. Accepts referrals from Paediatricians and Specialists (Not General Practitioners (GPs). Patients with all NF types. Only previously diagnosed patients.	Adult patients, 18 years and over. Accepts referrals from GPs, and specialists. Patients with all NF types. Both diagnosed and undiagnosed patients.	Only patients under 18-years-old. Accepts referrals from GPs, paediatricians and specialists. NF1 and NF2-related SWN patients only.	Adult patients, 18 years and over. Accepts referrals from GPs and specialists. All types of NF.

As these clinics are located within major cities in two jurisdictions, many people living with NF do not have sufficient access to a formalised NF clinic to receive appropriate treatment and care.

Additionally, there are a limited number of NF specialists nationally, which further limits people with NF from receiving the specialist expertise and care they need to manage NF, its symptoms, and its broader impacts.

Awareness and knowledge of NF in the general medical community is limited due to its inherently complex nature, making it difficult to receive targeted and best practice care in all situations. These challenges are explored in detail in subsequent sections of this report.

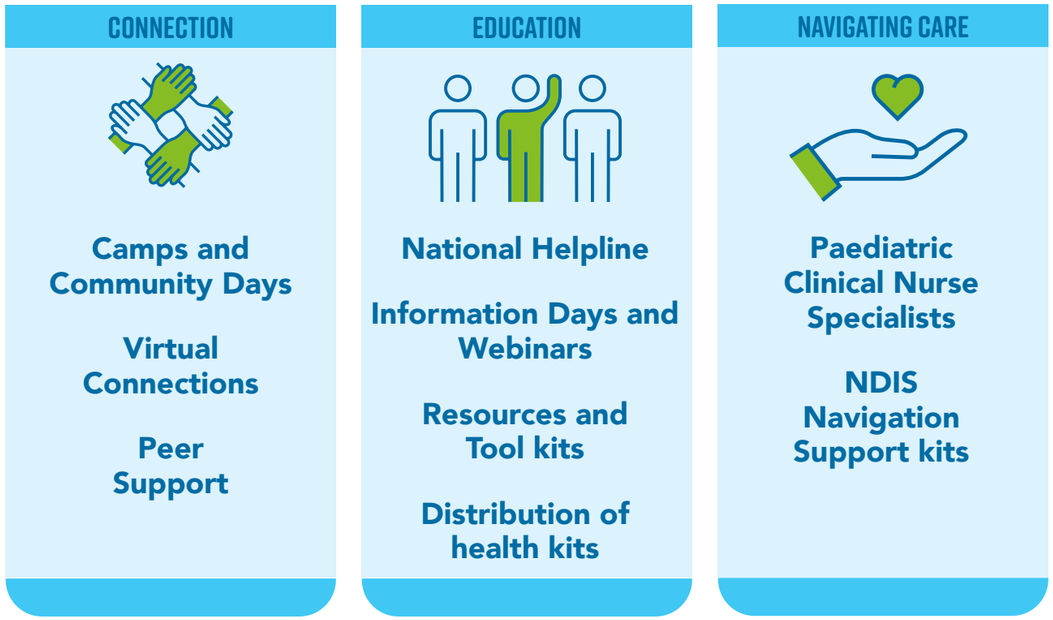
SUPPORT SERVICES

NF patients and families require holistic support to manage not only the medical aspects of the condition, but also the psychosocial impacts that come with a rare disease diagnosis. The Children's Tumour Foundation (CTF) is the only patient advocacy and support service for people impacted by NF in Australia.

The CTF invests in research, advocates for better access to care and treatment, and empowers individuals and their families with knowledge, connections and support needed at every stage of their journey. The CTF supports everyone from birth to adulthood. Without the CTF, the NF community lacks a focal point for networking or assistance in navigating a complex health system.

The CTF directly supports those with NF through a range of services, as depicted in the figure below:

Figure 1: CTF Support Services



ABOUT THE STUDY

Giving a voice to NF patients and caregivers for the first time in Australia.

MOTIVATION

Few studies in Australia have investigated the impacts of NF from the patient and caregiver perspective. Additionally, awareness about NF remains low. The need to understand the varied impacts of NF is critical to inform advocacy, support and action that can be used by clinicians, government, philanthropists, and industry partners to help meet the needs of the NF community.

In this context, the CTF is delivering the first Health and Social Impact Assessment of NF in Australia. The CTF engaged PwC Australia to undertake this study.

The purpose of the study is to understand the experience of Australians living with or impacted by NF, identifying gaps and priorities in healthcare, wellbeing, and social supports, while also providing an evidence base of lived experience.

STUDY OBJECTIVES

The objectives of the Health and Social Impact Assessment include the following:

- Understand the health and social impacts of the Australian NF community, including physical health impacts, mental health impacts, social impacts, psychosocial impacts, financial impacts, and impacts on education and employment.
- Understand and identify gaps with service and support needs of people with NF, their families and caregivers and measure quality of health system interactions.
- Explore interactions of people, families and caregivers impacted by NF around research, clinical trials, access to treatments, and connection to information.
- Identify what individuals would value most about a treatment, healthcare intervention, research, support, and services in NF.

METHODS

Health and Social Impact Assessment Survey

An online survey was distributed to the NF community between 5 April 2024 – 19 April 2024. The NF community from all jurisdictions were invited to respond to the survey. This included persons living with NF, parents and/or caregivers of people living with NF, and healthcare professionals. Individuals under 18 years of age were not eligible to participate in the survey.

Survey participation was entirely voluntary, with participants fully informed of the purpose, objectives, benefits, and potential risk of participating. Survey respondents were required to provide informed consent before continuing with the survey.

The survey was advertised by the CTF to attempt to reach as many people as possible within the NF community through the CTF's online newsletter; member network distribution list; social media presence; and NF clinics.

The survey captured the following types of information:

- Health and wellbeing impacts, including physical impacts, mental health impacts, social impacts, quality of life impacts, and impact on productivity and employment.
- Where and how patients were accessing treatment and management services for NF, and which health professionals they were engaging with.
- Experience of people interacting with the health system for NF related needs.
- Challenges and opportunities facing health professionals in providing treatment and care for NF.

The questions to be completed were dependent on who completed the survey, which included people with NF, families and care givers and health professionals.

Stakeholder consultations

A total of six, 1:1 online consultations were held with the CTF's Medical Advisory Panel (MAP) and Community Advisory Panel (CAP). These consultations were held between 16 April 2024 – 26 April 2024. The consultations involved three individuals from MAP and three individuals from CAP. Participation was voluntary.

An information sheet including key areas of focus for the consultation was distributed prior to the consultations to guide conversation. The consultations captured views on the following types of information:

Medical Advisory Panel

- Challenges in accurately diagnosing and monitoring NF.
- Gaps in treatment options for different manifestations of NF.
- Reflections on what is working well in current research efforts and what can be improved in the future.
- Specific programs or policies that could be implemented to better support the NF community.

Community Advisory Panel

- Public awareness and understanding of NF.
- Key challenges facing people with NF, their families and care givers.
- Specific support services available to people with NF, their families and caregivers, including opportunities for improvement.
- Specific policies or programs that could be implemented to better support the NF community.

The sessions were not recorded. Observations and key insights from the consultations were used as qualitative data.

Desktop scan

A desktop scan was conducted to gather information from publicly available online sources (publications, research articles, industry reports) on the prevalence and burden of NF in Australia and globally. This information is used in this report to supplement the survey and consultation data and fill any information gaps not collected via the survey or consultations.

Case studies

Case studies and short stories included in the report were sourced by the CTF in consultation with adults with NF and parents and caregivers.

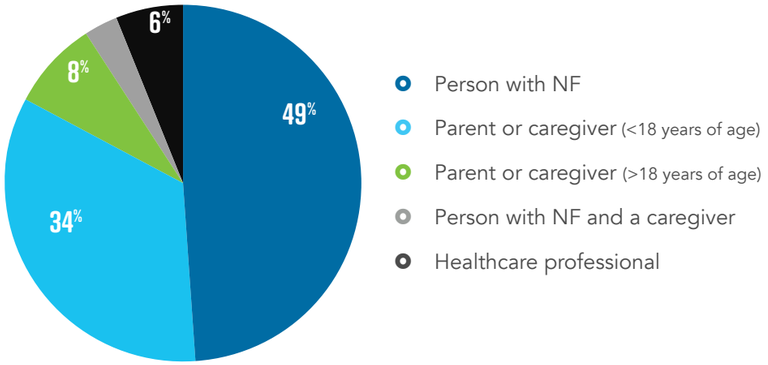
Ethics

Ethics approval for this study was granted on 3 April 2024 by the Human Research Ethics Committee (HREC) at Bellberry Limited in accordance with the National Statement on Ethical Conduct in Human Research (National Statement).

Survey participant profile

A total of 420 respondents completed the survey. A profile of the survey respondents is provided below.

