



NEURO MATTERS

**THE STATE OF NEUROLOGICAL CONDITIONS
& SUPPORT IN QUEENSLAND**

**UNDERSTANDING IMPACTS, ADDRESSING NEEDS
& SEIZING OPPORTUNITIES TO TRANSFORM LIVES**



NEED, IMPACT, OPPORTUNITY

TRANSFORMING THE LIVES OF QUEENSLANDERS WITH NEUROLOGICAL CONDITIONS

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1. Foreword

Despite their profound impact, neurological conditions as a disease group are often overlooked, under-reported and lack adequate funding. The authors of this vital report are, therefore, to be commended for shedding light on the significant challenges faced by Queenslanders living with neurological conditions.

This report represents the collaborative efforts of Epilepsy Queensland, MS Queensland, and Parkinson's Queensland. They have diligently collaborated to gather data, insights, and opportunities to enhance understanding of the prevalence and impact of neurological conditions throughout the state.

The findings are compelling. They reveal a pressing need for targeted action to address the stigma, discrimination, and healthcare challenges faced by those living with these conditions.

A key message from this report is that neurological conditions should not be treated in isolation. They are interconnected with other health issues and require a holistic and integrated approach to care and support. This calls for the development of both a State Neuro Action Plan and a National Neuro Action Plan.

Queensland now has a unique opportunity to take the lead in transforming the lives of those affected by neurological conditions. By implementing the recommendations outlined in this report, we can reduce the burden of disease, improve the quality of life for individuals and their families, and alleviate the strain on healthcare systems.

It is my hope that this report serves as a catalyst for further actions in other states and territories, culminating in a national action plan for neurological conditions.

The need is compelling. The impact is undeniable. It is now time to make a meaningful difference for the one-in-four Queenslanders with neurological conditions.



Rohan Greenland
Chair
Neurological Alliance Australia

CEO
MS Australia

2. CEO Perspectives

Queensland has a unique opportunity to craft a lived experience led framework facilitated by collaborative sector organisations to truly transform the lives of people and their families living with Neurological Conditions.

Epilepsy Queensland, MS Queensland and Parkinson's Queensland have been informally collaborating on improving the outcomes for people with Neurological Conditions for several years and bring forward this important foundational report outlining the state of play in relation to the prevalence and impact resulting from Neurological Conditions in Queensland.

For the first time we've collated data, insights and opportunities to outline a holistic picture across the many forms of Neurological Conditions and it is a sobering read.

We know from our own work over 70+ years that Neurological Conditions are often misunderstood and, setting aside any issues at the clinical end of the continuum of care, stigma and discrimination contribute significantly to the burden of disease for both the individual person and their family and in some cases is worse than the condition itself.

The *World Health Organisation's (WHO) Intersectoral Global Action Plan on Epilepsy and other Neurological Conditions* is a highly relevant framework to prioritise targeted responses for Epilepsy and other Neurological Conditions in the state public health systems. These critical actions should occur before the burden of disease has far reached impact not just on the 1 in 4 Queenslanders with a diagnosis, but also reducing the enormous pressure that will inevitably be endured by the people and systems that support them.

The **need** is clear based on this report. The **impact** is far reaching and profound. The **opportunity** is ours to collectively make a positive and critical transformation.



Chris Dougherty

Chief Executive
Epilepsy Queensland



David Curd

Chief Executive
MS Queensland

Contributors

Chris Dougherty (CEO, Epilepsy Queensland)

David Curd (CEO, MS Queensland)

Dr Janette Hancock (Associate Consultant, I-exchange Australia)

Samantha Billington (Executive Projects Lead, MS Queensland)

Regina Gleeson (Quality, Legal & Risk Manager, MS Queensland)



3. Glossary

Acronym	Full Name
ABI	Acquired Brain Injury
AIHW	Australian Institute of Health & Welfare
CALD	Cultural & Linguistic Diversity
D&FV	Domestic & Family Violence
DALYs	Disability-Adjusted Life Years
GDP	Gross Domestic Product
GP	General Practitioner
HCP	Home Care Packages
IGAP	Intersectoral Global Action Plan
MD	Muscular Dystrophy
ME/CFS	Myalgic Encephalomyelitis / Chronic Fatigue Syndrome
MND	Motor Neurone Disease
MS	Multiple Sclerosis
NAA	Neurological Alliance Australia
NCMCC	National Centre for Monitoring Chronic Conditions
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NHS	National Health Service
NSF	National Service Framework
NSW	New South Wales
NWH	Neuro Wellness Hub
NT	Northern Territory
PBS	Pharmaceutical Benefits Scheme
QLD	Queensland
SA	South Australia
WA	Western Australia
UK	United Kingdom
US	United States
WHO	World Health Organisation
YLD	Years Lived with Disability
YLL	Years of Life Lost

4. Introduction

“Neurological Conditions cause great suffering to the individuals and families they affect, and rob communities and economies of human capital”

Dr Tedros Adhanom Ghebreyesus, WHO Director-General.

Google ‘Neurological Conditions’ and you’ll find a series of staggering statistics.¹

- 9 Million deaths worldwide a year.
- 3.4 Billion people, or 43% of the world’s population, affected.
- 443 Million years of healthy life lost due to illness, disability, and premature death.

With numbers like these, it’s no surprise that Neurological Diseases, Disorders, and Injuries, referred to collectively as Neurological Conditions in this report, are now recognised as the **second leading cause of death globally** and the **fastest-growing cause of death among non-communicable diseases**.²

Australia is not immune to these disturbing trends. There are now **over 7 Million Australians with a diagnosed Neurological Condition**. Everyday lives are being interrupted by debilitating symptoms that impact people’s memory, movement, and ability to do basic tasks, compromising their safety, quality of life and independence. Loved ones, typically the caregivers, face immense emotional and financial stress while friends and communities feel the broader ripple effects over an extended period from diagnosis until death, most likely premature.

In Queensland, the numbers are no less alarming. **An estimated 1 in 4 Queenslanders now has a Neurological Condition. Every Queenslander knows someone living with a Neurological Condition** including Dementia, Epilepsy, Multiple Sclerosis, Motor Neurone Disease, Parkinson’s Disease, Polio or even migraine, Muscular Dystrophy, or Chronic Fatigue Syndrome.

Whilst each condition has different symptoms, mortality rates and risk factors, they all share a common trait – they profoundly disrupt lives for an extended period. The impacted employment, education, social interactions, family life and community participation for the individual with the condition and their families.

While Neurological Conditions have become increasingly common, our response and understanding of them as a 'collective whole' has not advanced at the same rate. A lack of data and research, combined with a greater focus on other chronic diseases, have hindered efforts to understand, value and protect brain health across all stages of life.

The tide is turning, however.

Recent attention from the WHO in their *Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders* has acted as a catalyst for Governments worldwide to start acting. The IGAP emphasised the need for coordinated efforts across health, education, employment and social services to improve Neurological Conditions' prevention, diagnosis, treatment, and care. It highlighted the importance of integrating Neurological care into primary healthcare systems, enhancing public awareness, and reducing the stigma associated with these conditions.

In Australia, recent statistics from the Australian Institute of Health and Welfare (AIHW) have highlighted the significant impact that Neurological Conditions have on everyday lives. According to the AIHW, **Neurological Conditions joined the top five contributors to the total disease burden in 2023**, causing 464,997 years of health loss to Australia each year. **The burden of Neurological Conditions is increasing while the burden of Cancer, Musculoskeletal, and Cardiovascular Diseases is going down.**

It is these statistics and advocacy from the Neurological Alliance Australia (NAA) that have helped secure a recent funding injection of \$550,000 from the Australian Government to AIHW to undertake more in-depth data collection on Neurological Conditions to better map their prevalence and forecast the impact in the years to come.

While this much needed step to developing improved insight means Neurological Conditions are finally being recognised, there is still a long way to go.

Whilst it will take time to collect and analyse robust data before it can truly be used to drive active evidenced based change and tackle the burden of Neurological Conditions, this does not prevent Governments from implementing new initiatives and programs now to create life-changing outcomes for people living with Neurological Conditions and their families.

1 in 4 Queenslanders are already living with a Neurological Condition, and thousands more are expected to be diagnosed in the coming years. As Queensland's population grows and ages significantly over the next few decades, **Queensland cannot wait for the projected tsunami of Neurological Conditions to arrive.**

The **need** is great. The **impact** is significant. There's a real **opportunity** to take decisive action now and lead within Queensland and across Australia.



5. Purpose & Scope

Like most Australian States and Territories, Queensland lacks sufficient data on the prevalence and impact of Neurological Disorders. This means the Queensland Government is limited in its ability to make informed, evidence-based decisions related to Neurological healthcare, social services, resource allocation and policy formulation. In turn, its ability to ensure the wellbeing of people living with Neurological Conditions and their families is compromised. So, too, is its capacity to maintain a fit for purpose and resilient public health system.

This report is intended to address some of this knowledge deficit and assist to enhance future public health policy decision-making. It does this by mapping and analysing Queensland's current 'Neuro' landscape, offering insights into the prevalence and impact of Neurological Conditions in Queensland and by providing insight regarding current and future support system gaps. It draws upon International and National studies to emphasise new findings, existing gaps and to propose opportunities for action.

The report is divided into eight sections, each outlining headline statistics, insights and potential action steps. The eight sections cover:

- Prevalence by Condition & Cohort.
- Impact of Neuro & Specific Conditions.
- Support Systems & Participation by Cohort.
- Support Gaps & Unmet Needs.
- Specific Demographic Considerations.
- Neuro Response in Other States / National.
- Neuro Response Internationally.
- Benefits of Awareness, Early Diagnosis & Targeted Response.

6. Approach

This report explores available data but does not claim to present a complete picture of Neurological Conditions in Queensland. What became evident in preparing this report, was the **significant data gaps on Neurological Conditions in Queensland**. Existing data is fragmented, sometimes contradictory, and scattered across various sources. This has necessitated the use of broad examples, often from overseas, and the inclusion of disparate statistics, estimations, and assumptions based on percentages of populations.

The proposed establishment of a Neurological National dataset will help address this critical data gap, enabling more focused research and substantially enhancing health outcomes Nationwide.

7. Executive Summary

Finding out you have a Neurological Condition can be confronting and confusing, especially if you don't have easy access to advice and support. Neurological Conditions are exceptionally difficult to diagnose and treat. They create substantial challenges for patients, caregivers, families and healthcare systems.

The prevalence of Neurological Conditions in Queensland and across Australia is on the rise. Its impact is significant and far-reaching, and yet Neurological Conditions do not garner the attention that many other chronic diseases receive.

Part of the reason for this collective ignorance or misunderstanding that has arisen is the lack of reliable, comprehensive data on the prevalence, incidence, and impact of Neurological Conditions, which is largely limited and fragmented. Significant data gaps hinder comprehensive understanding and effective planning. Awareness-raising campaigns are either non-existent or small-scale, focused on individual conditions rather than Neurological Conditions as a 'whole'.

This report identifies alarming statistics and presents promising ways to move forward. To help people with Neurological Conditions receive optimal care for their complex, often long-term conditions. It found that **many of the Conditions that fall under the banner of Neurological Conditions share common symptoms, care needs, and treatments and that addressing them requires well-designed, integrated, responsive, and multidisciplinary responses.**

The report shows that Neurological Conditions require a macro view to understand how they are connected and coexist with other health conditions and how they impact specific cohorts differently.

The most significant and costly risk for Queensland is to do nothing.

There is an opportunity now to take strategic yet impactful steps to build a comprehensive state wide response to tackling Neurological Conditions. The following condenses these steps into seven key actions:

- **Coordinate Efforts** by establishing a dedicated sector led Queensland Neuro Alliance to bring together lived experience, peak organisations and key government stakeholders. This 'Neuro Alliance' will provide timely advice and co-designed solutions for enhancing the quality of care and support for those people, families and communities impacted by Neurological Conditions.
- **Develop A Cross-Government Neuro Care Framework** that delivers a comprehensive approach to developing Neurological awareness and care throughout the state, focusing on providing timely, integrated, and effective responses tailored to the specific needs of different cohorts and communities.
- **Educate, Promote, & Raise Awareness** about the profound impact of Neurological Conditions on individuals, families, and communities through a targeted, collaborative and multi-channel campaign. The campaign should inspire action and engagement by highlighting real stories, providing critical

information and encouraging proactive steps towards better Neurological health.

- **Develop Innovative Engagement Tools** for people with Neurological Conditions to significantly enhance their quality of life by providing accessible, user-friendly interfaces for interaction and support, such as a centralised **Neuro Gateway** drawing on existing curated content from the sector.
- **Create New Models Of Integrated Care & Support** to help people living with Neurological Conditions access holistic services that address the physical, cognitive and emotional aspects of their condition, such as a network of 'Neuro Wellness Hubs' strategically located across Queensland.
- **Invest In Improved Research & Data** that maps Queensland's similarities and differences across diverse demographic and social determinants. This will help facilitate the development of tailored interventions and policies that effectively address the specific needs of various population groups, ensuring more equitable and effective outcomes for all.
- **Improved Navigation Support Between The NDIS, Aged Care, Health Care & Disability Care Systems** to ensure people affected by Neurological Conditions have their needs met, regardless of which system they access.

Immediate action is required from the government and stakeholders to address these pressing issues and create a sustainable support system. This report is just the start of a conversation that will hopefully underpin and inform tangible actions that will **create a life-changing positive impact for the 1 in 4 Queenslanders living with a Neurological Condition.**

8. Summary of Sections

Each section highlights detailed Neurological **data, insights** and potential opportunities for **action**.

Component 1: Prevalence Of Neurological Conditions By Condition / Cohort identifies that:

- Prevalence estimates across all Neurological Conditions are increasing in Australia and in Queensland.
- Prevalence data, where available, show clear age, sex and cultural patterns.
- First Nations Peoples are at a higher risk of developing a Neurological Condition and are likely to be more severely affected by their condition than non-First Nations Peoples.
- One in five Queenslanders were born overseas, yet ethnicity statistics for Neurological Conditions are severely underrepresented.
- More people are being diagnosed with early onset across many Neurological Conditions.
- Some Neurological Conditions are unequally distributed between sexes and across age groups.

Component 2: Explores The Impact of Neurological Conditions & highlights that:

- The chronic nature of many Neurological Conditions lasts for many years or often a lifetime.
- As the prevalence of Neurological Conditions grows, its contribution to the overall disease burden and social and economic impact in Queensland will escalate.
- Individuals and families living with Neurological Conditions share many of the same impacts and needs.
- Neurological Conditions can:
 - Include a range of functional impairments that affect mobility, dexterity, behaviour, communication or speech, cognition, consciousness, & emotion;
 - Result in chronic pain and discomfort;
 - Negatively diminish the quality of life, limit education and work opportunities, reduce the ability to participate in activities and



undermine financial security for the individual and their family;

- Cause significant emotional stress for families and caregivers due to their chronic and progressive nature;
- Lead to feelings of stigmatisation;
- Cause significant burden on the public healthcare system with conditions often requiring long-term care, including hospitalisations, medications, and rehabilitation;
- Result in indirect financial burden through loss of productivity, caregiver burden, and long-term disability;
- Negatively impact the individual's mental health due to their association with depression, anxiety, and cognitive impairment;

Component 3: Examines The Support Systems Available & Confirms That:

- Early access to funding packages and support can help people manage the symptoms more effectively and allow individuals to maintain a higher level of independence for a longer period.
- Many Queenslanders with Neurological Conditions are missing out on critical NDIS and Aged Care funding and supports.
- Thin NDIS markets in rural and remote Queensland locations exacerbate the burden of Neurological Conditions for people living in those areas.
- Incurable conditions like MS, early onset Parkinson's and Dementia, which have fluctuating functional impacts and are likely to meet NDIS full access criteria over time, need streamlined access pathways to the NDIS before substantial functional decline occurs.
- Comparable funding and accessible services between the NDIS and Commonwealth Government-funded Aged Care system, irrespective of age, is critical.