RESPONDANT GROUP



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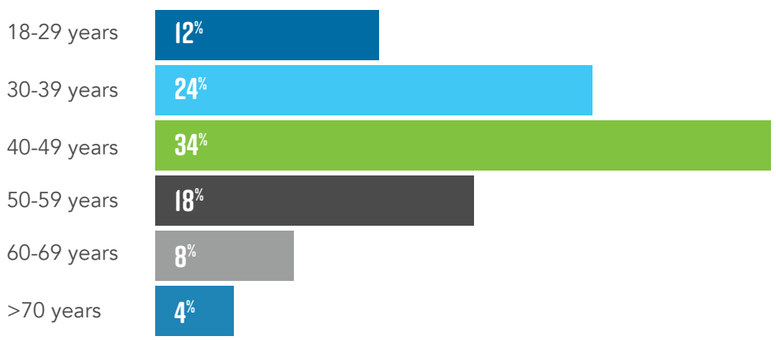

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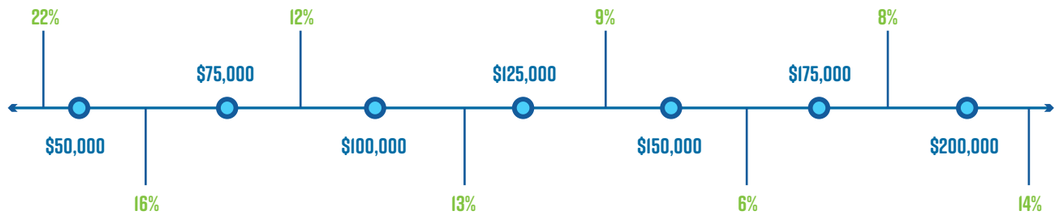

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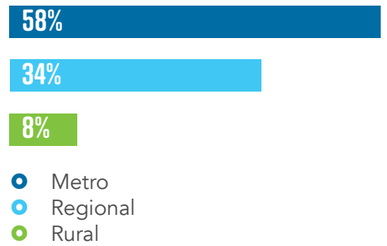
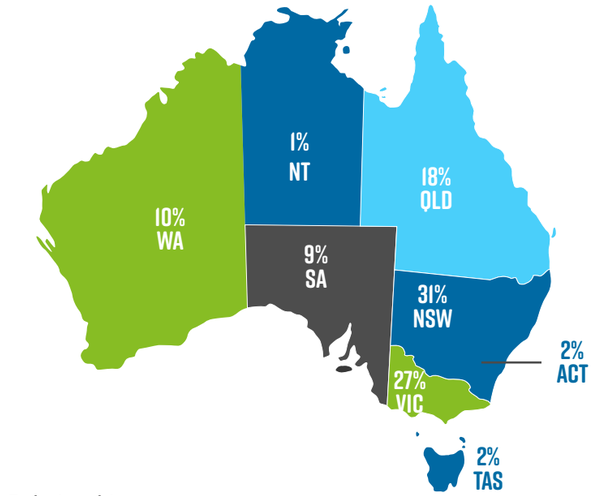


State and Territory



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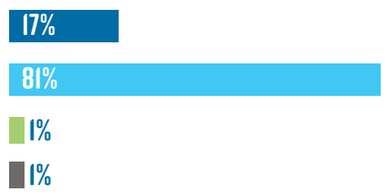

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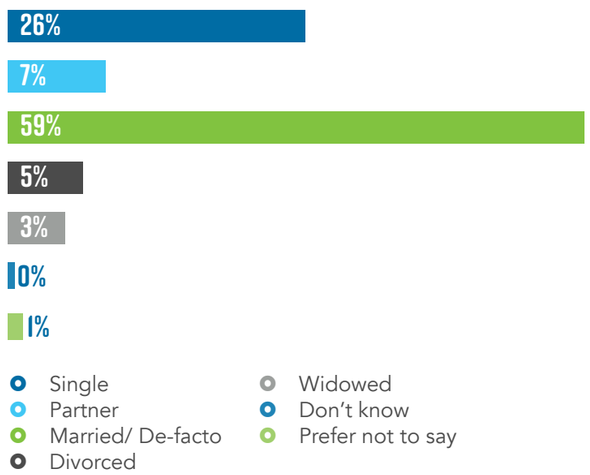
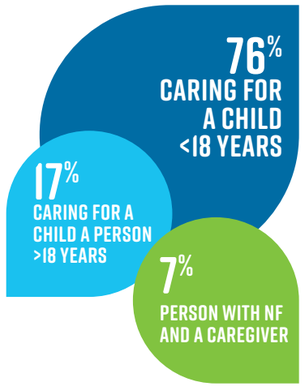


CARER PROFILE



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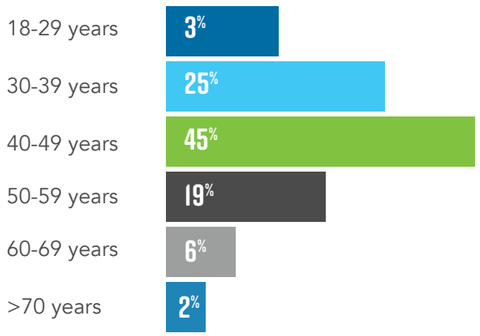

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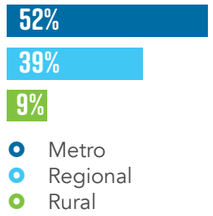
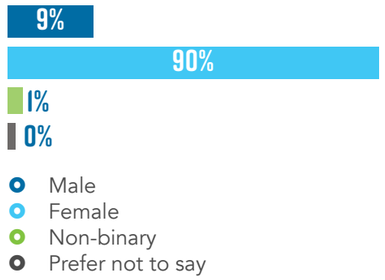
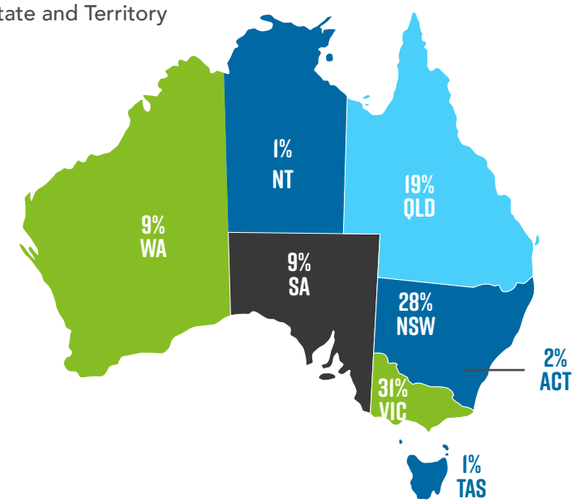


Gender



State and Territory



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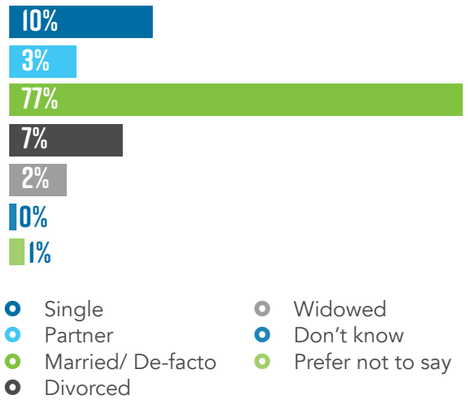

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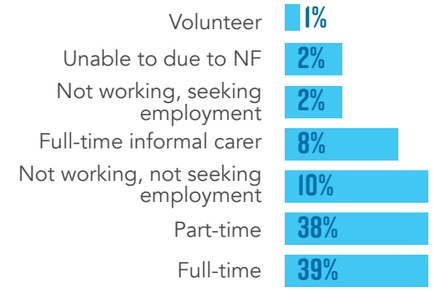


A mother's embrace: Hugging Jack in hospital on one of the harder days in his NF journey.

DETAILED KEY FINDINGS

This section outlines the key findings from the Health and Social Impact Assessment of NF, drawing on findings from the online survey, stakeholder consultations and desktop scan.

1. THERE IS A NEED TO CLOSE THE TIME GAP BETWEEN SYMPTOM ONSET AND DIAGNOSIS OF NF, ENSURING ACCESS TO EVIDENCE BASED TREATMENT OPTIONS.

DELAYS IN DIAGNOSIS

NF tumours can develop anywhere in the body and is associated with an increased risk of malignancy.[13] Early diagnosis of NF is critical to prevent further health complications through appropriate monitoring and management.

Specialist clinical expertise is required for a timely diagnosis of NF. However, the complex and varied nature of NF means that diagnosis is not straightforward. NF is a rare, multisystem condition with clinical manifestations that may be diagnosed and treated by different specialists without an underlying, unifying genetic diagnosis.[16]

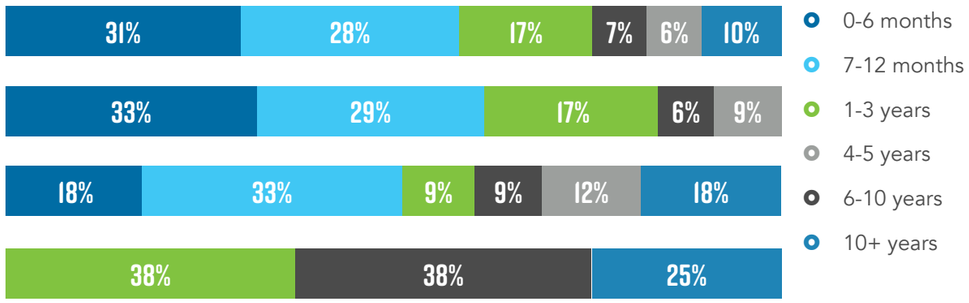
The 'diagnostic odyssey' or the time between presenting with symptoms to a definitive diagnosis is a long journey for many NF patients. Survey results indicate that nearly a quarter of NF patients waited over 4 years for a NF diagnosis (Figure 2).

A further 17% waited 1-3 years for a diagnosis. Delays are amplified for patients with NF2-SWN and SWN, 39% of patients with NF2 and 63% of patients with SWN waited over 4 years for a diagnosis, compared to 21% of patients with NF1 (Figure 2).

Nearly a quarter of NF patients waited over 4 years for an NF diagnosis.

Naomi was 13 when a tumour appeared near her eye, causing her significant pain and discomfort. It took six surgeries and 14 years before she received a definitive diagnosis of schwannomatosis (SWN).

Figure 2: Time to diagnosis following treatment



Time to diagnosis by states and territories found that roughly a quarter of respondents in NSW (24%), VIC (27%), QLD (24%) and SA (22%) waited over four years for a diagnosis. Comparatively, roughly 1 in 5 (18%) patients in WA waited over four years. Further, 14% (NSW), 18% (VIC), 15% (QLD), 22% (SA) and 18% (WA) of people waited between 1-3 years.

The proportion of respondents who only waited up to a year was higher in NSW (63%), QLD (61%) and WA (63%) compared to VIC (54%) and SA (56%). This indicates that regardless of location and access to existing clinics, many people across Australia experience significant delays to diagnosis. Proportions for other TAS, ACT and NT are not reported due to low sample sizes.

DELAY IN GETTING A DIAGNOSIS IMPACTS OUTCOMES

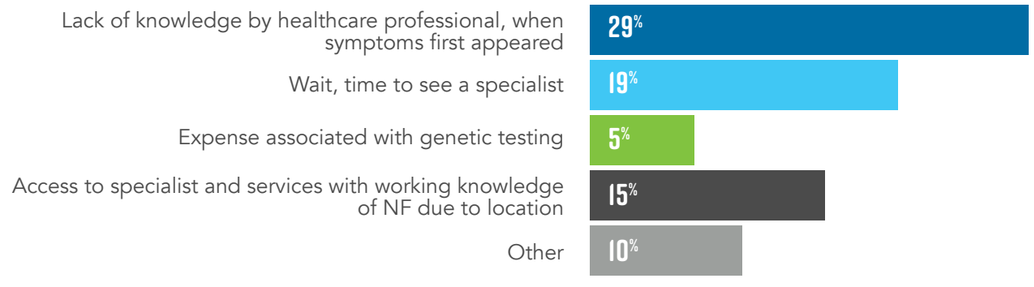
Parents who notice symptoms in their children are often met with scepticism or reassurances that everything is fine, despite clear signs indicating otherwise. This dismissiveness can lead to prolonged periods of uncertainty and anxiety for parents who are desperately seeking answers about their child's health. This was true for Alex's parents who were dismissed several times despite Alex meeting multiple diagnostic criteria.

The burden placed on parents to advocate for their children and push for further evaluation is immense, especially when faced with conflicting information from medical professionals. Ultimately, the delays in diagnosis not only prolong the emotional toll on families, but also hinder early intervention and management of NF, underscoring the need for improved awareness and education within the healthcare system.

Alex, aged 15, diagnosed with NF1, now living with significantly impaired vision

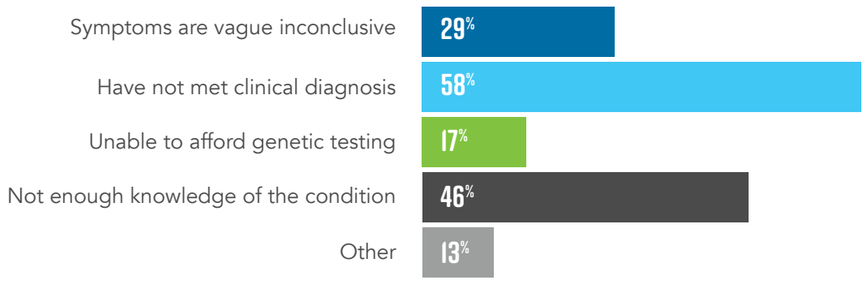
Limited knowledge of NF among healthcare professionals (29%), wait time to see a specialist (19%) and Limited access to NF specialists and services due to location (15%) were reported as key contributing factors to a delay or error in diagnosis by patients and caregivers (Figure 3).

Figure 3: Factors contributing to the delay or error of diagnosis



For healthcare professionals the key challenges in providing a formal diagnosis include, patient has not met clinical diagnosis (58%), not enough knowledge of the condition, (46%) and vague or inconclusive symptoms (25%) (Figure 4).

Figure 4: Biggest challenges facing practitioners in providing a formal NF diagnosis



Considerable efforts are being placed into diagnosing NF at an earlier stage, globally. The recently revised criteria (2021) for NF1, for example, include the presence of pathogenic variants in the NF1 gene and choroidal anomalies, which can help achieve an early and accurate diagnosis.[17]

While there is an opportunity to improve access to genetic testing to enable early diagnosis, stakeholders noted that genetic testing is expensive with many people having to pay out of pocket for these expenses. Australia is also faced with a shortage of geneticists and genetic counsellors[18] which further impacts on the ability to use genetic testing for early diagnosis of rare conditions such as NF.

LIMITED TREATMENT OPTIONS

There is no known treatment or cure for neurofibromatosis or schwannomatosis and symptoms can vary greatly from person to person. Medication can be prescribed to help with pain and many patients access allied health services to manage symptoms. In some cases, tumours may be removed surgically or reduced with radiation therapy, however they can regrow. Although surgery in some areas can cause injury to nerves and additional physical problems, it is an accepted standard of care however the benefits of surgery should always be weighed against its risks.[5]

In recent years, MEK (mitogen-activated protein kinase kinase) inhibitors have shown promise in treating particular NF tumours, including PNs and Optic Pathway Gliomas (OPGs).[19] Stakeholders noted that greater access to such evidence-based treatment options is essential to enable better outcomes for people with all types of NF.

LIMITED RESEARCH AND FUNDING

Investment into NF research in Australia has been limited. Funding via the Medical Research Future Fund (MRFF) was only awarded to NF-specific projects for the first time in 2021.[20] As highlighted by stakeholders, the slow progress in understanding NF and its symptoms means that many people are still struggling to comprehend their medical issues and find specialised care.

29% of surveyed healthcare professionals redirected NF patients to other health professionals or organisations due to lack of funding or resources in the past year.

2. NF AFFECTS ALL FACETS OF A PERSON'S LIFE, WITH SIGNIFICANT IMPACTS ON THEIR MENTAL HEALTH, PHYSICAL HEALTH, SOCIAL RELATIONSHIPS, WORK, EDUCATION AND FAMILY PLANNING DECISIONS.

IMPACT ON MENTAL HEALTH AND WELLBEING

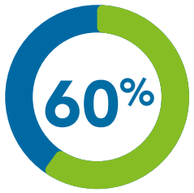
Living with a rare condition such as NF is a challenging and life changing experience that can have a significant impact on a person's wellbeing and overall quality of life.[21] A range of unique circumstances experienced by people living with NF can impact their mental health and wellbeing. These include, diagnosis delays, the significant disruption and ongoing uncertainty that comes with a rare disease diagnosis, feeling isolated, and prolonged and anticipatory grief attached to not leading the life one had imagined or hoped for, as well as the struggle to prioritise mental health needs amid the burden of medical needs.[11]

71% of survey respondents reported a significant or moderate impact on their mental health.[22]

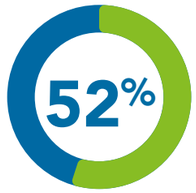
As a result, the psychosocial and emotional impacts can be significant and is often compounded by the lack of adequate support to manage psychosocial needs.

Interviewed stakeholders highlighted good examples of mental health screening for NF patients in some NF clinics; however, these clinics do not exist in every jurisdiction and many people are not receiving mental health support as part of their NF care.

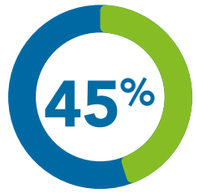
Most survey respondents reported considerable mental health impacts, with anxiety and worry, feeling depressed or unhappy, social isolation, and experiencing bullying being commonly reported impacts.



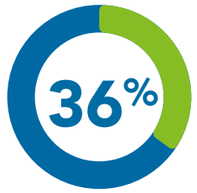
of patients felt anxious or worried through their NF journey.



have felt depressed or unhappy at some point since their NF diagnosis.



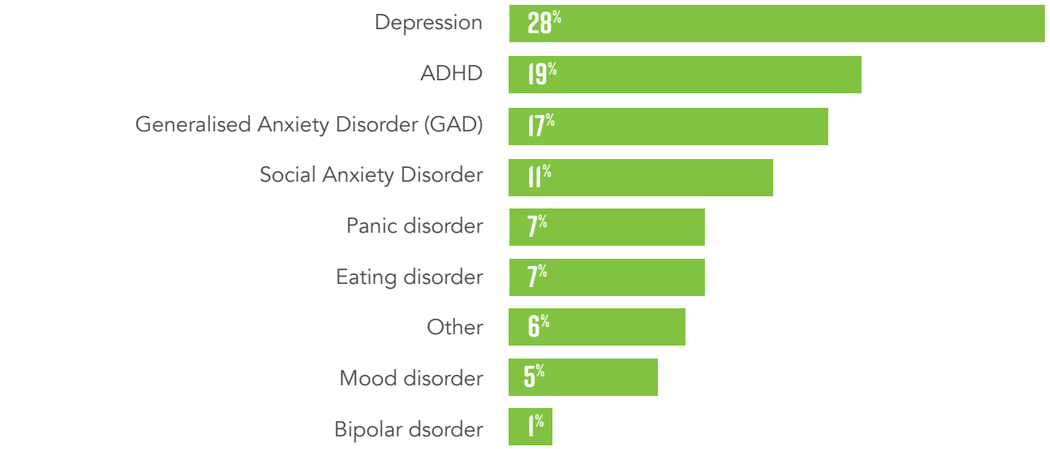
have been socially isolated.



have experienced bullying throughout their life.