Component 4: Examines Support Gaps / Unmet Needs for People Living with a Neurological Condition & Confirms That:

- There are not enough Neurological Specialists in Australia. This shortage leads to long wait times, delayed treatment & unnecessary presentations to hospital emergency wards.
- Timely and equitable access to Neurological Services is crucial for effectively treating and managing Neurological Conditions.



- Barriers to accessing Neurological Specialists can lead to delayed condition reviews, meaning individuals go without treatment, impacting multiple aspects of their life.
- A significant disparity of service distribution and accessibility, particularly in rural and remote areas, leads to uneven healthcare coverage and varied individual and family outcomes.
- Critical improvements are needed to enhance diagnostic communication, access to specialised care in rural and remote areas, and to improve individual's access to user-friendly health information.
- Urgent unmet needs of Queenslanders with Neurological Conditions require immediate attention to enhance the quality of these peoples lives through the provision of comprehensive care.
- Addressing the substantial challenges in Neurological care requires innovative holistic care and support solutions.

Component 5: Explores Specific Demographic Considerations for Neurological Conditions & Outlines That:

- Women and men may experience the impact of some Neurological Conditions differently.
- First Nations peoples face numerous barriers to diagnosis and support for Neurological Conditions. They experience greater lifetime exposure to potentially modifiable risk factors.
- The burdens of individual Neurological Conditions are attributable to various risk factors differing amongst people of different ages, sexes, socioeconomic status, and cultural backgrounds.
- Socioeconomic status influences health outcomes for people with Neurological Conditions.
- Disparity in healthcare access and support often leads to increased Disability and exacerbates the challenges associated with managing a Neurological Condition.
- Neurological, Mental Health and other Disorders rarely exist in isolation.
- Comorbidities significantly impact the severity, care needs, management and outcomes of Neurological Conditions.
- Caregivers are at risk of poor health too.

Component 6: Analyses of Neurological Strategies in Other Australian States / Territories Finds That:

- Despite the significant increase in the burden of Neurological Conditions in Australia, no Commonwealth, State or Territory has taken the lead in creating, implementing and measuring a comprehensive health plan to address this growing issue.
- The NAA's recommended initiatives and recent AIHW funding signal the existing and future importance of Neurological Conditions to public health.
- Doing nothing is a risky, costly and unacceptable option.

Component 7: Examines International Neurological Frameworks & Discovers That:

- There are consistent common themes throughout national Neurological care frameworks around the World:
 - Plans are co-designed with lived experiences and emphasise a patient-centred approach.
 - Integration of services across different levels of care is key, including coordination between primary care, secondary care, specialist services, and community health services.
 - Improving access to specialist Neurological Services is critical.
 - The use of interdisciplinary teams, including Neurologists, Nurses, Therapists, and Social Workers is a priority for responding to the multifaceted needs of Neurological patients and their families.
 - Investing in training and education for healthcare providers to build a skilled workforce is essential.
 - Raising public awareness about Neurological Conditions and reducing stigma is critical.
 - Ensuring equitable access to Neurological care for all population groups, including at-risk and vulnerable populations along with rural and remote communities, is vital.
 - Implementing robust data collection and monitoring systems is essential to track outcomes, measure effectiveness, and inform policy decisions.

Component 8: Reviews The Benefits of Awareness, Early Diagnosis / Targeted Response & Highlights That:

- Prevention and early detection are crucial for reducing the burden on individuals, communities, and the public healthcare system.
- If individuals do not receive timely and effective interventions after diagnosis, the impact on the health care system is significant.
- A more holistic approach to primary care for patients that unites general practitioners, specialists, and allied health professionals, along with access to assistive technology, is crucial for maintaining quality of life, social engagement, and independence.
- Specialist planning and care coordination, including a proactive decision-making framework are essential to achieving improved health care outcomes.
- Barriers in accessing care, such as a lack of access to specialists, insufficient GP training, exist in rural and remote areas, making it challenging for individuals to receive a constant standard of specialist care and support.
- Awareness campaigns for Neurological Conditions save money as their campaigns result in early diagnosis and support which reduces long term overall care cost.
- Robust, standardised, easily accessible data and research form the basis for effective planning and targeted interventions.
- The lack of a large-scale national or state Neurological survey makes it difficult to map the current gaps in the neuro service landscape fully.

9. Connecting Insights



Component 1: Prevalence Of Neurological Conditions By Condition & Cohort



An estimated **1.3 million** Queenslanders have a Neurological Disorder.



400,000 Polio survivors in Australia.



Queenslanders with Parkinson's will **double** from **15,072 to 34,344** by 2025.



MS going **up 7% every year**.



2 Australians die every day.



Almost **1 in 4 households** with at least **one person** suffering from migraines.



Approx. **200,000 Queenslanders** will get Epilepsy.



11,000 Queenslanders diagnosed with an ABI every year.

1 in 4 Queenslanders have a Neurological Condition which means that you or someone you know is likely affected.



1 in every 1,000 children have MD.



1 in 4 Queenslanders have a Neurological Condition.

First Nations People:



• **3-4 times more** likely to get Dementia.



• **3 times higher** to get a Traumatic Brain Injury.



• **3.5 more** likely to go to hospital with Epilepsy.

Prevalence By Condition & Cohort

Overview

The prevalence of Neurological Conditions across Queensland varies, but collectively, Neurological Conditions affect an estimated 25% of the state's population. No matter your age, gender, or cultural background, you or someone you know will likely have a Neurological Condition.

Alarming, the numbers are rising each year in Queensland. As the population both grows and ages, more people are being diagnosed.

It is estimated that, on average, one Queenslander is being diagnosed every hour with ABI, 8 are diagnosed per day with Epilepsy and 6 are diagnosed per day with Parkinson's Disease.

Some people and their families will live with their Neurological Condition for over 20 years, others for only a couple of years. Males are more likely to suffer from Motor Neuron Disease (MND) and Acquired Brain Injury (ABI), whilst women are more likely to suffer from Dementia, Multiple Sclerosis (MS) and Myalgic Encephalomyelitis (ME / Chronic Fatigue Syndrome).

First Nations people are 3-4 times more likely than the general population to get Dementia, 3 times more likely to acquire a Traumatic Brain Injury and 3.5 times more likely to have an Epilepsy-related hospitalisation than non First Nations Peoples.

Our knowledge of prevalence statistics in Queensland is limited by the absence of a comprehensive prevalence dataset for Neurological Conditions. This forces us to rely on data from various sources using different methodologies. This fragmentation results in significant gaps, making it difficult to piece together a complete and accurate picture of prevalence across different cohorts in the state.

The following is a snapshot of what we can piece together.



Prevalence Data

It is estimated that over 1.3 Million Queenslanders have a Neurological Condition.

Over 1 Million of these cases are **intermittent**, meaning symptoms can come and go, with frequency, duration, and intensity of symptoms varying depending on the specific condition and the individual.

Almost 200,000 cases are **progressive**, where symptoms worsen over time and lead to a continuous decline in neurological function.

At least 50,000 cases are **stable with changing needs**, typically meaning that primary symptoms or progression of conditions are not worsening rapidly, with individuals requiring care or support over time.

140,000 cases are **sudden onset**, with symptoms appearing abruptly and without warning and rapid development requiring immediate medical attention.

Table 1: Prevalence & Incidence of Neurological Conditions

Neurological Disorder / Disease	Categorisation	Prevalence (AUST)	Prevalence (QLD)	Rate / 100,000 Population (QLD)	Incidence
Acquired Brain Injury (inc. Stroke)	Sudden onset	700,000	140,000	1,247	11,000 Queenslanders are diagnosed every year – 4,000 of whom will develop a severe disability ³
Dementia	Progressive	472,000	94,400	1,729	250 Australians are diagnosed a day, 91,000 each year ⁴
Epilepsy	Intermittent	252,000	51,646	946	3,000 Queenslanders are diagnosed each year ⁵
Migraine	Intermittent	4,900,000	980,000	18,394	N/A
Motor Neurone Disease (MND)	Progressive	2,100	420	7	2 Australians diagnosed with MND each day ⁶
Multiple Sclerosis (MS)	Progressive	33,335	5,535	101	An average of 10 Australians is diagnosed every week ⁷
Muscular Dystrophy	Progressive	41,408	8,000 ⁸	112	N/A
Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)	Stable with changing needs	250,000	51,236	938	N/A
Parkinson's	Progressive	150,000	15,072	296	1 Australian is diagnosed every 27 minutes. 19,500 Australians every year ⁹ 2,236 diagnosed in QLD
Polio	Progressive	400,000	81,977	1501	N/A
Other Conditions [^]		83,290	17,070		
All Neurological Conditions		7,233,033	1,445,356		
Total Population		26,966,789	5,459,400		

Figures based on estimations of condition prevalence using the references end noted in 'Table 1'. Where only Australian prevalence figures were available a calculation has been made based on the ABS estimation of Australia and Queensland populations.¹⁰ **Prevalence:** The number of individuals in a population who have a disease at a specific time. **Incidence:** The number of individuals newly diagnosed with a disease during a particular period. **N/A:** data not available.



The most common Neurological Condition is migraine, estimated to affect almost 1 Million Queenslanders. Acquired Brain Injury (ABI), including Stroke, has the next largest prevalence, with approximately 140,000 people. Dementia and Polio both affect over 80,000 each, while Epilepsy and ME/CF together affect over 100,000. Less common conditions include MS, Parkinson's Disease, MND and Muscular Dystrophy.

When taken together, the rising prevalence and impact of these Neurological Conditions in Queensland are deeply concerning and require urgent action.

Table 2: Headline Data Figures

Condition	Headline data
ABI	<ul style="list-style-type: none">• 2% of all Australians live with a brain injury.• 3 in 4 Australians with ABI are aged under 65 years. 2 out of 3 of these acquired their brain injury before the age of 25.• Three quarters in Australia are men.• Every week 3 women in Australia are hospitalised with a Brain Injury due to Domestic and Family Violence.• Those in remote communities are 3 times more likely to acquire a brain injury than those in major cities.• Queensland has the highest prevalence compared to the rest of Australia. <p><i>Source: Brain Injury Australia¹¹</i></p>
Dementia	<ul style="list-style-type: none">• Dementia is the 2nd leading cause of death of all Australians; provisional data suggests it will soon be the leading cause of death.• An estimated 168,300 Queenslanders will be living with Dementia by 2054.• More than 5,900 Queenslanders are estimated to be living with younger onset dementia, almost 8,300 by 2054.• Dementia is the leading cause of death for Australian women <p><i>Source: Dementia Australia.¹²</i></p>
Epilepsy	<ul style="list-style-type: none">• 1 in 10 people will experience a seizure in their lifetime.• Approx. 200,000 Queenslanders (3 – 4% of our population) will acquire epilepsy during their lifetime irrespective of their age, gender, or geography.• There are more than 70 different seizure types, 40 different syndromes, and accurate diagnosis and treatment can take more than 5 years.• Hospitalisations for seizures alone in Queensland are higher than the national average and can occur more frequently than for seizures related to diabetes.¹³ <p><i>Source: Epilepsy Australia.¹⁴</i></p>



Migraine

- 4.9 million Australians experience migraine.
- 23% of households contain at least one person who has a migraine.
- 86% of migraine sufferers are of working age.
- 7.6% of migraine sufferers experience chronic migraine (more than 15 migraines days per month).
- 34% use opioids to treat their attacks.

Source: Migraine and Headache Australia.¹⁵

Motor Neuron Disease

- 2 Australians die from MND each day.
- The lifetime risk of MND is about 1 in 300 by the age of 85.

Source: MND Australia.¹⁶

Multiple Sclerosis

- 33,335 Australians were known to be living with MS in 2021, an increase of 30% (7,728) since 2017 (25,607).
- The incidence of MS is increasing by 7% each year.
- MS generally presents in people between 20 and 40 years, when many are starting families and building careers.

Source: MS Australia.¹⁷

Muscular Dystrophy

- MD affects about one in every 1,000 children.
- MD is usually diagnosed when a child is between the ages of 2 and 5.
- Most children with Duchenne MD use a wheelchair by the time they're 12-13 years old.

Source: Murdoch Children's Research Institute.¹⁸

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

- Studies estimate between 0.4-1% of the population have ME/CFS.
- Approximately 25% experience severe symptoms, leaving them housebound or bedbound.

Source: Emerge Australia.¹⁹

Parkinson's Disease

- Parkinson's is the 2nd most common neurodegenerative disorder worldwide, affecting 2-3% of the population aged 65 or over.
- The prevalence of Parkinson's Disease ranges from 41 people per 100,000 among people in their 40s to more than 1,900



people per 100,000 among those in their 80s and older.

- More than 1,100 Australians under 65 live with early onset each year.
- The estimated number of Queenslanders with Parkinson's is set to almost double from 18,500 to 34,344 by 2025..

Source: Parkinson's Australia.²⁰

Polio

- Estimated 400,000 polio survivors, predominantly aged over 50.
- Up to 40,000 Australians were diagnosed with the most severe form of the disease, paralytic polio.
- Many polio survivors are now experiencing the Late Effects of Polio, severely impacting their mobility.

Source: Polio Australia.²¹

An Aging Population

Prevalence Differences Between Men & Women

Some Neurological Conditions affect women more than men and vice versa, with variance across age groups as shown in table 3.

Table 3: Neurological Conditions by Sex & Most Prevalent Age Groups

Neurological Conditions	Males %	Females %	Most Prevalent Age Group
Acquired Brain Injury (inc Stroke)	75	25	Peaks in the age group 15-35 years.
Dementia	37	63	85 years and older.
Epilepsy	52	48	19-64 years (60%) - prevalent over 55. ²²
Migraine	25	75	The prevalence of migraine increases from 12 years to about 40 years, peaking in the ages of 30 to 40 years. The highest prevalence rate of episodic migraine (42.3%) occurs in females aged 35 to 39. ²³
Motor Neurone Disease (MND)	60	40	Average onset age of 59 years. Approx. 5% of people are under the age of 65. ²⁴
Multiple Sclerosis (MS)	26	74	Generally, presents in younger people between the ages of 20 and 40 years.
Muscular Dystrophy			It depends on the type of MD.
Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)	25	75	Higher rates for age groups 50-59 years and 40-49 years. ²⁵
Parkinson's Disease	52	48	Most prevalent in those aged 65 and over.
Polio	N/A	N/A	N/A

N/A: data not available.



First Nations Peoples Population

Prevalence Among First Nations Peoples

The prevalence of some Neurological Conditions among Australia's First Nation people is notably higher than the general population.