The most commonly diagnosed mental health conditions as reported by survey respondents were depression (28%), attention deficit hyperactive disorder (ADHD) (19%), generalised anxiety disorder (17%), social anxiety disorder (11%) and panic disorder (7%) (Figure 5). Some of these results are higher when compared to the Australian general population averages. Australia-wide, generalised anxiety disorder has a prevalence of 8.2%, panic disorder 6.3%, and the proportion of the public who have experienced a depressive episode is 11.7%.[22]

Figure 5: Mental Health diagnoses in NF patients



NF also impacts people's quality of life. As reported by survey respondents:

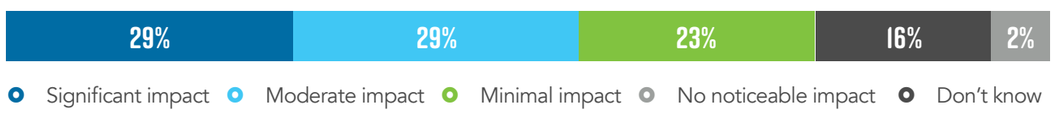
55% SAID EMOTIONAL HEALTH IMPACTED HOW MUCH THEY COULD ACCOMPLISH.

44% SAID THEY DID WORK OR OTHER ACTIVITIES LESS CAREFULLY BECAUSE OF THEIR NF.

IMPACT ON SOCIAL RELATIONSHIPS

NF has a considerable impact on social relationships, with 58% of survey respondents reporting a significant or moderate impact (Figure 6).

Figure 6: Social Relationship Impacts of NF



Additionally, 67% of survey respondents reported that NF interfered with their social activities some to all of the time in the past four weeks. This impact was amplified for people in regional and rural areas with 72% reporting interference compared to 63% in metro areas.

IMPACT ON WORK, EDUCATION AND FAMILY PLANNING

NF impacts on one's ability to live a productive life, affecting participation in education and employment. Over 1 in 3 (34%) individuals reported taking time off education and over **1 in 2 (57%) reported taking time off work due to NF.**

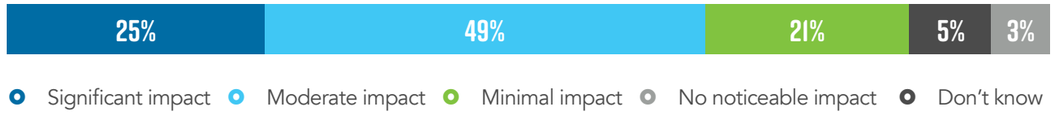
NF also impacts family planning decisions, with 1 in 2 (50%) reporting it had a moderate or significant impact.

IMPACT ON PHYSICAL HEALTH

The complex nature of NF often leads to significant physical impacts. Survey respondents reported a range of physical health impacts, as illustrated in Figure 7. When asked about the extent of physical health impacts, 70% of individuals reported a significant or moderate impact of NF on their physical health (Figure 8).

Figure 7: Type of health impacts experienced

Figure 8: Physical Health Impacts of NF



Physical health appeared to have impacted on work or other daily activities, with 46% saying physical health impacted how much they could accomplish and 45% saying physical health limited the kind of work or other activities they would normally do.

In particular, pain was reported as having a considerable impact on people's life. Nearly 3 in 4 (74%) survey respondents said they experienced bodily pain in the past four weeks. Of those who experienced pain, 6 in 10 (61%) said it interfered with their work.

Emily overcomes NF1 challenges with optimism and strength.

EMILY, AGED 17, DIAGNOSED WITH NF1

Emily was diagnosed with NF1 at just 10 months old. As an infant, she struggled with a severe curvature in her right leg due to NF-related pseudoarthrosis, which impaired her ability to stand or walk. This condition necessitated multiple surgeries and the use of a leg brace.

At age 4, Emily had two inoperable lesions in her frontal lobe and began experiencing epilepsy with frequent absence seizures. By age 5, she had undergone several leg surgeries, including the use of donor bones and an external frame to stabilise her tibia and fibula. During kindergarten, she relied on a walker and wheelchair for mobility.

By the time she was 6, Emily and her parents decided on a surgery to amputate part of her lower leg to prevent future fractures. Emily was optimistic about the surgery, and within three days post-operation, she was moving around the hospital in a wheelchair, excited about her new mobility.

3. THERE IS LIMITED ACCESS TO CARE COORDINATION AND MULTIDISCIPLINARY TEAMS, AND A LACK OF FORMALISED CARE PATHWAYS FOR NF PATIENTS.

CARE COORDINATION

The health system is complex and difficult to navigate, particularly when dealing with the stress and uncertainty of a rare condition such as NF. Interviews conducted for this study suggest there is a need for greater care coordination for people living with NF. There is inconsistency in triaging and referral systems and there is significant variability in how people are connected to needed services.

While NF clinics that currently exist provide some level of care coordination, these clinics do not exist in every jurisdiction and formalised models of care are lacking. Examples of how existing NF clinics attempt to coordinate care include:

- Access to a range of specialists and allied health professionals onsite, e.g., oncologists, neurologists, paediatricians, ophthalmologists, radiologists, and genetic counsellors.
- Willing clinicians taking on a coordination role between other specialists, particularly as people transition from paediatric to adult care.
- Access to clinical nurse specialist to support with care coordination and accessing the NDIS.
- Mental health screening to identify patients at risk.

Only 15% of survey respondents were very satisfied with NF related care coordination (Figure 9). Patients and caregivers are often faced with navigating the system on their own, with many having to self-advocate for their care. Many respondents noted having to retell their story each time they access a specialist, creating an additional emotional burden. A lack of connection and communication between care providers means that patient and caregiver concerns are often dismissed.

Satisfaction levels with care coordination by states and territories were also considered. The proportion of respondents that were very satisfied were similar across NSW (15%), VIC (16%) and QLD (13%). Comparatively, it was slightly higher in SA (19%) and lowest in WA (5%). Proportions for TAS, ACT and NT are not reported due to low sample sizes.

Only 20% of surveyed respondents were very satisfied about discussing concerns and fears regarding NF when accessing healthcare services (Figure 9).

LACK OF FORMALISED CARE PATHWAYS AS NF PATIENTS TRANSITION FROM PAEDIATRIC TO ADULT CARE

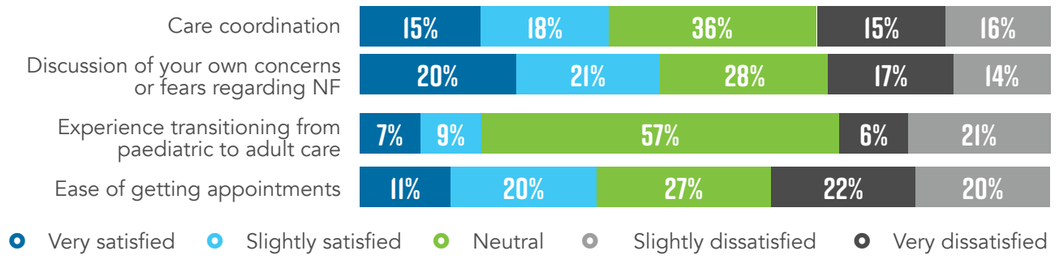
The lack of formalised care pathways was consistently identified as a key area of concern by interviewed stakeholders. Only 7% of surveyed patients and carers were very satisfied with their experience transitioning from paediatric to adult care (Figure 9). This result was consistent across eastern states as NSW, VIC and QLD reported 9%, 7% and 7% respectively who were very satisfied, while SA (4%) and WA (3%), reported lower satisfaction in comparison. Proportions for TAS, ACT and NT are not reported due to low sample sizes.

Patients with rare conditions such as NF transition to adult care during a vulnerable time of life, and as a result, many disengage from their care.[23] Young adults with NF are at a high risk of plexiform neurofibromas transforming into malignant sarcomas[24] - if not managed effectively, these patients face the possibility of being overlooked entirely, giving rise to further health complications and death.

Stakeholders noted that young patients transitioning to adult care without well-defined symptoms often do not receive appropriate care and many live with a limited knowledge of NF related medical risks, symptoms and complications. In cases where these NF patients do receive care, stakeholders noted that it is typically coordinated through the primary healthcare system with a GP who may not have the knowledge or awareness to optimally manage NF.

The absence of formalised systems and practices means that individual patients rely on their own efforts to navigate the health system and rely on clinician awareness of available services and willingness to facilitate connections.

Figure 9: Satisfaction with the various aspects of the healthcare system

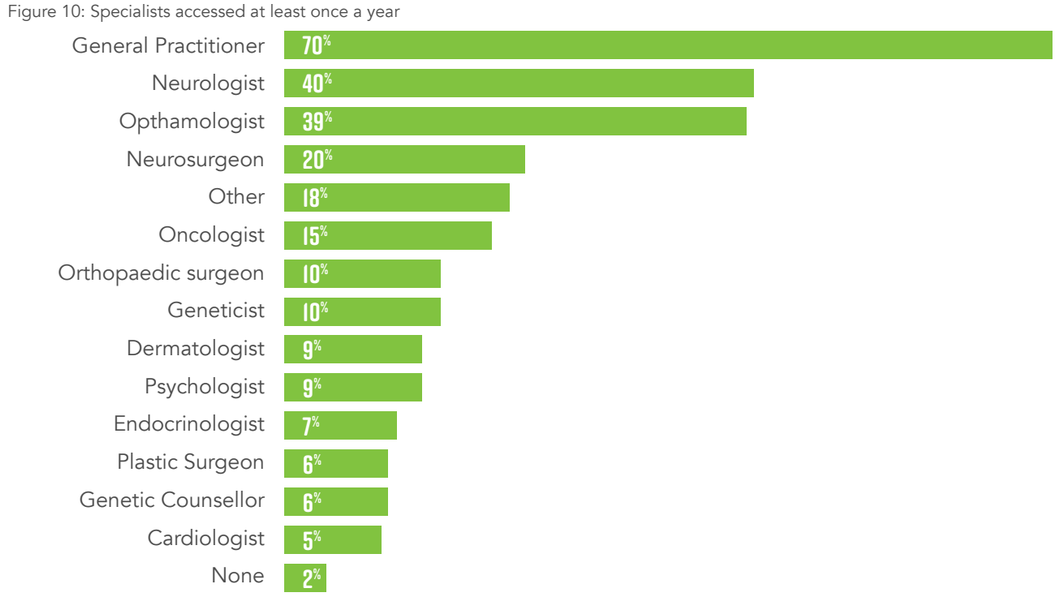


ACCESS TO MULTIDISCIPLINARY TEAMS

NF is multi-systemic with patients having very broad and complex medical needs. Most NF patients require treatment or consultations with a variety of specialists or a multidisciplinary team-based approach to care, with access to doctors, specialists, surgeons, geneticists, genetic counsellors, psychologists, nurses and allied health professionals.