- Approximately **46%** of First Nations peoples have at least one Chronic Condition, which includes Neurological Conditions like Dementia and Stroke.²⁶
- The prevalence of Dementia among First Nations Peoples across remote, regional, and urban areas is **3 to 5 times** higher than the prevalence for the general Australian population. It is nearly **3 times** greater among First Nations people in the Torres Strait and Northern Peninsula Area (NPA) communities at the tip of Far North Queensland (FNQ) for those aged 45.²⁷
- First Nation people experience Stroke and Traumatic Brain Injury at rates up to **3 times higher** than those of Non First Nations Peoples.²⁸
- First Nation peoples have a **1.7 times higher** rate of Stroke hospitalisations compared to Non First Nations Peoples.²⁹
- First Nation people are **twice** as likely to report having Epilepsy as Non First Nations Peoples and **3.5 times** as likely to have an Epilepsy-related hospitalisation.³⁰

Culturally & Linguistically Diverse Population

Prevalence Among Culturally & Linguistically Diverse (CALD) Communities

Numbers indicating the prevalence of Neurological Conditions among CALD Australians is relatively unknown due to incomplete data collection. Available data shows that **28% of people with Dementia in Australia were born in Non-English speaking Countries**. After controlling for age differences, people born in Italy have the highest rate, followed by those born in Greece and China.³¹ Statistics for other conditions are lacking, which is concerning considering one in five Queenslanders were born overseas.



Insights

- C1-I-1** Prevalence estimates across all Neurological Conditions is estimated to be rising in Australia and Queensland.
- C1-I-2** Prevalence data, where available, show clear age, sex, and cultural patterns.
- C1-I-3** Some Neurological Conditions are unequally distributed between sexes and across age groups. MS, Migraines, Dementia and ME/CFS are more common in women, whereas MND and brain injuries are more frequent in men.
- C1-I-4** Dementia, Stroke, and Parkinson's Disease are more prevalent as age increases; however, MS and ABI primarily affect younger and middle-aged adults, while Muscular Dystrophy is present in childhood, and Epilepsy is present across the lifespan, with the highest diagnosis in young people (under 5) and the elderly (over 55).
- C1-I-5** First Nations Peoples are at higher risk of and severity of acquiring some Neurological Conditions and will be impacted by their conditions more severely due to modifiable and structural risk factors such as unhealthy diet, lack of exercise, high rates of smoking and poorer access to healthcare services.
- C1-I-6** One in five Queenslanders are born overseas, yet ethnicity statistics for neurological conditions are severely underrepresented in current data collection. Stigma, cultural beliefs and lack of specific reporting are likely contributing factors to this.
- C1-I-7** Impact Data suggests more people are diagnosed with early onset across many Neurological Conditions.
- C1-I-8** The significant differences in how Neurological Conditions affect men, women, various age groups and populations highlight the importance of considering these patterns when planning health services and programs.

Opportunities

- C1-O-1 Data Collection Improvement:** Prioritise financial investment, resource allocation, and coordinated data collection strategies to address gaps in gender and ethnic - specific research on the profound difference between men and women and CALD and First Nations populations living with Neurological Conditions.
- C1-O-2 Targeted Messaging:** Implement early awareness and intervention campaigns tailored to the specific needs of different demographic groups, ensuring messages resonate with all gender identities, First Nations Peoples, and CALD groups.
- C1-O-3 Tailored Approaches:** Develop gender-specific medical treatments and preventive strategies, recognising that men and women often have distinct biological and physiological differences. These differences may require tailored diagnostic procedures and therapeutic approaches to effectively address gender-specific health needs and improve overall outcomes for both men and women.
- C1-O-4 Disparity Awareness:** Plan support services with a greater understanding of the disproportionate impact on caregiver burden, loss of productivity, and higher healthcare costs across different cohorts.

Component 2: Impact Of Neurological Conditions





Neurological Conditions in Queensland cost an estimated **\$24 Billion** every year.



An estimated **90,000 yrs** of **life lost** for Queenslanders with Neurological Conditions in 2023



More than 4 times the rate of Cancer & twice the rate of Mental Health & Musculoskeletal Disorders.



The disease burden of Neurological Conditions has **increased by 86%** over the last 20 yrs.



Dementia is estimated to cost Australia more than **\$1 Trillion** in the next 40 years.



870,000 GP Consultations each year across Australia for migraine sufferers.

Nervous System Disorders can create barriers that impact our ability to engage, to move, to remember and, over time, can change or take away the unique qualities that make us who we are. Or in the case of Disorders affecting children, who we may become. Over time, the physical, mental and emotional burden can be overwhelming.³³



For every person diagnosed with MND, an estimated further **14 family members & friends** will live with the effect of MND forever.



50% of people with MS have **personal incomes below \$16,000**.

Overview

Neurological Conditions are costly.

Neurological Conditions significantly burden individuals, families, communities, and public health systems. They impact not only the person with the diagnosis but also their family, friends, caregivers, employers, and their community.

The network of people socially, emotionally, and financially impacted by one diagnosis alone is not only significant but often hidden.

As the prevalence of Neurological Conditions grows, so too does the burden. It is estimated that in 2023, the disease burden of Neurological Conditions equated to over **90,000 years of life lost for Queenslanders**. That is an increase of 86% over the last 20 years alone (**more than four times the rate of Cancer and twice the rate of Mental Health and Musculoskeletal Disorders**). Together, **Neurological Conditions cost Queensland an estimated \$24 Billion every year**.

Queenslanders with Neurological Conditions, whether mild or severe, progressive or stable, managed or not, have unique challenges and specific needs.

For some people, the Chronic Condition does not shorten lifespan; it complicates it. Each condition's duration and unpredictability are physically and emotionally overwhelming, compromising safety and independence, the ability to work, have relationships, and interact socially. For those with and early onset Neurological Disease, their future is significantly altered.

Our data on the impact of Neurological Conditions tells a bleak story.



Impact Data

Neurological Conditions are now one of the top 5 contributors to the total Disease burden in Australia.

Table 4: Summary of 5 Leading Disease Groups in Australia Causing Burden in 2023

	Cancer	Mental Health & Substance Use	Musculoskeletal	Cardiovascular	Neurological
% of Total DALY	17	15	13	12	8
% of Total DALY (Fatal)	91	2	3	74	49
Change In Age Standardised Rates (2003-2023)	↓	↑	↓	↓	↑

Source: AIHW.³²

In 2023, Australians lost 464,997 years of healthy life (total burden, DALY) due to Neurological Conditions – Queenslanders over 90,000 years of life (estimated on the proportion of National population).



Table 5: Overview Of The Burden Of Neurological Disease In Queensland (2023)

Neurological Condition	Burden (Year)		
	DALYs	YLDs	YLLs
Acquired Brain Injury (inc. Stroke)*	N/A	N/A	N/A
Dementia	49,542	20,554	28,988
Epilepsy	9,069	7,112	1,957
Migraine	9,661	9,659	2
Motor Neurone Disease (MND)	3,350	315	3,035
Multiple Sclerosis (MS)	3,104	2,334	770
Muscular Dystrophy*	N/A	N/A	N/A
Myalgic Encephalomyelitis (Chronic Fatigue Syndrome)*	N/A	N/A	N/A
Parkinson's Disease	8,512	3,435	5,077
Polio*	N/A	N/A	N/A
Other Conditions^	9,687	4,040	5,647
Total	92,925	47,449	45,476

Estimates are based on the proportion of the national population. Australian population numbers sourced from AIHW. *Data not available. DALY (Disability-adjusted life years): total years lost due to illness, disability, or premature death. YLD (Years lived with a disease or disability): the years of life affected by a health condition. YLL (Years of life lost): due to early death from a disease or disability. N/A: Data not available or accessible.



The estimated numbers show that in 2023:

- Dementia was responsible for over 50% of the total Neurological Conditions burden in Queensland, reflecting both the high mortality rate and the significant impact on quality of life for those living with Dementia.
- Migraine contributed 10.4% of the total Neurological Conditions burden, driven by its prevalence and the degree of Disability caused during and between attacks.
- Epilepsy was responsible for 9.8%, with its YLD likely driven by the cognitive, psychological, and social impairments associated with Epilepsy and its YLL from premature death.
- Parkinson's, at 9.2%, contributed substantially to both the fatal and non-fatal components of DALYs, highlighting its increasing prevalence and progressive burden on the quality of life.
- MND contributed significantly to the Neurological Conditions Disease burden in Queensland in terms of YLL (6.7%), reflecting its high fatality rate and the severe reduction in life expectancy it causes.
- MS was responsible for almost 5% of YLD, likely due to its progressive nature and the variety of disabling symptoms it causes.

DALY, YLD & YLL statistics for ABI, Muscular Dystrophy & Chronic Fatigue Syndrome were unavailable from AIHW's Burden of Disease Study 2023.

However, globally, it has been reported that:

- The disease burden of Muscular Dystrophy is significant due to its debilitating nature and its effects on both longevity and quality of life.
- CFS/ME significantly impacts quality of life due to its chronic nature, leading to prolonged periods of severe fatigue, pain, and cognitive difficulties.



Financial Impact

Table 6: Total Cost to Australian Economy (\$ Billion)

Neurological Condition	Cost to Australian Economy Per Year (\$ billion)	Source
Acquired Brain Injury (inc. Stroke)	10.5	Deloitte's Access Economics (2009) ³³
Dementia	15.5	Brown (2022) ³⁴
Epilepsy	12.3	Monash University (2023) ³⁵
Migraine	35.7	Deloitte's Access Economics (2018) ³⁶
Motor Neurone Disease (MND)	2.37	Deloitte's Access Economics (2015) ³⁷
Multiple Sclerosis (MS)	2.50	Campbell, J. (2021) ³⁸
Muscular Dystrophy	6	
Myalgic Encephalomyelitis (Chronic Fatigue Syndrome)	14	Close, S (2023) ³⁹
Parkinson's Disease	10	Mellick (2024) ⁴⁰
Polio	N/A	
TOTAL	122.87	

The estimated cost of the Disease burden from Neurological Conditions in Australia is substantial, with costs exceeding \$100 Billion annually, noting that some of the data available is over 15 years old. The actual total figure is likely to be much higher.

The estimated cost to Queensland, if based on the population percentage, is upwards of \$24 billion annually.

Migraine has the largest proportion of total national burden cost at (28%) or \$35 Billion due to its prevalence, frequency and dual direct (healthcare and medication) and indirect (lost productivity) financial impact. Dementia is next at (12%) or \$15 Billion, followed by ME / CFS (\$14 Billion), Epilepsy (\$12.3 Billion), ABI (\$10.5 Billion), Parkinson's Disease (\$10 Billion), MD (\$6 Billion), MS (\$2.5 Billion) and MND (\$2.3 Billion).



Combined, these numbers highlight the escalating economic burden imposed by Neurological Conditions in Queensland.

Table 7: Headline Cost Statistics

Neurological Condition	Headline Cost Statistics
Acquired Brain Injury (inc. Stroke)	<ul style="list-style-type: none"> The average hospital treatment cost during the first 12 months after moderate to severe Traumatic Brain Injury in 2008 was estimated at over \$40,000 per patient.⁴¹ The estimated lifetime cost per incident case is AUD\$4.8 Million for moderate and severe TBI. 19% is borne directly by State Governments.⁴²
Dementia	<ul style="list-style-type: none"> Over 6.4 Million Australians will be diagnosed with Dementia in the next 40 years, at a cost of more than \$1 Trillion.⁴³
Epilepsy	<ul style="list-style-type: none"> \$750 Million in total burden of Disease in Queensland. In Queensland, emergency presentations and hospitalisations for Epilepsy are 20% higher than the National average and the annual cost of \$65.45 Million for acute care alone. Only 15% of people are unable to work; however, less than 50% are in paid employment. 8 times higher risk of Depression, 5 times higher risk of suicide, and 3 times higher risk of premature death.
Migraine	<ul style="list-style-type: none"> \$35.7 Billion annually, consisting of \$14.3 Billion in healthcare costs \$16.3 Billion in lost productivity, and \$5.1 Billion in other costs.⁴⁴ 62.7 workforce persons / days lost each year.⁴⁵ 870,000 GP consultations annually, costing the Government \$32 Million via Medical Benefits Schedule.⁴⁶



Motor Neurone Disease (MND)

- The total cost of MND in Australia was \$2.37 Billion in 2015, comprising \$430.9 Million in economic costs and \$1.94 Billion in burden of Disease costs.⁴⁷
- For every person diagnosed with MND, an estimated further 14 family members and friends will be impacted with the effect of MND forever.

Multiple Sclerosis (MS)

- Estimated average costs per person is \$74,000 per year.
- Annual per person costs increase with increasing disability levels from \$32,829 for people with MS with no Disability to \$123,333 for people with severe Disability.⁴⁸
- The total replacement cost for informal care families provide has been valued in Australia at over \$250M annually.⁴⁹
- Although most people with MS are working when diagnosed, 80% are unemployed within 10 years.
- Approximately half of the people with MS after diagnosis have personal incomes below \$16,000.

Muscular Dystrophy

- Mean healthcare costs for Duchenne Muscular Dystrophy (DMD) are approx. \$10,046 per affected person.
- The mean total cost is \$46,700 (median \$32,300).
- Healthcare costs contribute 22% of total costs.⁵⁰

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME / CFS)

- Av. annual total costs of \$63,400 per patient.
- Three-quarters of these costs are due to indirect costs (\$46,731).

Parkinson's Disease

- The mean annual cost per person to the health care system was \$32,556.⁵¹
- The burden to society is an additional \$45,000 per annum per person with PD.
- 69% of total costs were due to hospitalisation.
- The costs for people with moderate to severe Parkinson's Disease were almost 4 times those with mild PD (\$63,569 vs \$17,537).



Polio

- Details not readily accessible or available.

The financial cost of Neurological Conditions on affected families is substantial. They encompass direct medical expenses, loss of income, and long-term caregiving needs, which collectively place a significant economic strain on household resources.

Since many Neurological Conditions are chronic and progressive, this economic burden can persist for many years.

Table 8: Effects and Life Expectancy Of Neurological Conditions

Neurological Condition	Effects	Life expectancy	Mortality Rate
Acquired Brain Injury (inc. Stroke)	<ul style="list-style-type: none"> • Affects a wide range of cognitive, physical, sensory, and emotional functions. • Results from various causes, including Trauma, Stroke, infection, and degenerative Neurological Conditions. 	<p>People with ongoing support needs due to an ABI commonly live for 20 to 40 years after injury.⁵²</p> <p>A person hospitalised for TBI is 7.5 times more likely to die during the 12 months following their injury.⁵³</p>	2,400* ⁵⁴
Dementia	<ul style="list-style-type: none"> • Affects cognitive functions, leading to memory loss, difficulties in problem-solving, impaired judgment, and challenges with language and communication. • Significant behavioural and psychological symptoms. • Physical health decline, including difficulty with mobility, balance, and coordination. 	<p>8-10 years for Alzheimer's Disease, 4-8 years for Lewy-body and Frontotemporal Dementias, and 5 years for Vascular Dementia.</p> <p>People may live 20 years or more with Dementia.⁵⁵</p>	15,800 ⁵⁶
Epilepsy	<ul style="list-style-type: none"> • Recurrent seizures, which can vary in frequency and severity. • Cognitive impairments, including memory problems, attention deficits, and difficulties with learning and processing information. 	Reduction in life expectancy of up to 2 – 10 years with reductions in life expectancy highest at the time of diagnosis. ⁵⁷	1,100 ⁵⁸
Migraine	<ul style="list-style-type: none"> • Attacks can be frequent and severe, involve intense pain, nausea, and sensitivity to light and sound and last from hours to days. 	N/A	N/A
Motor Neurone Disease (MND)	<ul style="list-style-type: none"> • The progression of MND is typically rapid and relentless, leading to high levels of 	The average life expectancy is 2.5 years post diagnosis. ⁶⁰	862** ⁶¹



	<ul style="list-style-type: none"> disability. Individuals require various support services to respond to their complex needs.⁵⁹ 	
Multiple Sclerosis (MS)	<ul style="list-style-type: none"> A variety of progressive disabling symptoms impairing motor, sensory, and cognitive functions over several years. 	<p>Average life expectancy is between 7 to 14 years shorter than the general population.</p> <p>Many individuals live well into their 70s and beyond, depending on various factors such as the type of MS, the age of onset, disease progression, and access to effective treatments.</p>
Muscular Dystrophy	<ul style="list-style-type: none"> Chronic and progressive nature, causing muscle weakening and wasting over time. Results in profound Disability. 	<p>Life expectancy varies depending on the type of MD – there are more than 30 variations.</p> <p>Many forms of MD lead to premature death, often in early adulthood for severe types like Duchenne Muscular Dystrophy.</p>
Myalgic Encephalomyelitis (Chronic Fatigue Syndrome)	<ul style="list-style-type: none"> Serious, chronic illness that can cause pain and extreme fatigue lasting for at least 6 months. 	
Parkinson's Disease	<ul style="list-style-type: none"> Significant progressive motor and non-motor symptoms, including tremors, muscle rigidity, cognitive impairment, mood disorders and sleep disturbances. Increased Disability, including communication difficulties. 	<p>The median survival time after the onset of Parkinson's Disease symptoms is around 10 years, although people can live more than 20 years with comprehensive care.</p>
Polio	<ul style="list-style-type: none"> Late effects of Polio, including Post-Polio Syndrome (PPS), can include new muscle weakness, fatigue, muscle and joint pain, and in severe cases, problems with breathing, swallowing or speaking. Increased Disability experienced overtime. 	<p>The life expectancy for Polio survivors is generally like that of the general population.</p>

*Number is for head injury deaths in 202-21.

** Based on 2019 AHW numbers.



Disease Burden Insights For Neurological Conditions

Neurological Conditions can have varying effects both within and across specific conditions.

- **Acquire Brain Injury's:** Impose a significant burden on people, often leading to Disabilities that can significantly limit daily activities. The needs of those affected by this condition can be diverse and complex, sometimes requiring extensive rehabilitation services, care and support. This has long-term social and economic implications for all, including the high numbers of young men under 25 years with ABI who may struggle with work and require ongoing medical and psychological support.
- **Migraines:** Significantly impact Neurological-related DALYs in Queensland due to their prevalence and the degree of disability they cause. The frequent and severe nature of migraine attacks, which can last from hours to days and cause intense pain and discomfort, leads to substantial personal suffering, impaired quality of life, and financial costs. Nearly all people with migraine and 60% of those with tension-type headaches experience reduced social interaction activities and work capacity.⁶² The impact can be years of debilitating suffering, particularly for women in their 30s who have the highest prevalence of migraine.
- **Epilepsy:** Accounts for a significant portion of Neurological-related DALYs in Queensland with roughly 1/3 of the population group that have been diagnosed unable to gain control of their seizures with current treatment regimes. This is due to the chronic nature of the condition, the frequent episodes of seizures, and the associated comorbidities that affect safety, quality of life and longevity. Queenslanders with the condition often require ongoing medical care, lifestyle and practical living adjustments and, often, social support. These supports might be needed for many years, with 60% of people with Epilepsy under the age of 65.
- **Motor Neurone Disease:** Has a profound impact on YLL due to its aggressive progression and high mortality rate. Its rapid deterioration in muscle function and respiratory failure means most individuals with MND die within 1 to 3 years of diagnosis; 10% may live 10 years or longer. Its rapid progression and need for intensive care highlight the need for immediate financial and care support assistance once diagnosed.
- **Multiple Sclerosis:** Significantly impacts the burden of disease by causing substantial disability and reducing the quality of life, as reflected in its high rates of YLD. Its chronic and progressive nature requires long-term healthcare management and support over many years given that the average age of diagnosis is 30 years.
- **Muscular Dystrophy:** Significantly reduces the quality of life with people experiencing severe physical limitations, including difficulties in mobility, respiratory complications, and cardiac issues. The need for ongoing comprehensive healthcare services, rehabilitation, and supportive care is critical.
- **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome:** Imposes a significant burden, significantly affecting quality of life. The chronic and debilitating nature of



the condition can lead to social isolation, financial strain and difficulty maintaining full-time work.⁶³

- **Parkinson's Disease:** Accounts for a considerable portion of Queensland's Neurological Disease burden. The disease leads to progressive disability, impacting the quality of life and increasing dependency on healthcare services. With a median survival time after the onset of Parkinson's Disease symptoms at approximately 10 to 20 years, Queenslanders with the condition and their families face years of significant disease, emotional, social, and financial burden.
- **Polio:** Imposes debilitating late effects on individuals who survived the initial infection. These effects can lead to increased physical disability over time. Many survivors experience mobility issues and require long term healthcare and support. Some who once walked independently may eventually need braces, crutches, or wheelchairs and make significant lifestyle adjustments.⁶⁴ Managing these effects involves ongoing medical care and physiotherapy to maintain quality of life.

Insights:

- C2-I-1** The chronic nature of many Neurological Conditions lasts several years or even a lifetime.
- C2-I-2** As the prevalence of Neurological Conditions grows, its contribution to the overall disease burden in Queensland will escalate.
- C2-I-3** Individuals with Neurological Conditions share many of the same impacts and needs. Neurological Conditions can:
- cause a range of functional impairments that affect mobility, dexterity, behaviour, communication or speech, cognition, consciousness, and emotion;
 - result in chronic pain and discomfort;
 - diminish the quality of life, limit education and work opportunities, reduce the ability to participate in activities and undermine financial security;
 - cause significant emotional stress for families and caregivers due to their chronic and progressive nature;
 - lead to feelings of stigmatisation;
 - cause a significant healthcare burden, with conditions often requiring long-term care, including hospitalisations, medications, and rehabilitation;
 - result in indirect financial burden through loss of productivity, caregiver burden, and long-term disability;
 - negatively impact mental health due to their association with depression, anxiety, and cognitive impairment; and
- C2-I-4** Neurological Conditions can affect:
- men and women differently, with some Neurological Conditions being more common in men and others more common in women.
 - children at birth or a young age, or adults in mid to late life, significantly changing their life trajectories as well as impacting their families; and
 - informal caregivers, especially those looking after individuals with cognitive impairments or behavioural and mental health issues.

A comprehensive understanding of these patterns is vital for effective public health planning and the development of strategies to mitigate the burden of Neurological Conditions.

Opportunities

- C2-O-1** **Coordinate Efforts:** By establishing a dedicated sector led Queensland Neuro Alliance to bring together lived experience, peak organisations, and key government stakeholders. The Neuro Alliance **would** provide timely advice and co-designed solutions for enhancing the quality of care and support for those people, families and communities impacted by Neurological Conditions.
- C2-O-2** **Develop A Neuro Care Framework:** Create a comprehensive approach to Neurological care throughout the state, focusing on providing timely, integrated, and effective responses tailored to the specific needs of different patient groups. A Neuro Action Plan would form an important element of the Framework.
- C2-O-3** **Educate, Promote, and Raise Awareness:** About the profound impact of Neurological Conditions on individuals, families, and communities through a targeted, collaborative and multi-channel campaign. The campaign would inspire action and engagement by highlighting real stories, providing critical information and encouraging proactive steps towards better Neurological health.

Component 3: Financial Support Systems & Participation By Cohort



REPORTERS	
10	\$475,000
	\$5,000,000
	\$25,000
	\$575,000
	\$975,000



52,290 Queenslanders are Home Care Package recipients.



19,597 Queenslanders are **waiting** on a Home Care Package.



17,896 Queenslanders living with a Neurological Condition have a NDIS Plan.



1,851 First Nations peoples from Queensland are Home Care Package recipients.



11% of NDIS Participants with Neurological Conditions in Queensland **live in remote areas.**



95% of Queenslanders with an ABI or MS **do not** have a NDIS Plan.

Getting funding & support levels right for individuals with Neurological Conditions is crucial for managing their condition at home, at work, & in the community for as long as possible.



National Cost to Service Systems

Migraine ~\$35 Billion.
Dementia ~\$15 Billion.
ME/CFS ~\$14 Billion.
Epilepsy ~\$12.3 Billion.
ABI ~\$10.5 Billion.
Parkinson's ~\$10 Billion.
MD ~\$6 Billion.
MS ~\$2.5 Billion.
MND ~\$2.3 Billion

Overview

The immense financial burden of managing Neurological Conditions places an overwhelming strain on individuals, their families, and the states public health system.

Extensive medical and healthcare expenses and those associated with consultations, medication, treatment, and the costs of assistive technologies, social support, rehabilitation, and increased utility bills, place a substantial financial burden on individuals and families living with a Neurological Condition.

While government subsidies and funding for some people may cover some expenses related to healthcare, daily living, and overall wellbeing, out-of-pocket costs can still be considerable. Co-payments for medication, gap fees for specialist consultations, or payment for extensive modifications add up and can significantly affect everyday life.

Even with economic assistance such as Medicare rebates, the National Disability Insurance Scheme (NDIS), Aged Care funding and Pharmaceutical Benefits Scheme (PBS) subsidies, people living with Neurological Conditions, especially those from more vulnerable and disadvantaged populations, can experience severe economic hardship.

Getting adequate funding levels for individuals with Neurological Conditions is crucial for enabling them to manage their conditions effectively at home, at work, and within the community for as long as possible.

At present, Queenslanders with Neurological Conditions are lagging other states in receiving funding support. For example, NDIS eligibility rates for Neurological Conditions are lower in Queensland by 26%, with participation rates also lower.

With Neurological Condition prevalence and incidence expected to increase over coming decades, state-specific approaches are urgently needed to address Queensland's unique demographic and geographic challenges compared to all other states and territories across Australia.

Service Support and Prevalence Data

Economic Impact

Neurological Conditions impose significant health and economic burdens on state health systems and individuals. The financial consequences of direct and indirect healthcare costs, lost productivity, and informal care are substantial.

In Queensland alone, the management of Neurological Conditions costs an estimated \$24 Billion every year based on the percentage of the Australian population.

Table 9: Economic Impacts and Advocacy Priorities for Neurological Conditions in Queensland

Condition	QLD Cases	National Cases	Total Annual Cost in AUS	Trends & Advocacy Focus	Source
Acquired Brain Injury & Stroke⁶⁵	140,000	700,000	\$10.50 Billion	Enhanced rehabilitation services are needed due to increasing cases.	Stroke Foundation Australia.
Dementia⁶⁶	94,400	472,000	\$15.5 Billion	The urgency for advanced care and research due to rising numbers.	Dementia in Australia Report Brown (2022).
Epilepsy⁶⁷	51,646	252,000	\$12.3 Billion	Improved treatment options and support systems are essential.	Epilepsy Australia.
Migraine⁶⁸	980,000	4.9 Million	\$35.7 Billion	Preventive strategies and management practices are needed.	Deloitte Access Economics.
Motor Neurone Disease (MND)⁶⁹	420	2,100	\$2.37 Billion	Focus on research funding and patient support due to high costs.	MND Australia.
Multiple Sclerosis (MS)⁷⁰	5,535	33,335	\$2.5 Billion	Comprehensive MS-specific health services are required for prevalence.	MS Australia Campbell (2021).
Muscular Dystrophy⁷¹	8,000	41,408	\$6 Billion	Long-term care strategies and financial support for families.	Muscular Dystrophy Australia.



ME / CFS⁷²	51,236	250,000	\$14 Billion	Effective management strategies to alleviate healthcare burden.	Emerge Australia.
Parkinson's⁷³ Disease	15,072	150,000	\$10 Billion	Increased investment in care facilities due to the growing population.	Parkinson's Australia.
Polio Survivors⁷⁴	81,977	400,000	Significant Ongoing Costs	Sustained support and resources are needed as survivors age.	Polio Australia.

Note: Specific data on the number of people living with each Neurological Condition in Queensland is limited. Where specific data is unavailable, estimates are based on the proportion of national prevalence, with Australian population numbers sourced from peak bodies. Cost burden estimates for Queensland are based on the ABS estimation of Australia and Queensland populations.

The projected prevalence increases across all Neurological Conditions and the associated costs are expected to rise exponentially over the coming decades.

Neurological Conditions which impose significant lifetime costs estimated at emphasise the need for sustainable long-term care strategies and financial support systems. The high per-patient costs of MND stress the urgency for focused research funding and enhanced patient support. As an example, in the case of Muscular Dystrophy, the lifetime cost is estimated to be \$17.4 billion.

Similarly, the economic impact of conditions like migraine and ME/CFS calls for the development of preventive strategies and effective management practices to alleviate both personal and financial burdens.

Government Funded Support Systems

Government-funded support systems, including the NDIS, Home Care Packages (HCP), Early Learning Connections, the Medicare Benefits Scheme, and PBS, support individuals with Neurological Conditions in Queensland.

National Disability Insurance Scheme

The NDIS provides funding to eligible people with disabilities to facilitate for greater independence and skill development and to support those people to be a part of their community, to realise employment opportunities, and improved quality of life. The NDIS also connects individuals with disabilities to health and community services, including doctors, support groups, and educational institutions, and offers information on State and Territory support. To be eligible for NDIS funding, a disease or medical condition must cause permanent impairment (physical, intellectual, cognitive, neurological, visual, hearing, or psychosocial) resulting in significant disability.⁷⁵



There are almost 650,000 Australians with a disability currently accessing the NDIS. 81,805 of those people have a Neurological Condition as their primary condition. In Queensland, 17,896 people with a Neurological Condition have an NDIS Plan, representing 12.8% of all NDIS Participants (n=139,608) in the state. The average annual 2024 NDIS Plan value for Neurological Conditions in Queensland range from \$67,500 to \$151,000, compared with an average of \$63,200 for all QLD NDIS participants.¹

Table 10: Number Of Active Participant Plans by Those Living with Neurological Conditions At 31st March 2024

Primary Disability Group	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	National
Acquired Brain Injury	5,055	4,814	4,189	1,654	1,794	476	232	317	18,537
Multiple Sclerosis	2,927	3,286	1,845	1,052	991	381	230	23	10,735
Stroke	3,235	2,093	2,119	724	714	190	149	200	9,426
Other Neurological*	7,272	5,584	4,916	2,320	1,786	507	424	224	23,041
Other Physical*	5,840	4,602	4,827	1,852	1,809	411	521	199	20,066
Total Participants (w/ Neurological Conditions)	24,329	19,479	17,896	7,602	7,094	1,965	1,556	963	81,805
All NDIS Participants	193,468	173,758	139,608	56,185	55,826	13,947	10,780	5,925	649,623

Source***

¹ National Disability Insurance Agency (NDIA) - NDIS Payments Datasets, December 2023



Table 11: Proportion Of Active Participant Plans by Those Living with Neurological Conditions on 31st March 2024

Primary Disability Group	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	National
Acquired Brain Injury	3%	3%	3%	3%	3%	3%	2%	5%	3%
Multiple Sclerosis	2%	2%	1%	2%	2%	3%	2%	0%	2%
Stroke	2%	1%	2%	1%	1%	1%	1%	3%	1%
Other Neurological*	2%	1%	2%	2%	1%	2%	1%	3%	1%
Other Physical*	3%	3%	3%	3%	3%	3%	5%	3%	3%
Total Participants (w/ Neurological Conditions)	12%	10%	11%	11%	10%	12%	11%	14%	10%
Total Remaining NDIS Participants	88%	90%	89%	89%	90%	88%	89%	86%	90%