Surveyed patients and carers reported accessing a range of specialists to manage their condition at least once a year (Figure 10). The most commonly used specialists were GPs (70%), Neurologists (40%), and Ophthalmologists (39%), while notably psychologists were only used by 9% of respondents.

Figure 10: Specialists accessed at least once a year



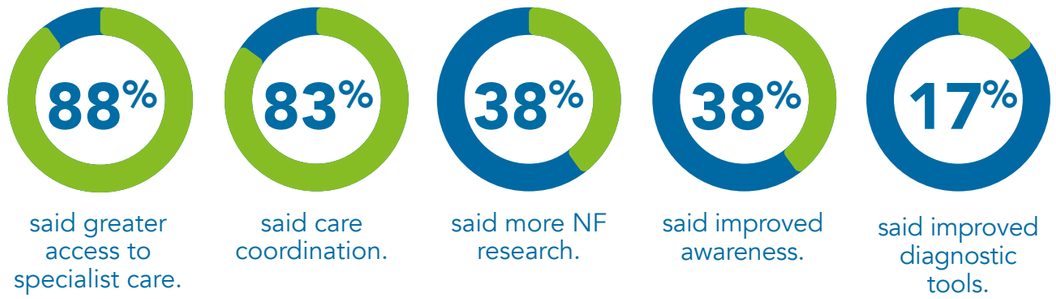
A major barrier to accessing specialty care is the limited care options closer to patients' homes. Existing NF clinics are not available across all jurisdictions. Patients experience long wait times to see a specialist and many need to wait for multiple appointments with different specialists to receive comprehensive care. With limited access to care coordination, patients are often left with the responsibility of finding a suitable specialist on their own.

Many (1 in 10) could not access a specialist. By location, respondents who could not access a specialist was higher in NSW (11%) and QLD (12%) compared to VIC (5%), SA (8%), and WA (8%). Proportions for TAS, ACT and NT are not reported due to low sample sizes.

Only 11% of survey respondents were very satisfied with ease of getting appointments (Figure 9).

By location, those who were very satisfied was lowest in NSW (8%), followed by VIC (12%) and QLD (15%). Comparatively, 23% of respondents in SA said they were very satisfied.

When health professionals were asked about the most important areas for system improvement:

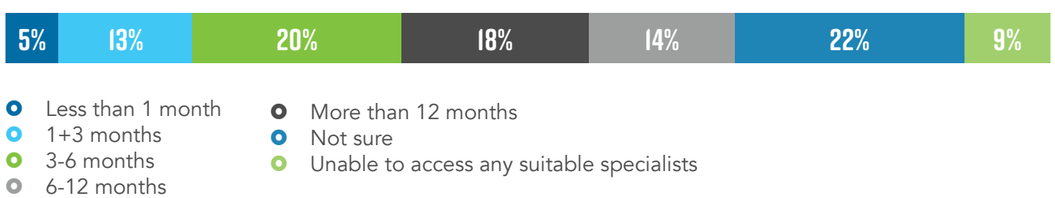


WAIT TIMES TO SEE A SPECIALIST

One in five survey respondents waited 3-6 months to see a specialist; 18% waited 6-12 months and 14% waited over a year (Figure 11).

By location, those who waited over a year to see a specialist was lowest in NSW (9%), followed by QLD (14%), VIC (15%) and SA (15%). It was highest in WA (19%). Proportions for TAS, ACT and NT are not reported due to low sample sizes.

Figure 11: Wait time to see a specialist



From secrecy to strength — after years of hiding, Janu now embraces her NF diagnosis.

FOR MORE THAN THREE DECADES, JANU KEPT HER GENETIC CONDITION A SECRET.

Janu's family migrated from Sri Lanka when she was 18 months old, so she spent much of her childhood balancing Australian customs with the traditions of her culture. Her family was fortunate to have built a strong support network, but after she was diagnosed with NF at age 9, it was decided by her well-intentioned extended family that her NF diagnosis should be kept private. As she got older, she started to realise the blessing of unity that this community provided did not always apply to her.

"I was different and sat firmly outside of the expected mould. I did not meet traditional beauty standards, I was uncoordinated and self-conscious, and regularly in need of medical attention to monitor my symptoms. Growing up, I struggled a lot at school and had learning difficulties."

Lumps began to cover her entire body during puberty, and as a result, she was bullied relentlessly at school, struggled to make friends, and endured a lot of humiliating moments.

"It's physically exhausting holding onto a secret like that.

When you're not able to truthfully explain something so noticeable, people know you're hiding something, so they assume the worst — so it made it very hard to connect in an authentic way with people."

The transition to adulthood was a rough road. Janu fell into a medical abyss – there was no proper handover and, at the times, no adult NF clinic in Sydney. Her physical condition worsened, as did her mental health.

"There wasn't anyone. All I had were plastic surgeons to remove lumps, but I couldn't get my tumours scanned or tested. I was depressed, anxious and alone."

Janu made the decision to finally open up about her diagnosis at age 37, just as she was about to have 162 tumours removed from her head, neck and face. She finally decided she was done hiding her diagnosis and in so doing, lifted an immense burden of secrecy. She has since become an ambassador for the Children's Tumour Foundation and is a source of strength for many in Australia and around the world battling their own feelings of shame, fear, or confusion.

"When I finally stopped hiding, I started living. By sharing my story, I have finally realised that I am worthy of love and kindness. I now recognise that pain is inevitable, but suffering is optional."

"We have always had to research, co-ordinate everything, advocate and ensure that he is receiving the best possible care. At times this is completely overwhelming, and I have only been able to do this because I work part-time - a choice we have made as a family in order for my son to be able to attend all of his appointments and therapy."
– Parent/Caregiver

"When seeing a new specialist, they dismiss other doctors' concern, sometimes even my own. Not having my concerns taken seriously has created anxiety within myself as a carer." - Parent/Caregiver

"It seems that I'm handed from one practitioner to another and there is a lack of communication about the needs of a NF patient. It's emotionally exhausting explaining the condition over and over again and what they should be looking for." – Person living with NF

"I think care co-ordination is critical, particularly during transition to adult care. I think patients need easy access to professionals with expertise in NF1 so they can be assessed about the significance of a lesion quickly. Similarly, I think GPs need access to professionals who can provide advice about NF1." – Healthcare Professional

"A lot of times depending on area of concern from waiting 6 months to see neurologist then to see a neurosurgeon then they refer you to another neurosurgeon. Same with other parts of the body e.g., Orthopaedic surgeons etc." – Person living with NF

NF patients and caregivers emphasise the critical need for coordinated, expert care.

DISABILITY SUPPORTS

Although not the primary focus of this study, survey data revealed that many individuals with NF are not engaged with the National Disability Insurance Scheme (NDIS). Stakeholders consistently identified accessing the NDIS as a major obstacle for people with NF. The complex and varied nature of NF means that it does not fit in easily into a disability category, which in turn makes it challenging to secure funding and support from the NDIS. Some stakeholders noted that extensive advocacy was required to access NDIS services.

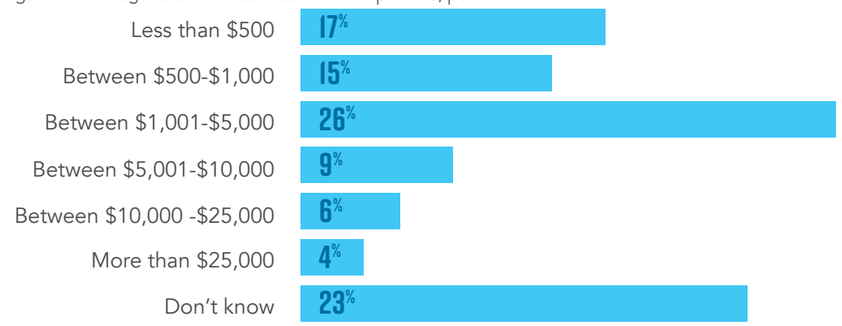
60% OF SURVEY RESPONDENTS DO NOT RECEIVE SUPPORT FROM THE NDIS TO MANAGE NF.

"NDIS not recognising NF1 as a condition requiring support and encompassing other diagnosis such as ADHD/ASD. Applying and funding the many applications and reviews to NDIS. Anxiety around the next NDIS review after being approved for one year only."
– Person living with NF

HEALTHCARE COSTS

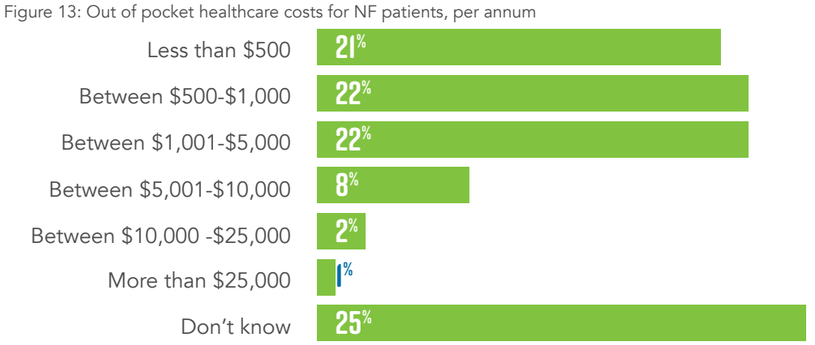
There is a significant financial burden on NF patients and families. NF patients spend on a range of healthcare services including specialist visits, hospital stays, pharmaceutical costs, and medical tests and procedures. Survey results show the annual cost of healthcare for NF, as shown in Figure 12. This demonstrates that for nearly 1 in 5 (19%) NF patients, the total healthcare cost exceeds $5000, while 1 in 4 (26%) NF patients have healthcare costs between $1001-$5000.