Source***

Table 12: Access Decisions & Met Criteria by Neurological Condition Across Australia for the Year Ending 31st March 2024

Primary Disability Group	Access Decisions	Access Met	Eligibility Rate
Acquired Brain Injury	1909	1353	71%
Multiple Sclerosis	965	829	86%
Stroke	1,365	1,102	74%
Other Neurological*	3,183	2,122	67%
Other Physical*	5,327	1,067	20%
Total Participants (w/ Neurological Conditions)	12,749	6,473	51%
All NDIS Participants	95,676	73,621	77%

Source***



Table 13: NDIS Plan Access Met By Age Band for Neurological Conditions Across Australia in the Year Ending 31st March 2024

Age Group	All Active Participants ⁷⁶	Acquired Brain Injury		Multiple Sclerosis		Stroke		Other Neuro		Other Physical	
		Access Met	%	Access Met	%	Access Met	%	Access Met	%	Access Met	%
0 – 6	104,039	32	2%	<11	n/a	<11	n/a	58	3%	65	6%
7 – 14	173,388	43	3%	<11	n/a	<11	n/a	56	3%	62	6%
15 – 18	59,507	30	2%	<11	n/a	<11	n/a	20	1%	29	3%
19 – 24	54,087	45	3%	<11	n/a	<11	n/a	22	1%	24	2%
25 – 44	105,342	346	26%	284	34%	114	11%	225	11%	203	19%
45+	153,260	857	63%	535	65%	884	87%	1,741	82%	684	64%
Total	649,623	1,353		829		1,012		2,122		1,067	

Source***

Table 14: Vulnerable Demographics of NDIS Participants Across Australia with Neurological Conditions for the Year Ending 31st March 2024

Primary Disability Group	Male	Female	Other gender	Remote / Very Remote	First Nations	CALD
Acquired Brain Injury	12,138	6,201	198	562	1,662	1,979
Multiple Sclerosis	2,658	7,958	119	124	159	1,111
Stroke	5,320	3,975	131	340	715	1,821
Other Neurological*	12,380	10,391	270	528	1,023	2,838
Other Physical*	9,666	10,154	246	547	1,086	2,823
Total Participants (w/ Neurological Conditions)	42,162	38,679	964	2,101	4,645	10,572
All NDIS Participants	397,313	242,409	9,901	13,587	51,176	58,490

Source***



Table 15: Financial Support for Neurological Conditions in Queensland

Primary Disability Group	Average Payment Per Participant (Ending 31 st March 2023)	Average Payment Per Participant (Ending 31 st March 2024)	Q3 FY23/24 Average Committed Support (For 6 Months)	Total Payments For Support (Ending 31 st March 2024)
Acquired Brain Injury	\$133,500	\$151,000	\$95,056	2759753000
Multiple Sclerosis	\$97,800	\$90,300	\$64,465	1029998000
Stroke	\$120,300	\$120,300	\$86,678	1255050000
Other Neurological*	\$120,100	\$137,300	\$89,213	3126282000
Other Physical**	\$60,300	\$67,500	\$45,986	1353306000

***NDIS Quarterly report to disability ministers Q3 2023-24 Full report & NDIS Condition-Specific data to 31st March 2024.

*Included in Other Neurological are Muscular Dystrophy, Myalgic Encephalomyelitis, and Polio.

**Included in Other Physical are Dementia, Epilepsy, Migraine, and Motor Neuron Disease. A comprehensive list of conditions in these categories is unavailable on the NDIS.

The absence of detailed breakdowns of NDIS funding by Neurological Condition outside of ABI, MS and stroke makes it difficult to map the NDIS Neurological landscape fully.

Given the number of people who have been diagnosed with a Neurological Condition in Queensland compared to the number of NDIS recipients, it is clear many Queenslanders with Neurological Conditions are either not receiving any support or not receiving adequate levels of support.

An estimated 140,000 Queenslanders live with an ABI (including Stroke), but only 6,308 of these people have a NDIS Plan. An estimated 5,535 people have MS, yet only 1,845 of them have a NDIS Plan. This implies that the remaining



95% of Queenslanders with an ABI and MS are either ineligible or have not pursued a NDIS Plan.

Table 16: Gaps In NDIS Support for Queenslanders Living with Neurological Conditions

Key Insight	Implications	Impact of NDIS Reforms
<p>Disability Prevalence & Support Demand:</p> <p>17,896 Queenslanders with a Neurological Condition have an NDIS Plan. This means there is a large proportion of Queenslanders with Neurological Conditions not currently receiving the support they need.</p>	<p>An estimated 140,000 Queenslanders live with an ABI (inc. Stroke), but only 6,308 of these have a NDIS Plan.</p> <p>An estimated 5,535 have MS, yet only 1,845 have a NDIS Plan.</p> <p>The remaining number of NDIS Participants with a Neurological Condition is only 9,743. Yet over 92,000 Queenslanders have either Epilepsy, MND, MD, or Parkinson's Disease, many of whom are under the age of 65 years. The implication is that people are not receiving treatment as they need.</p>	<p>Expanding NDIS resources and coverage is essential to meet this vulnerable population's needs effectively.</p> <p>Improving understanding of Neurological Conditions by NDIA staff to enhance access.</p>
<p>Eligibility & Access:</p> <p>Eligibility rate for Neurological Conditions in Queensland is 51%, significantly lower than the overall NDIS eligibility rate of 77%.</p>	<p>There are barriers to accessing support needs.</p>	<p>Streamlining eligibility criteria and reducing barriers could improve access to necessary services.</p>
<p>Demographic Distribution:</p> <p>Substantial representation of First Nations participants (4,645) and those from CALD backgrounds (10,572).</p>	<p>Dedicate culturally appropriate services and support in regional and remote areas are needed.</p>	<p>Enhancing culturally sensitive services and improving access in regional and remote areas are essential for equitable care.</p>
<p>Geographic Distribution:</p> <p>11% (n=2,101) of NDIS Participants with Neurological Conditions in Queensland live in regional and remote areas.</p>	<p>There are often thin NDIS Provider markets in regional and remote areas. This leads to limited access to support, an insufficient and poorly trained workforce, travel and accommodation issues, and poor connectivity.</p>	<p>Improving thin markets and the availability of specialists in regional and remote areas is essential for equitable care.</p>
<p>Data Gaps in NDIS Funding Breakdown:</p> <p>Absence of detailed breakdowns of NDIS funding by Neurological Condition, categorised by age band and demographic distribution.</p>	<p>This significant gap highlights the need for targeted data collection to ensure the needs of individuals with Neurological Conditions can be addressed.</p>	<p>Targeted data collection and analysis would enable better understanding and addressing needs within the NDIS framework.</p>



“People affected by MS and other Neurological Conditions have previously had choice and control through independent living. They had a sense of belonging, safety, and security.

They had opportunities and were making valuable contributions to society, but the symptoms associated with their experience of MS have caused their barriers and functional impairments.

Most people affected by MS and other Neurological Conditions will have already utilised informal supports – often exhausting these – before considering access to the NDIS.”⁷⁷

Home Care Packages (HCP)

As of 31st December, 2023,

Home Care Packages (HCP) provide funding for older Australians to access various services that help them stay at home. There are four levels of HCP tailored to the individual's needs. HCPs provide personal care, nursing services, and allied health support. To qualify for a HCP, an individual must be 65 or older (50 or older for Aboriginal or Torres Strait Islander people). Younger individuals with Disabilities, Dementia, or other unmet care needs may also qualify.

Eligibility is determined by health, mobility, and personal circumstances based on an independent aged care assessment.

As of 31st March, 2024⁷⁸

- 284,429 Australians had access to an HCP.
- 53,631 of these are from Queensland, representing 19.1% of the total number of HCP recipients.
- An additional 19,597 Queenslanders are waiting on an HCP at their approved level.
- 1,851 First Nations peoples from Queensland, representing 21.4% are on HCPs.

Table 17: HCP Participant Numbers

Statistics / Metric	Value
National HCP Participation	284,429 Participants
National Active HCP Participants	273,306 Participants
Queensland Active HCP Participants	53,631 Participants

Source: AIHW.⁷⁹

Table 18: HCP Levels



Home Care Level	No. of QLD Participants	Max Funds Available
Level 1 Package (Basic Care Needs)	2,393	\$10,000 per annum
Level 2 Package (Low-Level Care Needs)	20,821	\$18,000 per annum
Level 3 Package (Intermediate Care Needs)	17,655	\$39,000 per annum
Level 4 Package (High-Level Care Needs)	11,421	\$60,000 per annum

Source: AIHW.⁸⁰

Dementia Example

Outside of Dementia, specific breakdowns detailing how many HCP participants live with a Neurological Condition are challenging to access, highlighting a significant data gap. The information available on Dementia shows:

- 54% of residents in permanent Residential Aged Care have Alzheimer's or other Dementia.
- 8% of Community Aged Care recipients have moderate to severe symptoms of Dementia.⁸¹
- Dementia was the most recorded health condition for younger people living in residential aged care.
- Almost \$3.7 billion of the total direct health and aged care system expenditure in 2020–21 was directly attributable to diagnosing, treating, and caring for people with Dementia.

Table 19: Breakdown Of Aged Care Costs for Dementia

Breakdown of Costs	Value
Residential Aged Care Services	\$1.8 Billion (49% of total expenditure)
Community-Based Aged Care Services	\$741 Million (20% of total expenditure), which includes Home Care Packages, Commonwealth Home Support Programme, Veterans' Home Care Program, and DVA Community Nursing program.
Hospital Services	\$662 Million (18% of total expenditure), which includes public and private admitted patient hospital care, public hospital outpatient clinics, and public hospital emergency department care. ⁸²



Funding Disparities

Organisations like MND Australia have drawn attention to the significant funding disparity between the National Disability Insurance Scheme (NDIS) and the aged care system for individuals with neurological conditions. For those diagnosed at 65 years or older, reliance on the aged care system, which is capped, means-tested, and primarily designed to address the needs of ageing rather than disability, results in profound inequities. This system's limitations lead to insufficient funding, extended waiting periods, and, ultimately, a higher likelihood of financial hardship or premature admission into Residential Aged Care.

For example, MND Australia highlighted a stark contrast in funding, revealing that an NDIS package could provide up to \$200,000 more annually than a Home Care Package (HCP). This considerable difference emphasises the detrimental impact on those who cannot access the NDIS, as the HCP often fails to meet the complex needs of people with disabilities, further exacerbating their challenges and diminishing their quality of life.

	NDIS	Home Care Level 4 Package
Max. Funds Available For Participants w/ MND (Diagnosed Under 65 Yrs)	<ul style="list-style-type: none"> Average Annualised Committed Support \$242,000 per annum. No wait lists. Can access approved care when required. Funding available for vital equipment. 	
Max. Funds Available For Participants w/ MND (Diagnosed Over 65 Yrs)	<ul style="list-style-type: none"> Not eligible 	<ul style="list-style-type: none"> \$50,990.50 per annum. Can be on a waitlist for over 8 months. No funding for vital equipment.

Based on the 2020-2021 financial year. Source: MND Australia.⁸³

The funding difference highlights a significant funding disparity, demonstrating that people over 65 with some Neurological Conditions are at risk of receiving inadequate support under an HCP comparable to those on the NDIS.⁸⁴



Government Funded Support Systems

Medicare Benefits Schedule & Pharmaceutical Benefits Scheme

The Medicare Benefits Schedule (MBS) helps individuals with Neurological Conditions pay for patient care, including Chronic Disease Management plans through your GP practice. The Pharmaceutical Benefits Scheme (PBS) helps every Australian pay for medicines, including Australians living with Neurological Conditions.

Insights

- C3-I-1** The costs associated with living with a Neurological Condition can be significant. These costs can impact daily living, from poor symptom management and financial stress to difficulties in maintaining employment and increased social isolation.
- C3-I-2** The management of Neurological Conditions in Queensland incurs a significant economic burden, with an estimated annual cost of **\$24 Billion to the Government**.
- C3-I-3** The substantial economic burden highlights the urgent need for targeted planning and resource allocation to manage the projected growth of Queenslanders living with a Neurological Condition.
- C3-I-4** Early access to funding packages and support can help those with a Neurological Condition manage their symptoms effectively and maintain a higher level of independence for a longer period.
- C3-I-5** There is a notable lack of comprehensive state-specific data on Neurological Conditions in Queensland, hindering a complete understanding of impact on Queensland's public health system and the broader economy. This includes an absence of detailed NDIS and Aged Care funding breakdowns by Neurological Condition, categorised by age band and demographic distribution. The recent announcement of a \$550,000 grant from the Australian Department of Health and Aged Care to the Australian Institute of Health and Welfare (AIHW) to develop a Neurological Condition dashboard will help address these data gaps.
- C3-I-6** What little data is available suggests some Queenslanders with Neurological Conditions are missing out on critical NDIS and Aged Care funding and supports.
- C3-I-7** Thin NDIS markets in regional and remote areas exacerbate the burden of Neurological Conditions for people living in those areas.
- C3-I-8** Incurable conditions like MS, early onset Parkinson's Disease and Dementia, which have fluctuating functional impacts and are likely to meet NDIS full access criteria over time, need streamlined access pathways to the NDIS before substantial functional decline occurs.



- C3-I-9** Every person with a disability must have equity of access to services and support to facilitate quality of life, independence, safety, and community participation, especially for those with rapidly progressing, degenerative, and complex disabilities like MND.
- C3-I-10** It is critical that Commonwealth Government-funded systems, including the NDIS and HCP systems provide comparable funding and accessible services, irrespective of age.
- C3-I-11** Increasing awareness, education, and understanding of Neurological and Neuromuscular Conditions among NDIA staff is essential for better administration of the NDIS. The recent approval to establish a Neurological Working Group within the NDIA will help address this issue.

Opportunities

- C3-O-1** **Improve Access to the NDIS:** Improve access to the NDIS for people diagnosed with Neurological Conditions to ensure early intervention support is applied at the earliest possible stage of the course of the Disease.
- C3-O-2** **Enhanced System Navigation:** Mandate and facilitate the navigation between public health disability and aged care systems to ensure coordinated service delivery and improved outcomes for people affected by Neurological Conditions, regardless of the system they access.
- C3-O-3** **Enhance Data Collection:** Invest in comprehensive data systems that track detailed information on system usage and patient demographics to improve decision-making and targeted healthcare interventions.



Estimated **128 Neurological Specialists** in Queensland.



Patients in Queensland can **wait up to 420 days** to be seen in Neurology for **crucial** appointments.



By 2034, there will be an estimated **deficit of 197,137 initial & 881,755 follow-up** Neurology appointments **annually** across Australia.



Appointment costs in Brisbane & Gold Coast range from **\$350-\$500**.



Patients in Toowoomba face fees of **\$600-\$670** per appointment.



Bundaberg & Toowoomba each have **fewer than 2 Neurologists**.



Several locations, including Cairns, Rockhampton, & Mackay, have **NO Neurologists** within a **50km** radius.

Despite Queensland's network of Neurological Specialists, Government investment, & advanced facilities, there remains a significant gap in the availability of Neurologists relative to the demand.

Overview

Neurological Conditions impact more than 1 million Queenslanders, affecting their cognitive functions, emotional wellbeing, and social interactions. These conditions can strike anyone at any age, are generally chronic, and progressively debilitating. They worsen over time and require robust and integrated care strategies to manage their long-term impact.