Figure 12: Average total healthcare costs for NF patients, per annum



Additionally, 65% of respondents reported that they spend over $1000 a year out of pocket, as shown in Figure 13. Out of pocket cost was largely similar by state, respondents in NSW (24%), VIC (30%), SA (33%) and WA (29%) reported spending over $1000 out of pocket a year respectively. QLD reported a higher proportion with 44% of individuals paying over $1000 on healthcare costs out of pocket. Proportions for TAS, ACT and NT are not reported due to low sample sizes.

Figure 13: Out of pocket healthcare costs for NF patients, per annum



Healthcare costs can be a huge barrier for patients and families, with some deciding not access care or treatment due to high costs.

MORE THAN A QUARTER (28%) OF SURVEY RESPONDENTS SAID THEY DID NOT ACCESS CARE OR TREATMENT DUE TO ITS EXPENSE AS AN INDIVIDUAL OR FAMILY.

"We have had to delay appointments with ophthalmologists, paediatricians because we simply can't afford to do it. We have had to borrow money from family multiple times to make ends meet and get our daughter the help she needs. No one seems to even know what NF is and I am always having to explain it. It's so isolating."
– Parent/Caregiver

"These specialist appointments are expensive, even with Medicare rebates. I have to travel to a metropolitan area for these appointments. It involves long car drives, sometimes overnight accommodation, and the related costs associated (such as meals, fuel, etc.). This is a financial burden."
– Person living with NF

"NF is a chronic and lifelong condition that requires regular reviews and surveillance, and health care costs can be a huge barrier for families."
– Healthcare Professional

4. EXPERIENCES OF INEQUITY ARE AMPLIFIED FOR PEOPLE WITH NF LIVING IN REGIONAL AND RURAL AREAS.

Generally, there are fewer health services in regional and rural Australia compared to metro areas. For example, people living in remote and rural areas are more likely to report not having a GP nearby as a barrier to seeing one. Similarly, the barrier to seeing a specialist due to not having one nearby is almost 10 times greater for people living in remote and rural areas.[25]

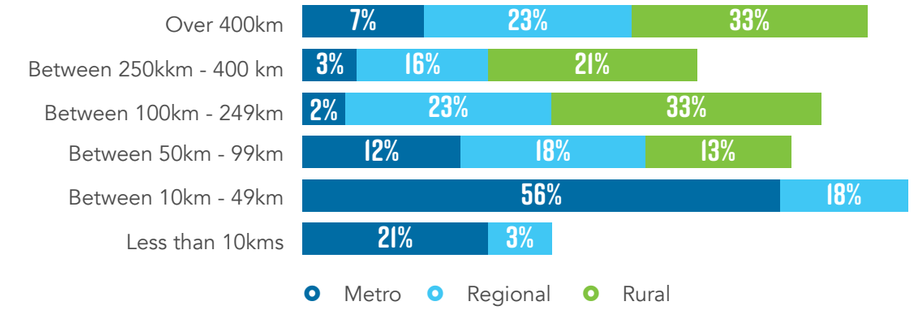
Within the context of NF, the survey data indicates that 58% of individuals with NF live in metropolitan areas whilst 42% live in regional (34%) or rural areas (8%). This is disproportionate to the estimated 28% of Australians living in regional and remote areas.[26]

There are only four clinics in Australia specialising in the care of people with NF, located in two major cities. Therefore, access to services for NF patients in regional and remote areas are impacted by the need to travel long distances to access NF clinics and specialists, reflecting a significant gap in care.

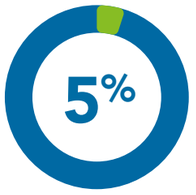
ACCESS TO SERVICES

According to survey results, 1 in 3 (33%) rural respondents and nearly 1 in 4 (23%) regional respondents need to travel over 400 kilometres to access the nearest NF specialist or clinic, compared to 7% of metro respondents. Furthermore, 54% rural respondents and 39% of regional respondents need to travel between 100-400 kilometres to access a NF specialist or clinic, compared to 5% of people in metro areas (Figure 14).

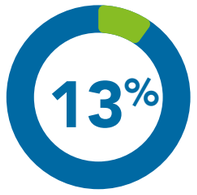
Figure 14: Distance to nearest NF specialist or clinic



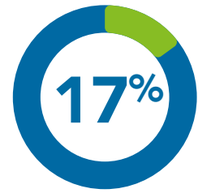
This location-based inequity is further shown in through survey results on access to specialist care.



of respondents in metro areas said they could not access a specialist.



of respondents in regional areas said they could not access a specialist.



of respondents in rural areas said they could not access a specialist.

EASE OF GETTING APPOINTMENTS

Survey results indicate a higher level of dissatisfaction with ease of getting appointments for those in rural areas. Over 1 in 2 (52%) rural respondents said they were dissatisfied with the ease of getting appointments, compared to the 2 in 5 (42%) metro and regional respondents.

HEALTHCARE COSTS

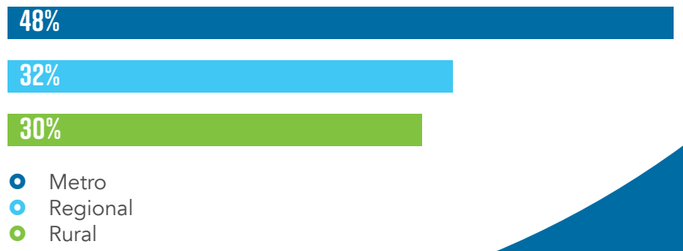
Notably, there was variability in the financial burden experienced by geographic location. When asked if they had ever had to decide not to access care or treatment due to the expense as an individual or family:

22% OF METRO RESPONDENTS SAID THEY HAD NOT ACCESSED CARE DUE TO ITS EXPENSE.

35% OF REGIONAL AND RURAL RESPONDENTS SAID THEY HAD NOT ACCESSED CARE DUE TO ITS EXPENSE.

This inequitable financial impact extends to out of pocket spending, shown in Figure 15. Nearly 1 in 2 (48%) rural respondents spent over $1000 out of pocket, compared to 3 in 10 in Regional (32%) and Metro (30%) areas.

Figure 15: Spending greater than $1000 out of pocket per annum, by region



Regional healthcare gaps leave NF patients struggling for proper care and support.

"There's nowhere regionally (Griffith NSW) to access health care for NF apart from travelling to a major city which financially is not doable for a single income family. I have multiple health issues from NF and it's hard to find a doctor willing to help me. I feel I've fallen through the cracks and my health has worsened because of that."
– Person living with NF

"Living in a regional area means there are no specialists nearby. We need to travel interstate which requires a flight and at least one overnight stay. Because I have other small children and don't wish to be separated from them, we all go as a family. While this is our choice to do it this way, it works out incredibly expensive and kind of turns the specialist appointment into a 'holiday' meaning that we can't then justify the cost of having a holiday somewhere else of our choice."
– Parent/Caregiver

"The regional nature of Tasmania means that there are very few specialists, and the wait times are long to get into a specialist. Even seeing a specialist privately can have a long wait time."
- Person living with NF

ARCHIE, AGED 5, DIAGNOSED WITH NF1

At just three months old, Archie was diagnosed with a kidney condition, leading to three surgeries by the age of 3, including an ENT surgery. Initially, he met all developmental milestones, but around the same time, his speech and motor skills were starting to lag.

Hearing tests led to grommets, but no improvement was seen. Other concerning signs included café-au-lait spots, muscle weakness, and unsteadiness. Each of these symptoms in isolation could have seemed relatively harmless, but further assessments eventually led to a diagnosis of neurofibromatosis type 1 (NF1).

With no family history of the condition, Archie's parents were naturally shocked and devastated. His diagnosis also caused a considerable re-assessment of their lives as the family of six were living in remote Queensland at the time.

"After speaking with the specialists and therapists in Brisbane, it was clear that we needed to move to be closer to high-quality services and support," says Archie's mum Kate.

The move was essential but came at a significant financial and emotional cost. Selling their home, renting and then attempting to purchase a new home in Brisbane, all while being unable to access early intervention through the NDIS, led to substantial financial and personal stress.

Moving meant uprooting the family of six, including a newborn baby, leaving behind friends and family, to establish a new life, while taking steps to ensure Archie received early intervention required tremendous effort from the family.

"The constant uncertainty of NF looms over the whole family and Archie's condition often pulls him back from being the energetic child he wants to be," says Kate.

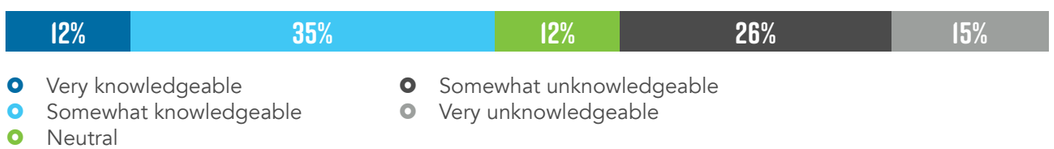
Relocating has been a crucial step for Archie's well-being, but it underscores the significant burden on caregivers and families who must manage the complexities of NF and cannot access services in rural or remote locations.