Despite Queensland's extensive network of specialists and services, there are noticeable disparities in access and quality of care for people living with a Neurological Condition, particularly in rural and remote areas.

Timely and equitable access to Neurological services is crucial for effectively treating and managing Neurological Conditions. Waiting months to see a specialist and having limited access to information and support can significantly impact an individual's quality of life and delay critical early intervention and treatment.

Improving diagnostic communication and access to specialist care in rural and remote areas and integrating service models across health conditions are vital elements of providing good Neurological care. The concerted efforts of stakeholders, including Neurological peak bodies, healthcare providers, corporate partners, and state and federal government agencies, are pivotal in driving advancements in care.

Current Support Systems Data

A desktop analysis shows Queensland has a network of 128 Neurological Specialists housed within public hospitals, clinics, and private practices. These specialists cover a wide range of Neurological Conditions, including Brain Injury, Dementia, Migraines, Epilepsy, Multiple Sclerosis, Motor Neuron Disease, Muscular Dystrophy, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Parkinson's Disease, and Polio. These specialists provide targeted care tailored to the specific needs of each Neurological Condition.

Clinics

Specialised clinics provide targeted services to diagnose and treat various Neurological Conditions. Services provided include:

- **Diagnosis:** Identifying the nature of the Neurological Condition and ensuring that each patient receives an accurate understanding of their health condition.
- **Ongoing Treatment:** Offering continuous support and management strategies, utilising appropriate medications and therapies tailored to each patient's needs.
- **Rehabilitation:** Supporting patients in regaining skills and managing symptoms.

Queensland Health Neurological Services Through Hospital Care

Queensland Health provides Neurological Services across the state through its network of Hospitals and Health Services. These facilities are equipped with the latest technology and staffed by Neurology Specialists. Since July 2015, the Queensland Government has invested \$595 million in executing its Specialist Outpatient Strategy, which aims to improve specialist outpatient wait times while ensuring patients and their General Practitioners (GPs) get the right specialist service at the right time.⁸⁵

Demand Outstrips Supply

Despite Queensland's network of Neurological Specialists, Government investment, and advanced facilities, a substantial gap remains between the availability of Neurologists and the growing demand for their services.

Data shows that:

- In 2016, only 33 Neurologists were working in regional and remote areas across Australia with an estimated 6 Neurologists operating across rural and remote across Queensland.⁸⁶
- In 2020, there were 128 Neurologists* in Queensland, spanning 1.73 Million square kilometres.
- Patients in Queensland can wait up to 420 days to be seen in Neurology.⁸⁷

**Source: Based on the 'Modelling accessibility of adult neurology care in Australia, 2020-2034*

Neurologist availability ascertained via the Zable Health medical specialist database shows several key locations across Queensland are left unserved.⁸⁸ This database will help Queenslanders find Neurologists more easily. As of July 2024, the database shows no service referrals for Neurologists within a 50km radius of several locations, including Cairns, Rockhampton, Mackay, Hervey Bay, Gladstone, Maryborough, Mount Isa, Gympie, Yeppoon, Warwick, Emerald, Dalby, and Cape Tribulation.

In Bundaberg, which has only one Neurologist, patients face a wait time of over six months. In 2023, the ABC reported that specialist wait times data show patients are waiting years for crucial appointments, with patients in Queensland waiting up to 420 days.⁸⁹

As a function of high demand, Neurologist appointment costs are higher in regional and remote areas. Patients in Toowoomba face fees of \$600-\$670 per session, compared to \$350-\$500 in Brisbane and Gold Coast. There is also a notable disparity in Neurologist availability, with Brisbane and Gold Coast collectively having 28 Neurologists, while Bundaberg and Toowoomba each have fewer than two Neurologists.

“Depending on the acuteness of the situation, category 3 can be over 12 - 16 months”

Dr Prakash Pattnaik, Townsville GP.

It is not just patients who are adversely impacted by the shortage of Neurologists in regional and remote areas; the neurologist shortage places increased pressure on GPs who are managing patients with neurological conditions as they are awaiting specialist input and often need regular monitoring. The lack of specialist advice can cause stress for GPs, particularly those in regional and remote areas with limited



access. Consequently, some conditions will worsen without specialist support resulting in more patients than necessary presenting to emergency departments.

“Often not being able to access non-GP specialists will lead me to refer to public services acutely.”

Dr Tony Bayliss, Queensland GP.

Even without the servicing challenges imposed by the shortage of Neurologists across Queensland, accessing critical health information can be challenging for many patients, especially those from CALD backgrounds and elderly individuals. Often, information about clinic locations and specific services is unavailable in suitable formats or confusing for those people, hindering timely access to specialised care and support.

Furthermore, the lack of a centralised resource for neurological services information is evident. For instance, while Metro North Health Hospital & Health Services has dedicated pages on their website for cancer care and other services on its website, it lacks a specific section for neurological services, making it harder for patients to find the care they need.

Case Study

An Australian Epilepsy longitudinal survey revealed that people with Epilepsy believed health professionals outside of Neurology, including emergency department staff, Pharmacists, Nurses, & GPs, are not equipped with the necessary knowledge to provide good quality care.

People don't understand, they don't know enough about Epilepsy, wait times are too long, I did not receive the care, Specialist Services are limited (in rural communities), for dealing with my Epilepsy.⁹⁰

GPs & Health Professionals: The Frontline of Neurological Care

GP's and allied health professionals are essential in the early stages of diagnosing and managing Neurological Conditions. They provide initial diagnoses and manage these conditions, including referrals to specialised Neurology Services.

Role of GPs in Coordinating Care

- **High Demand:** GPs often face an overwhelming demand to coordinate and manage the additional support necessary for individuals with Neurological Conditions. This involves providing medical treatment and facilitating access to



community services and specialised care.

- **Time Constraints:** The significant time required to arrange these supports means that GPs frequently need to provide extended consultations or additional follow-ups, which can strain their time. This can result in a flow onto other patients who are left unable to get an appointment with those GPs.

Consultation Details

- **Scheduled Visits:** On average, patients with Neurological Conditions typically receive two biannual specialist consultations. 'The duration of a specialist appointment can vary, but most initial consultations last 30 to 60 minutes.'⁹¹
- **Medicare Support:** Medicare offers a rebate of \$39.75 for standard GP consultations, helping offset some costs.
- **Out-of-Pocket Costs:** If not bulk billed, the average GP appointment costs \$102, leading to considerable out-of-pocket expenses for frequent care.
- **Extended Consults:** Consultations under GP Chronic Disease Management Plans and Mental Health Care Plans are often lengthened to provide comprehensive care, doubling the usual consultation time and adding to the cost burden.

Allied Health Services

- **Essential Services:** Allied health professionals such as Physiotherapists, Occupational Therapists, and Dietitians are critical in treating and managing Neurological Conditions.
- **Cost Barriers:** These vital services often come at a high cost, making them prohibitively expensive for underinsured or economically disadvantaged individuals. This impacts their access to necessary ongoing care.

Community-Based Services

In Queensland, a range of community-based organisations provide specialised support for people with specific Neurological Conditions. These services are vital in helping individuals manage their conditions effectively and improve their quality of life.



Table 20: List Of Queensland - Based Neurological Community Organisations

Organisation / Support	Description
Acquired Brain Injury Outreach Services (ABIOS)	<ul style="list-style-type: none"> • Comprehensive support for community integration. • Offers therapy sessions and caregiver support. • Focuses on long-term recovery and independence.
Alzheimer's Association of Queensland	<ul style="list-style-type: none"> • Supports those with Dementia and Alzheimer's Disease. • Provides information, support, and assistance to individuals and healthcare professionals.
Brain Injury Foundation	<ul style="list-style-type: none"> • Supports individuals and families impacted by acquired Brain Injuries. • Provides services and advocacy to support families and individuals.
Epilepsy Queensland	<ul style="list-style-type: none"> • Builds capability in people living with Epilepsy and their families to manage their own condition. • Provides psycho-social, practical and advocacy supports to overcome barriers to participation. • Provides information, referral and education services and facilitates peer support groups. • Builds capability in service providers, schools and workplaces to support people in their care living with Epilepsy. • Provides guidance and assistance on navigating the NDIS.
FND Australia Support Services Inc	<ul style="list-style-type: none"> • Focuses on Functional Neurological Disorder (FND). • Offers peer and carer support. • Engages in research and advocacy to improve care quality.
Huntington's Queensland	<ul style="list-style-type: none"> • Provides comprehensive support for individuals and families affected by Huntington's Disease. • Offers information and referral services, one-on-one support, and support groups.
MS Queensland (Neuro Wellness Hub in Milton)	<ul style="list-style-type: none"> • Provides specialised services like physical therapy and counselling. • Offers tailored programs for the individual needs of Neurological patients. • Enhances patient wellbeing and autonomy through support groups.



**Migraine & Headache Australia
(Queensland Chapter)**

- Focuses on supporting those with migraines and other headache disorders.
- Advocates for improved care and treatment options.

**Motor Neurone Disease
Association Queensland**

- Provides support and services for those affected by MND.
- Offers equipment, advice, and resources.
- Conducts advocacy and fundraising for research and support.

**Muscular Dystrophy
Queensland**

- Supports individuals with Muscular Dystrophy and related conditions.
- Provides equipment, therapy, and advocacy.
- Engages in community building and awareness campaigns.

Neuro Junction

- Specialises in physiotherapy and allied health services for Neurological Conditions.
- Focuses on symptom management and improving functional capabilities.

Parkinson's Queensland

- Provides information and support for Parkinson's Disease through an Info Line and support staff.

Polio Network Queensland

- Supports survivors of Polio.
- Offers resources on managing Post-Polio Syndrome.

**Queensland Health Psychology
& Neuropsychology Services**

- Provides Neuropsychological assessments.
- Supports medical diagnosis and rehabilitation for those with suspected Neurological issues.

**Synapse
(Australia's Brain Injury Organisation)**

- Delivers information, referral, and direct support.
- Offers community living initiatives and advocacy.

Support Groups Queensland

- Provides a directory of over 800 support groups across Queensland.
- Helps individuals find appropriate support for various Neurological Conditions.

UQ Neurological Society (UQNS)

- A Student Club at the University of Queensland dedicated to Neuroscience.
- Offers educational and support activities.

Note: This is not an indicative list of all Neuro-specific community-based organisations in QLD.



Community-based Neurological organisations are purposeful parts of the healthcare system, providing vital continuity of care and support. They go beyond just filling in the gaps in the healthcare system by offering comprehensive services aimed at enhancing the quality of life and well-being of individuals with Neurological Conditions and their families.

These organisations play a crucial role in advocacy and raising public awareness. Their campaigns are instrumental in educating the community, reducing stigma, and promoting early diagnosis and intervention. This ensures continuous, comprehensive care and support and significantly contributes to public health. They provide valuable resources, including educational materials, support groups, and access to specialised care.

By fostering connections among patients, healthcare providers, and other stakeholders, they establish a support network often absent in traditional healthcare settings, thus enhancing overall well-being. Direct support services such as counselling, therapy, and assistance in navigating healthcare systems are crucial for managing the daily challenges and long-term impacts of Neurological Conditions. This direct support significantly enhances the quality of life for those affected.

Future Projections

Modelling from the study "Modelling accessibility of adult Neurology care in Australia, 2020-2034" projects that by 2034, the shortage of Neurology Services will significantly impact the ability to provide timely and adequate care. There is an estimated deficit of 197,137 initial and 881,755 follow-up Neurology appointments annually across Australia.⁹²

Even with more Neurologists, significant gaps in access to Neurological care are expected to continue.

Barriers To Care for Individuals with Neurological Conditions

An Australian study on the mental health status and treatment patterns among individuals with Neurological Conditions found that over 70% of participants faced significant barriers to accessing emotional and cognitive care. The main obstacles attributed were a lack of resources and insufficient services, which has driven more people to access online self-care solutions.⁹³

A study in the UK has similarly found a general lack of information available for Neurological patients. In the "Together for the 1 in 6: UK Findings from My Neuro Survey,"⁹⁴ approximately 40% of respondents did not receive any information when diagnosed, and nearly 20% were not given a clear explanation of their diagnosis, highlighting a critical gap in initial patient communication.

The study further found:

- Over 50% of respondents experienced delays in routine neurologist appointments, with some delays extending up to a year, severely impacting their condition management.
- Nearly 40% of respondents indicated that information about their care was not effectively communicated among their health professionals, suggesting a fragmented healthcare system.
- 67% of respondents indicated that their mental well-being needs are met to a small extent or not at all, emphasising a significant deficiency in mental health support.

According to the 2019 "The Needs of People Living with MS, Their Families and Carers' Report⁹⁵," 45% of carers are paying for health professionals' support, indicating a substantial burden on informal caregivers. The same report noted that one in four people had an unmet service need, with issues mainly arising from affordability (41%) or accessibility (25%).

Similarly in the case of Epilepsy the Australian Epilepsy Longitudinal Study found that despite 70% of people achieving seizure control with the right diagnosis, treatment and **supports**, only 10% of respondents report having access to the **right supports**.

Table 21: Key Areas of Concern for Individuals with Neurological Conditions

Category	Issue	How It Impacts
Resource Accessibility	• Adaptation Aids	• Increased access to adaptive aids and tools is crucial for maintaining independence, safety and improving quality of life.
	• Financial Support	• The financial burden of care is substantial, impacting the affordability of treatment, rehabilitation, and mental health services.
Healthcare Services	• Integrated Care	• The healthcare system is fragmented and requires coordinated and integrated care approaches.
	• Rehabilitation Services	• Essential for recovery and maintaining abilities, yet often underprovided or inaccessible.
	• Timely & Specialised Care	• Delays in wait times and access to specialised care can significantly impact treatment and quality of life.
Information & Communication	• Access to Information & Diagnosis	• Inadequate diagnosis information hampers effective management and treatment planning, worsening outcomes.
	• Information & Education	• Accessible, comprehensive educational resources for patients and families can assist individuals make informed decisions.
		• Gaps in knowledge among non-specialist health professionals can delay diagnosis and treatment and access to vital supports and services.
Mental Health Care	• Mental Health Support	• High costs and insufficient coverage of mental health services pose significant barriers despite Medicare rebates and NDIS support.
Research & Development	• Research & Innovation	• Lack of R&D means delays in understanding Neurological Conditions, developing treatments, and discovering cures.
Support Systems	• Community & Peer Support	• Poor community support networks can increase isolation, and impact quality of life.
	• Support for Families & Caregivers	• Caregivers lack adequate resources and respite care, necessitating enhanced support systems.
	• Transportation	• Poor transportation support can affect how often a patient accesses healthcare services and effectively manages daily activities.



Community-Centric Neuro Wellness Hubs

A proven initiative aimed at ensuring people with Neurological Conditions are active partners in their care and support is the Neuro Wellness Hub (NWH) established by MS Queensland. These hubs are designed to provide comprehensive resources and support services to Queenslanders living with Neurological Conditions. The first NWH, launched in Milton in April 2024, serves as a central point for vital services such as allied health, employment assistance, and NDIS support coordination. It also hosts community events and wellness initiatives, fostering a sense of community among individuals with Neurological Conditions.

A standout feature of the Milton NWH is its state-of-the-art gym, where leading physiotherapists offer essential support to help maintain mobility and functionality. The NWH is designed to be an open and welcoming space, providing a lifeline of human connection within a like-minded community. This connection is essential as Neurological Conditions can often lead to feelings of isolation and disconnection.