5. MANY HEALTH PROFESSIONALS ARE NOT FULLY AWARE OF NF. THIS LIMITS THEIR ABILITY TO PROVIDE APPROPRIATE TREATMENT AND ONGOING MANAGEMENT OF NF.

While some research and initiatives aimed at increasing the knowledge and understanding of NF in Australia exist[27], it is important to note that NF is a complex condition and expert knowledge in this field is still limited.

When asked about the level of understanding and awareness demonstrated by healthcare professionals, only 12% of survey respondents said health professionals were very knowledgeable. A further 41% of survey respondents said health professionals were somewhat or very unknowledgeable about NF (Figure 16).

Figure 16: Level of awareness and understanding of NF demonstrated by healthcare professionals, according to patients and caregivers



Stakeholders noted that while awareness of NF among health professionals has improved over time, this is mainly within NF1. This sentiment is echoed among the surveyed health professionals – when asked what type of NF they were most familiar with, none of the respondents said they are familiar with NF2 and SWN, reflecting a significant gap in care. Patients and caregivers also responded that limited awareness and understanding was more pronounced for SWN, with 56% saying health professionals were unknowledgeable in SWN compared with 40% for NF1 and 33% for NF2.

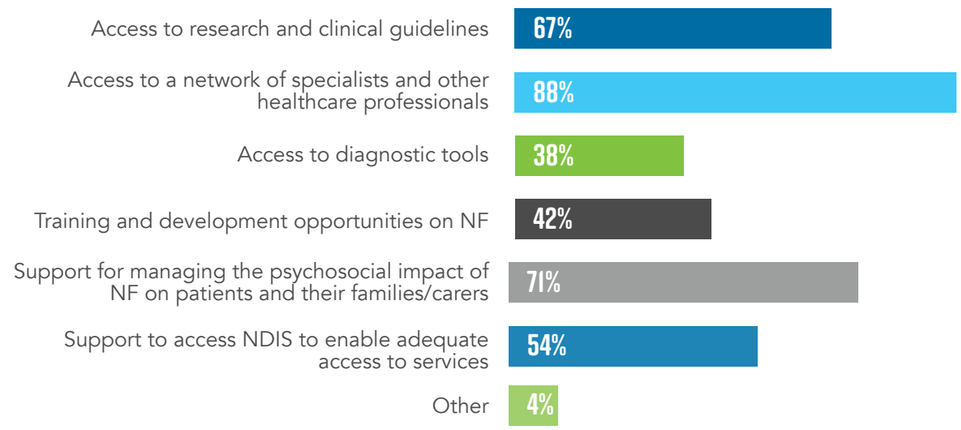
"The lack of informed decisions and vague knowledge base of various health professionals, I noticed various health professionals were not up to date with NF research and had to do my own research and take my own initiative when deciding on a care plan for my child."
- Parent/ caregiver

"I have been told to go home and take Panadol when I have concerns about my health. I have virtually been told, well there's nothing we can do, and we haven't seen this before, so we will monitor it and see how we go. More understanding is needed across the medical community."
- Person living with NF

"The biggest burden is finding medical professionals who have knowledge of NF2, who you can see regularly. Also, very few know how to work with someone with NF2 as well as the patient also having autism and ADHD too."
- Parent/ caregiver

Health professionals were asked what resources and support would be most beneficial to manage NF. As illustrated in Figure 17, access to a network of specialists (88%), support for managing the psychosocial impacts of NF on patients and their families (71%), access to research and clinical guidelines (67%), and support to access NDIS (54%) to enable adequate access to services were identified as being most beneficial by more than half the respondents.

Figure 17: Resources and support that would be most beneficial to manage NF, according to surveyed healthcare professionals



There is an opportunity for Australia to apply lessons from international best practice to better support clinicians, as well as improve outcomes for the NF community. For example, the USA has several formalised centres of excellence for NF, including the John Hopkins Comprehensive NF Centre[28], the NF Centre at the University of Florida[29] and the Washington University NF Centre.[30] The UK has formalised centre of excellence at Guy's and St Thomas' NHS Foundation Trust.[31] Key characteristics of these centres of excellence include:

- Health professionals with access to a network of peers through formalised NF clinical networks.
- Education and training for health professionals.
- NF specialists involved in training the next generation of physician-scientists and leaders in the field of neuro-oncology.
- Research active with ongoing clinical trials.
- Access to a range of specialists.
- Co-location of healthcare professionals with expertise in NF1 and NF2.
- A national centre for NF2 (UK).
- Paediatric and adult care teams.

Centres of excellence can serve as hubs for collaboration among healthcare professionals, researchers, and patient advocacy groups, facilitating the exchange of ideas and best practices to advance NF diagnosis, treatment and ongoing management.

MICHAEL, AGED 33, DIAGNOSED WITH NF2-SWN

At just 16, Michael picked up the phone and found himself struggling to hear the person on the other end clearly. Switching ears didn't help, and he knew something was wrong.

Seeking answers, Michael visited an audiologist, hoping for a simple solution. Little did he know this decision would uncover a life-changing discovery.

An MRI results revealed a ~30mm benign acoustic neuroma near his brain stem that was causing his hearing loss, amongst four or five other smaller brain tumours. Following the surgery to remove this tumour, Michael still faced significant challenges. The procedure resulted in nerve damage to the left side of his face, and he needed time to learn to walk again.

After his surgery, Michael underwent yearly MRIs to monitor around nine tumours of varying sizes in his brain and neck. In 2021, a geneticist reached out, prompting a genetic test. While the test yielded inconclusive results, the geneticist suggested a strong likelihood of NF2-SWN.

In 2022, more than four years of persistent back pain led to an MRI, revealing a small 10mm spinal cord tumour in the L3/L4 region that was causing electrical-like jolts throughout his body every time he sneezed. Surgery soon followed, necessitating a two-week hospitalisation and a two-month home recovery period. But this is not the last of these surgeries, with Michael having another this month.

"After each surgery I wake up from, I don't feel that sense of accomplishment and clarity because I know that this won't be my last surgery or hospitalisation. I will have to have scans in the future, more tumours will come up impacting me in different ways, and I must go through the surgery again," says Michael.

Following his most recent surgery, Michael sought out online communities related to brain tumours and NF2-SWN. He connected with the Children's Tumour Foundation and soon joined an online NF Connect session for NF2-SWN patients. Connecting with others who shared his condition provided invaluable support, filling a void he'd felt since diagnosis. Michael is scheduled to have another brain surgery in 2024, to remove two more brain tumours.

"In some ways, NF has been somewhat of a blessing in disguise because it makes you look at life from a different perspective. It grounds you and helps you to understand what's important in life."

6. THERE IS A SIGNIFICANT EMOTIONAL AND FINANCIAL BURDEN ON NF CAREGIVERS.

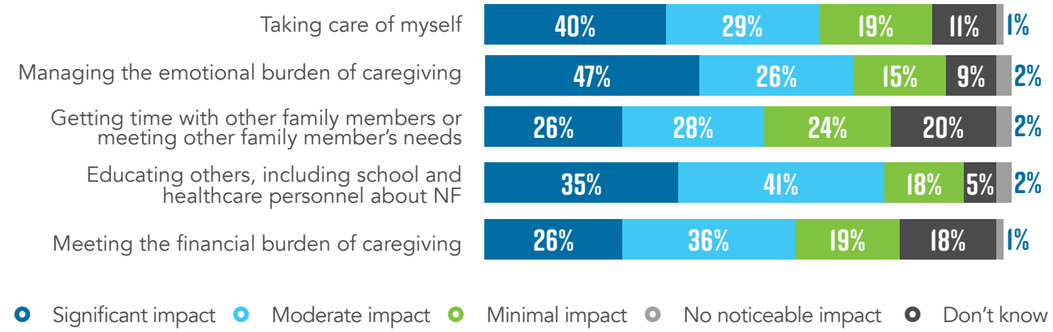
Caregivers of people with a rare condition often face significant mental, physical and financial burdens. Healthcare professionals often lack knowledge about individual rare diseases, which means patients and their caregivers are left to become experts in their specific condition. This places a significant burden on family life, as caregivers are forced to juggle multiple roles in addition to their unique caring responsibilities, such as acting as an advocate, case manager, and health system navigator.

Within the context of NF, survey results indicate that caregiving impacts all aspects of a caregiver's life, with significant impacts on the ability of a person to care for themselves (Figure 18). Most caregivers reported that caring for a child or adult with NF had a significant or moderate impact on their ability to care for themselves (69%); managing the emotional burden of caregiving (73%); time with other family members and meeting their needs (54%); educating others about NF (76%); meeting financial burden of caregiving (62%).

68.9 hours

on average per week was spent on providing care and assistance to a child or person with NF in the past month.

Figure 18: Impact of various aspects of caregiving for someone with NF



There is a tremendous toll on the mental and physical health of NF caregivers. As reported by survey respondents:

77% OR NEARLY 4 OUT OF 5 CAREGIVERS EXPERIENCED A SIGNIFICANT OR MODERATE IMPACT ON THEIR MENTAL HEALTH.

57% OR MORE THAN HALF OF CAREGIVERS EXPERIENCED A SIGNIFICANT OR MODERATE IMPACT ON THEIR PHYSICAL HEALTH.

66%

of caregivers said their work status was impacted to a significant or moderate extent due to caregiving responsibilities.

Comparatively, the 2022 Carer Wellbeing Survey suggests that across all conditions, 48.1% of carers experience moderate to high levels of psychological distress, whilst 25% Australian adults more broadly experience these levels of distress.[32] Many caregivers reported taking time off work, 3 in 10 (29%), which can cause financial strain due to high cost of medical care and lost income (Figure 19).

Figure 19: Caregivers who had to take extended time off work to care for their child with NF

Maria balances care for Alex's NF1 while supporting her older daughter Georgie

WHOLE FAMILIES ARE IMPACTED BY THE DIAGNOSIS

As a mother of two girls, Maria has her hands full. The girls possess wonderful, yet distinct personalities. One stark contrast between them is that her youngest, Alexandra (Alex), now 6 years old, was born with NF1, a condition she has also lived with her entire life.

Despite facing delays in fine and gross motor skills, common among children with NF, Alex underwent speech therapy, occupational therapy, and physiotherapy to aid her development.

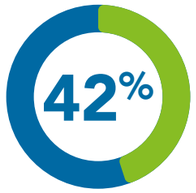
Regular MRIs tracked the growth of a plexiform neurofibroma on her face, which required surgeries under general anaesthesia from a tender age, a heart-wrenching experience for her parents.

The family's frequent trips to Melbourne from Geelong for appointments and treatments have had an impact on the whole family with much time spent travelling between various appointments and specialists.

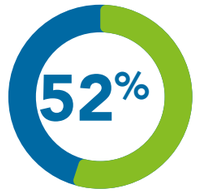
"My other daughter Georgie is 12 and struggles with me being away so much and is concerned for her sister. I am managing all of Alex's appointments, as well as my own, but that is simply the hand we have been dealt and we make the most of every moment together," says Maria.

Survey results indicate that the vast majority of NF caregivers are female (90%), meaning that women are disproportionately impacted by burden of caregiving. This is particularly significant because lost income from taking time off work can have considerable life impacts for women. Generally, women are more likely to work part time or in low paying jobs,[33] which means that taking time off work can lead to range of negative consequences, including reduced opportunities for career advancement,[34] and lower lifetime earnings and superannuation at retirement[33]. This can have a significant impact on their overall quality of life as well as their ability to provide for themselves and their families.

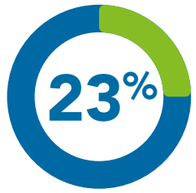
The impact of NF extends beyond the caregiver and to other family members of those with NF. This includes, but is not limited to, siblings of people with NF. This typically presents through the limited time parents and caregivers have to give siblings the attention and support they need; the emotional toll of having a sibling with NF and missed opportunities for siblings due to financial burdens of caring of someone with NF. Through survey responses, caregivers described this extensive burden.



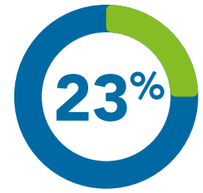
said their child's NF burdened their sibling(s).



of caregivers said the NF diagnosis of one child make it challenging to provide the same level of care to their other children.



said their other children had accessed mental health services for emotional wellbeing support.



said their other children have missed opportunities (e.g. sport or social) due to the financial burden of caring for their sibling with NF.

"Being a single mother, I have to fund it all and carry the mental burden myself.

I have to manage my own NF alongside my children's."
- Parent/ caregiver

"Our biggest challenge has been the transport from Canberra to Sydney for appointments. Most appointments are managed in daily travel; however some appointments require overnight stays. For me this means time off work, travel and medical costs, loss of time with my other child and fatigue from travelling."
- Parent/ caregiver

DETAILED RECOMMENDATIONS

To tackle the inequities that people living with or caring for those with neurofibromatosis in Australia experience, we have developed six key recommendations and some opportunities that will help to bring these recommendations to life.

The CTF believes that acting on these recommendations, combined with a vision to create an environment that invests in research and innovation will significantly change the course and outcome for anyone living with or impacted by NF.

1. DEVELOP AND IMPLEMENT A NATIONAL STRATEGIC APPROACH THAT DRIVES EQUITABLE AND TIMELY CLINICAL CARE FOR NEUROFIBROMATOSIS.

ACTIONS:

- Establish an NF expert advisory group to play a key role in informing the development of consistent evidence-based guidelines for diagnosis, clinical and social care, referral pathways, effective data collection and use that informs regulation and reimbursement pathways, and has a key role in progressing NF research.

2. ENSURE DELIVERY OF COORDINATED CARE ACROSS A PERSON'S NF LIFESPAN AS PEOPLE WITH NF REQUIRE ACCESS TO A RANGE OF MEDICAL AND SOCIAL SUPPORT SERVICES.

ACTIONS:

- Building on existing models of care to establish fit for purpose, sustainable, hybrid Centres of Expertise in each state and territory that provide coordinated multi-disciplinary care and acts as an NF knowledge and referral hub.

3. DELIVER TARGETED SUPPORTS FOR THE MENTAL HEALTH AND WELLBEING NEEDS OF NF PATIENTS AND THEIR CAREGIVERS.

ACTIONS:

- Federal funding to provide ongoing, sustainable funding to enable CTF to enhance the services and support they provide that relieve the psychosocial burden experienced by NF patients, caregivers and families.
- Inclusion in NF clinical care guidelines to screen for mental health risk and support needs, and adequately refer to support networks under individualised care plans and whole of life models of care.
- Raise awareness among people living with NF about the care and support services available to them and identify gaps and opportunities for improvement.

4. INCREASE NATIONAL AWARENESS AND EDUCATION OF NF TO ELEVATE KNOWLEDGE OF CONDITION IMPACT, AND VARIABLE HEALTH AND SUPPORT NEEDS OF THE NF COMMUNITY.

ACTIONS:

- Address funding gap for CTF to build capacity to increase NF awareness and education through activities including hosting information sessions, workshops, conferences and distributing awareness materials.
- Facilitate the inclusion of NF consumer voice and lived experience through consultation into key policy areas including the disability, health, education, housing and employment.
- Relieve the caregiver burden in NF through coordinating awareness of and access to financial and practical supports.

5. ADDRESS KNOWLEDGE GAPS AMONG HEALTHCARE PROFESSIONALS OF NF TO IMPROVE DIAGNOSIS, TESTING AND TREATMENT, AND FURTHER ENABLE HEALTHCARE PROFESSIONALS TO MEET THE HEALTH AND SUPPORT NEEDS OF THOSE DIAGNOSED WITH NF.

ACTIONS:

- Leveraging the Recommendations from the National Strategic Action Plan for Rare Disease (2020), and the National Recommendations for Rare Disease Health Care (2024), take an active and collaborative approach to partnering with existing peak bodies, and clinical and health technology stakeholders to improve access to information and education across primary and specialty care networks, with focus on NF Centres of Expertise as hub of knowledge network.

6. INCREASE DATA COLLECTION, INVESTMENT IN GENOMICS AND RESEARCH INTO NF, AND ACCESS TO CLINICAL TRIALS TO DRIVE INNOVATION AND NF INTERVENTIONS AND CARE.

ACTIONS:

- Continue to provide research funding for NF via the Medical Research Future Fund and advocate for timely and equitable access to clinical trials in NF through the national implementation of the One-Stop-Shop for Clinical Trials.
- Improve equitable access to testing and genomics services to better identify and support families at risk.

TOM, AGED 10, DIAGNOSED WITH NF1

When Tom was around 6 months old, his parents noticed his right pupil was larger and irregular in shape compared to his left. They took him to their local GP, who referred them to an ophthalmic surgeon in Newcastle. After consulting with a specialist in Sydney, an MRI under general anaesthetic was recommended. He was diagnosed with an arrested primary congenital glaucoma. **It would take another two years to learn he had neurofibromatosis type 1 (NF1) when a paediatrician noticed his café-au-lait spots.**

The traumatic experience marked the beginning of numerous tests, MRIs, and eye surgeries for Tom.

Over time, Tom faced increasing challenges. He underwent emergency trabeculectomy surgery twice in early 2020 due to excessive pressure in his eye. Additionally, he developed right-sided facial fullness, leading to asymmetry over the past four to five years. Multiple MRIs and visits to Westmead revealed a thin, infiltrative type of plexiform neurofibroma in his right-sided facial bones, along with other issues such as sphenoid wing dysplasia and dural thickening.

Due to his medical complications, Tom and his family regularly travel from the Hunter Valley for access to specialist care in Newcastle and Sydney. Lynda knows that for the next decade at least, her priority is Tom, his health and ensuring his siblings have the support they need as well.

"For me, that means setting aside any professional aspirations I may have to ensure I have the flexibility I need to be able to take frequent or extended time off work. This is simply my normal for right now and am grateful to have the support of the Children's Tumour Foundation to walk this path with us," says Tom's mum Lynda.

For kids like Tom, early diagnosis and regular monitoring and interventions can make all the difference to his quality and length of life.

"Knowing I have no control over tumours that are in his brain and pushing on his eye is devastating, realising this is just the beginning of our NF journey is terrifying," admits Lynda.

GLOSSARY

ACT	Australian Capital Territory
ADHD	Attention Deficit Hyperactivity Disorder
CAP	Community Advisory Panel
CTF	Children's Tumour Foundation
GP	General Practitioner
HREC	Human Research Ethics Committee
IVF	In-vitro fertilisation
MAP	Medical Advisory Panel
MDT	Multi-disciplinary team
MEK	Mitogen-activated protein kinase kinase
MRFF	Medical Research Future Fund
NDIS	National Disability Insurance Scheme
NF	Neurofibromatosis
NF1	Neurofibromatosis Type 1
NF2	NF2-related schwannomatosis
NSW	New South Wales
NT	Northern Territory
QLD	Queensland
SA	South Australia
SWN	Schwannomatosis
TAS	Tasmania
VIC	Victoria
WA	Western Australia

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TOGETHER WE CAN CONQUER NF!

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