Recognising the importance of accessibility, MS Queensland plans to expand these hubs across the state, with upcoming locations in Toowoomba, Springfield, and other key regional centres. Services will also be virtual to ensure those who cannot physically access the NWHs receive support. This investment in virtual capacity ensures that everyone, regardless of location and accessibility, can benefit from the Neuro Wellness Hub.

The Neuro Wellness Hubs stand as a model of community-centric care, enhancing access and engagement while reducing service fragmentation. This initiative highlights the importance of integrated health services in Neurological care, showcasing how a community-focused approach can significantly impact the well-being and support of individuals with Neurological Conditions.



Insights

- C4-I-1** There are not enough Neurological Specialists to meet the current, let alone future, growing needs of people with Neurological Conditions. This leads to long wait times, delayed treatment, unnecessary presentations to hospital emergency wards, extended hospital stays and significant emotional distress.
- C4-I-2** With the number of people requiring Neurological care growing daily, it is critical to address service disparities, augment data collection, and guarantee comprehensive access to Neurological care.
- C4-I-3** Timely and equitable access to Neurological Services is crucial for treating and managing conditions effectively.
- C4-I-4** Barriers to accessing specialists can lead to delayed reviews and treatments, impacting multiple aspects of a patient's life.
- C4-I-5** A significant disparity in service distribution, particularly in rural and remote areas, leads to uneven healthcare coverage. It is essential to find ways to ensure everyone in Queensland can access a Neurological Specialist when needed, regardless of their location.
- C4-I-6** Critical action is needed to improve diagnostic communication, access to specialised care in rural and remote regions, and user-friendly information.
- C4-I-7** Urgent unmet needs of Queenslanders with Neurological Conditions require immediate attention to enhance their quality of life and ensure comprehensive care.
- C4-I-8** Addressing the substantial challenges in Neurological care requires innovative holistic care and support solutions. This includes integrating health services with neurological care, as exemplified by the Neuro Wellness Hub initiative.



Opportunities

- C4-O-1 Enhanced Diagnostic Communication:** Establish clear guidelines and training programs for healthcare providers to improve their communication skills and ensure patients fully understand their diagnoses, treatment, and support options.
- C4-O-2 Integrated Mental Health Support:** Incorporate mental health services into Neurological departments by employing specialists and training staff to blend care approaches, providing comprehensive care for psychological and physical health needs.
- C4-O-3 Centralised Support Platform:** Create a digital Neuro gateway listing all Neurological Support Services in Queensland to simplify patient access to necessary care, make information more accessible, and reduce fragmentation.
- C4-O-4 Community-Centric Neuro Wellness Hubs:** Establish community-centric hubs, especially in rural and remote areas, to provide comprehensive resources and support services, enhancing access and community engagement while reducing service fragmentation.
- C4-O-5 Rural Neurologist Incentives:** Provide incentives for Neurologists to work in rural areas and support the adoption of Telehealth technologies, improving access to Neurological Services in underserved regions.
- C4-O-6 Navigating Support:** Establish a personalised centrally led but locally focused service that provides critical and timely over the phone or virtual support and advice for people at the point of diagnosis to help simplify the complex maze of health and support systems.

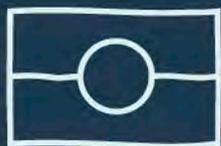


Component 5: Demographic Considerations

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273,119 First Nations people live in Queensland.



Neurological Conditions were the **4th leading Disability burden** of Disease for **First Nations** Queenslanders in 2018.



1 in 3 people suffering from **Chronic Migraines** also experience **Depression & Anxiety**.



50% of people **Worldwide** with Epilepsy have coexisting physical or psychiatric conditions.



One in five Queenslanders born overseas, with over **300 languages** spoken in the community.



38% of the Queensland population that live in **rural & remote areas**.



20% of Queensland's population reside in the most **disadvantaged quintile**.



People with Dementia are **6 times at risk** of having a seizure.



65% of informal Dementia caregivers are **over 65**, & **46%** have a disability.

Neurological Conditions impact some cohorts more than others. Where you live and your cultural background matters. Your age and sex can make a difference too. The risk factors you're exposed to are also important.

Every factor counts.

Demographic Considerations

Overview

Neurological Conditions affect certain groups disproportionately. People's ability to manage their Neurological Condition can be affected by their age, sex, economic status, cultural beliefs, access to health care and comorbidities. Exposure to certain risk factors, such as smoking, alcohol misuse and obesity, can also be an exacerbating factor.

Vulnerable people, including women, older people, those living in poverty, rural or remote areas and other vulnerable populations, such as First Nations peoples and CALD communities, are often disproportionately affected.

The interplay between Neurological Conditions and geographic location, cultural background, age, sex, comorbidities, and exposure to risk factors requires extensive and localised mapping. Understanding how these factors and Neurological Conditions coexist and their impact on prevalence, patient outcomes and quality of life is critical for providing a holistic approach to awareness raising, care, and support needs in the future.

Disparity Of Facts & Figures

Differences Between Men & Women

Unfortunately, research on the varied impacts of Neurological Conditions on different cohorts in Australia is limited, highlighting the need for more in-depth analysis. What information is available demonstrates profound differences between men and women across Neurological Conditions.

Table 22: Differences Between Men & Women

Women	<ul style="list-style-type: none">• The frequency of stroke is expected to differ for women before and after menopause, with post-menopausal women being at higher risk compared to men of the same age.⁹⁶• Migraines are more common in women and primarily affect people aged 15 to 49, a critical time for school and work. Even though they cause significant problems, migraines are often ignored by policy makers because they are not fatal.⁹⁷• With a ratio of three women to 1 male, MS has significant economic consequences for women. Predominately affecting them when they are in the productive prime of their lives (30s and 40s) means many will face tough decisions about career adjustments or early retirement.
Men	<ul style="list-style-type: none">• Young men are often at a higher risk of ABI primarily through their involvement in contact sports, higher rates of risk-taking behaviour, and increased likelihood of experiencing motor vehicle accidents or assaults.⁹⁸ Physically and emotionally, the consequences can be far-reaching. Many will struggle with reduced mobility, chronic pain, depression, anxiety, and irritability, affecting their relationships, work and social integration.• MND is generally more common in males. The male-to-female ratio is often reported as around 1.5:1. Approximately 58% of people with MND are under the age of 65, the average age being 59 years – a prime personal and professional time of life. The emotional and financial stress on both people with MND and their loved ones is profound.• Symptoms of the most common MND begin in childhood, primarily in boys. Progressive Muscle Degeneration and mobility issues significantly impact independence, education, and career aspirations.

Disproportionate Impacts for First Nations Peoples

The burden of disease among First Nations peoples is 2.3 times that of non-First Nation Australians.⁹⁹

In 2018, Neurological Conditions were the 4th leading disability burden of disease for First Nations Queenslanders and accounted for 2,588 DALYs.¹⁰⁰



Table 23: Neurological Health Burden For First Nations Queenslanders, 2018

	Male	Female	Total
DALYs	1,215	1,373	2,588

Source: health.qld.gov.au

Table 24: Headline Neurological Statistics for First Nation Peoples

Neurological Condition	Headline Statistic for First Nation Peoples
Dementia	<ul style="list-style-type: none"> • 3 times higher rate of Dementia in First Nations people aged 45 years and over than overall Australian estimates for the same age group. • Approx. 46% have at least one Chronic Condition, which includes Neurological Conditions like Dementia and Stroke.¹⁰¹
ABI (inc. Stroke)	<ul style="list-style-type: none"> • 3 times more likely to experience Stroke and TBI than Non First Nations Australians.¹⁰² • 21 times more likely to suffer a head injury due to an assault.¹⁰³ • Commonly occurs at a younger age and is more likely among First Nation people living in rural and remote areas.¹⁰⁴ • A lower rate of access to rehabilitation services than the general population. • 1.7 times higher rate of stroke hospitalisations compared to Non First Nations Peoples.¹⁰⁵
Epilepsy	<ul style="list-style-type: none"> • Twice as likely to report having Epilepsy compared to Non-First Nation Australians. • 3.5 times as likely to have an Epilepsy-related hospitalisation.¹⁰⁶

In addition to carrying a higher risk of Neurological Conditions, First Nations peoples living in rural and remote areas are more likely to suffer from and die prematurely due to Diseases or injuries. Health loss rates for people in these areas are significantly higher, by 23.8% to 25.2%, respectively, compared to those in major cities.¹⁰⁷

Exposure to risk factors is also seen as a major contributing factor to disease burden for First Nation Australians. A recent study of the Dementia burden among First Nations residents of the Torres Strait and Northern Peninsula Area, for example, estimates that 52.1% of people with Dementia attribute their disease to 11 potentially modifiable risk factors. The most significant contributors include Hypertension (9.4%), Diabetes Mellitus (9.0%), Obesity (8.0%), and smoking (5.3%).¹⁰⁸



With 273,119 First Nations people living in Queensland, representing 29% of the total First Nation's population across Australia and 4.6% of Queensland's total population, understanding the unique environmental and socioeconomic factors influencing the prevalence and progression of Neurological Conditions within this cohort is critical.

Challenges for Culturally & Linguistic Diverse Queenslanders

In addition to language and cultural barriers, low health literacy, difficulties navigating the health system, socioeconomic obstacles, and discrimination, Neurological Conditions can present additional challenges for CALD groups due to cultural misunderstandings and stigma.

Such challenges can lead to delayed diagnosis, poorer health outcomes, and increased DALYs. This has severe implications for those with Neurological Conditions where early diagnosis and treatment are crucial to lessen the burden of Disease.

Epilepsy is one such example where misconceptions and cultural beliefs about the condition within some CALD communities can lead to discrimination and social isolation, resulting in sufferers' increased reluctance to seek medical treatment.¹⁰⁹

Specific data on Neurological Conditions in CALD communities in Queensland is limited. Statistics collected at a national level indicate that some Neurological Conditions are more prevalent in specific CALD communities than others.

Dementia is one Neurological Condition for which people from Italy, Iraq, Vietnam, Greece, Lebanon, and Scotland have a higher prevalence than the Australian-born population.

Table 25: Prevalence Of Dementia By Country Of Birth, 2021



Country	Prevalence Of Dementia
Italy	0.94
Iraq	0.83
Vietnam	0.77
Greece	0.72
Lebanon	0.69
Scotland	0.64
Australia	0.61

Source: AIHW.¹¹⁰

Iraq and Lebanon also have a higher prevalence of stroke compared to the Australian born population.

Table 26: Prevalence Of Dementia By Country Of Birth,2021

Country	Prevalence Of Dementia
Iraq	1.16
Lebanon	0.90
Australia	0.84

Where data is available in Queensland, it shows that people from North Africa, particularly those from Sudan (3.19) and Somalia (2.38), have a significantly higher rate of convulsions and Epilepsy compared to the Australian-born population (1.00). North African males have a higher rate of Epilepsy than females from the same region.¹¹¹

The data on Dementia and Epilepsy, although minor, points to the need to better understand the prevalence and impact of Neurological Conditions on CALD populations.

With more than 1 in 5 Queenslanders born overseas, over 300 languages spoken in the community, and a projected annual increase of 27,000 in the state's CALD population over the next decade, the need to gain deeper insights into the effect of Neurological Conditions on CALD populations is essential.¹¹²

Socioeconomic Disparities

Research shows that people in lower socioeconomic groups are at greater risk of experiencing Chronic Disease or injury and have a shorter life expectancy than higher socioeconomic groups. This is due to poor nutrition, limited preventive care access, and higher risk factors exposure. When compared access to people living in the highest socioeconomic areas, they are.¹¹³

- 1.6 times as likely to be obese.
- 1.3 times as likely to be insufficiently active.
- 1.2 times as likely to have uncontrolled high blood pressure.
- 1.1 times as likely to die from Dementia.

Specific statistics on Neurological Conditions and socioeconomic status in Australia are challenging due to limited targeted research. What we know from overseas studies is that:

- Migraine prevalence is inversely related to household income in the USA.¹¹⁴



- In Canada and the UK, Lower socioeconomic status is associated with a higher risk of disability progression in people with MS due to lifestyle or comorbidity.¹¹⁵
- In the USA, Children with epilepsy are more likely than children without Epilepsy to live in lower-income households, visit Emergency Departments, and not receive needed healthcare.¹¹⁶

With 20% of Queensland's population residing in the most disadvantaged quintile,¹¹⁷ and studies demonstrating a close link between socioeconomic status and Neurological Conditions, greater research on these dual challenges is warranted.

Comorbidity Across Conditions

There is 'consistent evidence of poor mental health and wellbeing' for Australians with a Neurological Condition.¹¹⁸

As shown in Table 27, numerous Studies have established that Australians living with Neurological conditions:

- can experience high levels of comorbid psychological distress (Depression, Anxiety);¹¹⁹
- are at greater risk of developing secondary health problems; and¹²⁰
- can suffer from multiple Conditions (Diabetes & Cardiovascular Disease) alongside their Neurological Conditions, particularly in the case of First Nations peoples.

Table 27: Neurological Conditions & Comorbidities Headline Statistics

Neurological Condition	Headline Comorbidity Statistic
ABI (inc. Stroke)	<ul style="list-style-type: none"> There are high rates of comorbidity between ABI and mental illness.¹²¹
Dementia	<ul style="list-style-type: none"> People with Dementia have.¹²² <ul style="list-style-type: none"> 6 times increased risk of having a seizure. 5-fold increased risk of developing delirium. Up to 50% higher risk of Oral Disease for those in aged care.
Epilepsy	<ul style="list-style-type: none"> The WHO report approx. 50% of people with Epilepsy have coexisting physical or Psychiatric Conditions.¹²³ The stigma and discrimination in relation to Epilepsy is often worse than the impact of the seizures themselves.¹²⁴
Migraine	<ul style="list-style-type: none"> 1 in 3 people suffering from chronic migraine also experience depression and anxiety. Other comorbid medical conditions include Allodynia (Central Pain Sensitisation), obesity, sleep disorders, Fibromyalgia, Arthritis, Hypertension and Heart Disease.¹²⁵
Motor Neurons Disease	<ul style="list-style-type: none"> A study of anxiety and depression in people with MND in NSW found that compared with the general NSW population, they had a: <ul style="list-style-type: none"> Higher rate of inpatient mental health service use (2.23 times the rate). Higher rate of outpatient mental health service use (3.58 times the rate).¹²⁶
Multiple Sclerosis	<ul style="list-style-type: none"> A study by MS Australia found that the top four most common comorbidities of research recipients with MS were: <ul style="list-style-type: none"> Depression (45%). Anxiety (42%). Allergies (38%). Migraines (30%).¹²⁷
Muscular Dystrophy	<ul style="list-style-type: none"> People with Muscular Dystrophy are commonly afflicted with Psychological Disorders such as depression and anxiety.¹²⁸
Parkinson's Disease	<ul style="list-style-type: none"> Comorbid Medical Conditions can include Constipation, Dementia, Visual Impairment Hyposmia, Sleep Behaviour Disorder, Diabetes and Mood Disorders.¹²⁹
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome	<ul style="list-style-type: none"> Comorbidities can include Fibromyalgia, Myofascial Pain Syndrome, Irritable Bowel Syndrome, Interstitial Cystitis, Migraines, Allergies, Multiple Chemical Sensitivities, Reactive Depression.
Polio	<ul style="list-style-type: none"> Polio survivors can have more Cardiac Disease, Respiratory Disease, Endocrine / Metabolic Disease, and Bone Disease.¹³⁰



Comorbidity can exacerbate disease burden and complicate treatment, leading to more complex healthcare needs and higher rates of hospital admissions, primary care visits, and prescriptions¹³¹. Numerous studies have emphasised the benefits of a holistic multidisciplinary team approach for people with Neurological Conditions that address the Neurological Condition and its associated health challenges.

A 2019 review of the burden of disease for Neurological, mental health and substance use disorders by Mindgardens Neuroscience Network, for example, recommended the establishment of clinics that simultaneously examined a person's overall health as a way of improving health outcomes, managing complex cases more effectively, and reducing the costs associated with separate services.¹³²

Location Matters

Australians in rural and remote areas face unique challenges compared to those in Metropolitan regions and have higher rates of hospitalisations, deaths, and injuries. They have poorer access to primary healthcare services and use them less frequently than those in major cities.¹³³

The cost burden of having a Neurological Condition is significant for people living in rural and regional areas. There is a shortage of disease-specific clinicians, Specialist Nurses, and Allied Health Professionals trained in Neurological Conditions. Patients in rural and remote areas are often required to travel long distances at their own expense for care, rehabilitation, and medication access. Unreliable internet, lack of IT equipment, and limited tech knowledge in remote areas also hinders access to virtual healthcare, making managing the condition more difficult.

Rural and regional areas commonly lack local support networks for individuals with Neurological Conditions. This absence can lead to increased social isolation, contributing to mental health challenges and negatively impacting overall well-being.

In a state that covers over 1.7 million square kilometres, the 38% of Queenslanders who live in rural and remote areas, including the 2 in 3 First Nation Peoples who live outside Greater Brisbane, are placed under a significant burden.¹³⁴

Table 28: Queensland Regions with the Highest Prevalence

Neurological Condition	Regions with Highest Prevalence
Acquired Brain Injury (inc Stroke)	<p>Areas that report higher overall mortality and hospitalisation rates for.¹³⁵</p> <ul style="list-style-type: none"> Stroke: Darling Downs, Mackay, Wide Bay, Townsville, Metro North, Metro South. Road traffic accidents / injury & poisoning: Wide Bay, Darling Downs, Cairns & Hinterlands.
Dementia	<p>Highest to lowest prevalence (2022).¹³⁶</p> <ul style="list-style-type: none"> Central Queensland, Wide Bay, Sunshine Coast: 17,664 people. Northern QLD: 5,989. Darling Down & Western Moreton: 9,044. Western QLD: 723.
Epilepsy	<p>Most reported cases of Epilepsy are found in the major urban centres such as Brisbane, the Gold Coast, and the Sunshine Coast.</p>
Migraine	N/A
Motor Neurone Disease (MND)	<p>Regions with the highest reported cases of MND include the southeast areas, particularly around Brisbane and the Gold Coast.</p>
Multiple Sclerosis (MS)	N/A
Muscular Dystrophy	N/A
Myalgic Encephalomyelitis (Chronic Fatigue Syndrome)	N/A
Parkinson's Disease	<p>SA4 Code Areas with the highest prevalence (2020):¹³⁷</p> <ul style="list-style-type: none"> Gold Coast (2,135). Sunshine Coast (1,665). Wide Bay (1,450). Moreton Bay North (1,038). <p>SA4 Statistical Region - Greater Brisbane (7,065)</p> <ul style="list-style-type: none"> Rest of QLD (9,142)
Polio	N/A

N/A: data not readily accessible or available.



Caregivers: The Hidden Impact

Chronic Neurological Conditions like MS, Dementia, Epilepsy and Parkinson's Disease have unpredictable courses and durations. As these conditions progress, symptoms vary and often require family members to provide care. This burden usually falls on a partner, spouse, or child. The long-term nature of these conditions means caregivers frequently manage multiple roles and responsibilities, sometimes for many decades.

Studies overseas have shown that the levels of distress when caring for an individual with a Neurological Condition double compared to caring for an individual without a Neurological Condition. The distress is even greater if the Neurological Condition is accompanied by cognitive impairment or behavioural issues.¹³⁸

Table 29: Impact Of Caregiving

Caregivers Can Often...	<ul style="list-style-type: none">• Injure themselves during caregiving tasks (lifting, transferring).• Neglect their own routine health care needs.• Fail to participate in wellness activities.• Bear the weight of financial burden.• Work low paid jobs that allow for flexibility.
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Caregiving can disproportionately impact women, who often assume the primary caregiving role.¹³⁹ Research from the US shows that 19% of women Alzheimer's caregivers had to quit work either to become a caregiver or because their caregiving duties became too burdensome.¹⁴⁰

Many caregivers are often elderly or disabled themselves. 65% of informal Dementia caregivers are over 65, and 46% have a disability. Those in remote areas face even greater challenges due to distant medical centres and limited treatment options.¹⁴¹

CALD Dementia caregivers also tend to experience higher levels of psychological distress than their counterparts.¹⁴²

Queensland is estimated to have 533,200 carers who provide support to those with neurological conditions. It is crucial to ensure that caregivers receive adequate support, as their well-being directly influences the quality of care offered to those with neurological conditions. By supporting carers, we can better meet the needs of people living with neurological conditions.

Insights

- C5-I-1** Women and men experience the impact of some Neurological Conditions differently.
- C5-I-2** First Nation Peoples face numerous barriers to diagnosis and support for Neurological Conditions. They often have poorer access to healthcare services, which exacerbates their conditions. Key barriers include availability, cost, and the lack of culturally appropriate services.
- C5-I-3** First Nation peoples experience greater lifetime exposure to potentially modifiable risk factors for some Neurological Conditions.
- C5-I-4** The burden of individual Neurological Conditions attributable to various risk factors differed among people of different ages, sexes, socioeconomic status, and cultural backgrounds.
- C5-I-5** Socioeconomic status influences health outcomes for people with Neurological Conditions.
- C5-I-6** Disparity in healthcare access and support often lead to increased disability and exacerbates the challenges associated with managing a Neurological Condition.
- C5-I-7** Neurological Conditions mental health and other disorders rarely exist in isolation.
- C5-I-8** Comorbidities significantly impact the management and outcomes of Neurological Conditions.
- C5-I-9** Caregivers are at risk of poor health, too. People with Chronic Neurological Diseases are in the constant care of their families throughout much of their condition, placing significant physical and emotional burdens on caregivers.

Opportunities

- C5-O-1 Improved Research & Data:** Boost investment in research that maps the similarities and differences across diverse demographic and social determinants to understand the prevalence and impact of Neurological Conditions in Queensland.
- C5-O-2 Enhanced Data Linking:** Link existing data to better identify and understand the specific needs of all populations, informing more effective and equitable healthcare strategies.
- C5-O-3 Preventative Policies:** Focus on preventive health policies, health promotion, and education that addresses the different burdens of Neurological Conditions across age groups and sexes.
- C5-O-4 Overall, Health Approach:** Explore interventions for Neurological Conditions that combine treatments for comorbid conditions, particularly for First Nations Peoples.
- C5-O-5 User-Friendly CALD Supports:** Invest in culturally accessible entry points and navigation support for CALD people in Queensland with Neurological Conditions and their families.
- C5-O-6 Making Family Caregivers Visible:** Recognise caregivers' significance as part of the healthcare team and provide them comprehensive support for their mental, physical, and overall well-being.

Component 6: Neuro Response In Other States / Territories



Queensland is not unique in its absence of specific Neurological policies or plans. Governments around the world have generally failed to prioritise Neurological Conditions. According to the WHO's Neurological Atlas (2017), only 12% of countries report having a dedicated budget for Neurological Disorders.¹⁴³

Across Australia, Neurological Conditions have been largely overlooked in Commonwealth, State and Territory-based public health priorities, **often viewed in isolation as separate diseases rather than a collective concern.**

The release of the WHO's Intersectoral Global Action Plan (IGAP) on Epilepsy and other Neurological Disorders, along with the recent burden of disease findings from the Australian Institute of Health and Welfare, serves as a timely 'wake-up' call to all Governments around Australia.

The AIHW findings present an opportunity for Queensland to take a leadership role in addressing Neurological Conditions.

Overview

What Other States & Territories Are Doing

An analysis of Australian and territory public health and Disability Plans across Australia shows that while they address a broad range of health priorities are addressed. Neurological Conditions are not specifically highlighted as a growing concern. Instead, 'Neurological Conditions' as an umbrella term is used sporadically, if at all, and only when referencing risk reduction behaviours related to Chronic Diseases. Conversely, other Diseases / Conditions such as Diabetes, Kidney Disease, Heart Disease, Mental Health, and Cancer are referenced throughout many of the plans.

This is perhaps not surprising given the following:

- Many plans were likely developed before Neurological Conditions were listed in the top 5 AIHW burden of diseases and given prominence by the WHO.
- 'Neurological Conditions' were not represented in the Federal Government's National Strategic Framework for Chronic Conditions (NSFCC), developed in 2017 to respond to the current and future challenges of Chronic Conditions. The absence of Neurological Conditions from the framework was likely a result of the Non-Disease specific intent of the NSFCC.¹⁴⁴

In addition to their overarching public health plans, most States and Territories have standalone health plans dedicated to specific Diseases/ Conditions, including Mental Health, Cancer, Diabetes, Kidney Disease, and Heart Disease. Standalone First Nation Health plans have also been developed in some states and territories.



Australian Government's Current Health Plans / Frameworks

The Australian Government likewise does not specifically reference the prevalence and impact of Neurological Conditions in its current Public Health and Disability plans and frameworks.

Table 31: Australian Government Health & Disability Plans

Plan	Overview	Neurological Condition Referenced
<p>Australia's Long Term National Health Plan</p>	<p>Focuses on several key areas:</p> <ul style="list-style-type: none"> • Mental Health: Includes a specific strategy for children under 12. • Primary Health Care: A 10-year plan to strengthen primary health care services. • Preventive Health: A 10-year National Preventive Health Strategy to reduce Chronic Disease. • Medical Research: A 10-year investment plan through the Medical Research Future Fund to support health and medical research. 	<p>No</p>
<p>Australia's Disability Strategy 2021-2031</p>	<p>Key objectives include promoting inclusion, improving access to services, and ensuring that people with disabilities can participate as equal members of society.</p>	
<p>The National Strategic Framework For Chronic Conditions</p>	<p>Overarching plan was developed in 2017 to address Chronic Diseases Nationwide. It aims to improve health outcomes related to Chronic Conditions by coordinating efforts across Australia. It recognises that there are often similar underlying principles for preventing and managing many broad-range Chronic Conditions.</p> <p>The framework is structured around three primary objectives.¹⁴⁵</p> <ul style="list-style-type: none"> • Focus On Prevention for a Healthier Australia: Emphasising early intervention and preventive measures to reduce the incidence of Chronic Conditions. • Provide Efficient, Effective, & Appropriate Care to Support People with Chronic Conditions: Ensuring that healthcare services are accessible, integrated, and tailored to the needs of individuals with Chronic Conditions. • Target Priority Populations: Addressing the needs of specific groups who are disproportionately affected by Chronic Conditions, such as Indigenous Australians, people from low socio-economic backgrounds, and those living in rural and remote areas. <p>In March 2024, a refresh of the NSFCC was initiated to update the framework based on the latest evidence and stakeholder feedback. It is expected to be finalised late 2024.</p>	<p>Neurological Condition is not listed as a Chronic Condition.</p>



It is worth noting that while Neurological Conditions are rarely mentioned in the Federal, State & Territory Public Health and Disability Plans, strategies and actions aimed at improving overall mental and physical health by reducing modifiable risk factors would nevertheless significantly impact Neurological health outcomes.

The plans also highlight that every person's health and wellbeing are influenced by multiple intersecting identities, needs, and experiences. They emphasise that by acknowledging intersectionality, health responses can better identify overlapping social and demographic factors that amplify impacts and create barriers, enabling more effective and inclusive support.

Table 30: Overview Of Other Australian States & Territory Health & Disability Plans

State	Plan	Overview	Neurological Condition Referenced
NSW	Future Health: Guiding The Next Decade of Health Care in NSW 2022-2032	<p>Focuses on several key priorities:</p> <ul style="list-style-type: none"> • Patient-Centred Care: Ensuring patients are active participants in their care. • Community Health: Addressing health disparities and improving access to services across diverse populations. • Innovation & Digital Health: Leveraging research, data and technology to enhance healthcare delivery. • Workforce Development: Supporting and growing a skilled health workforce. • Sustainability: Promoting environmental responsibility and financial sustainability. 	No
	NSW Disability Inclusion Plan	Focuses on improving access to services, promoting community participation, and ensuring that people with disabilities can live independently.	
	NSW Health Disability Inclusion Action Plan	Includes measures to enhance staff training, improve physical accessibility in healthcare facilities, and ensure that health information is available in accessible formats.	
Victoria	Victorian Public Health & Wellbeing Plan 2023-2027	<p>Focuses on several key areas to promote health equity, prevent Chronic Diseases, and enhance the quality of life for all Victorians. Main objectives and strategies include:</p> <ul style="list-style-type: none"> • Promoting Health & Wellbeing: Healthy eating, physical activity, and mental wellbeing. • Preventing Illness & Injury: Such as Cardiovascular Disease, Cancer, and Diabetes and measures to prevent injuries and reduce the 	Only once as an umbrella term, linked to the use of e-cigarettes.



impact of harmful alcohol and drug use.

- **Strengthening Prevention Systems:** Enhancing public health systems to better respond to health challenges through improved data collection, research, and evidence-based policymaking.
- **Addressing Health Inequities:** Reduce health disparities by targeting vulnerable and disadvantaged populations.
- **Climate & Health:** Strategies to mitigate climate change effects and promote sustainable practices that benefit both health and the environment.

Inclusive Victoria: State Disability Plan 2022-2026

Priorities focus on systemic reform in key areas, including health, housing, education, employment, and community participation.

Disability Action Plan 2024-2025

Outlines specific measures to advance Disability inclusion and address barriers faced by people with Disabilities in accessing services and opportunities.

South Australia	State Public Health Plan 2019-2024	<p>Focuses on four strategic priorities:</p> <ul style="list-style-type: none"> • Promote: Building stronger communities and healthier environments. • Protect: Safeguarding against public and environmental health risks, including responses to climate change. • Prevent: Preventing Chronic Diseases, Communicable Diseases, and injuries. • Progress: Strengthening systems that support public health and wellbeing. 	No
	South Australian Health & Wellbeing Strategy 2020-2025	<p>Emphasises delivering better Public Health Services, supporting local service accountability, providing more out-of-hospital services, and investing in areas that reduce health system pressures.</p>	No
	Inclusive SA - State Disability Inclusion Plan	<p>Priorities focus on promoting inclusive communities, enhancing leadership and collaboration, ensuring accessible communities, and improving learning and employment opportunities.</p>	
ACT	ACT Preventive Health Plan 2020-2025	<p>Focuses on reducing the incidence of Chronic Diseases and improving overall public health through lifestyle interventions, public education, and promoting healthy environments. It includes initiatives targeting tobacco control, nutrition, physical activity, and alcohol consumption.</p>	No
	ACT Health Directorate Strategic Plan 2020-2024	<p>Key areas include enhancing Mental Health Services, addressing Chronic Diseases, and promoting preventive health measures.</p>	No



	ACT Disability Health Strategy 2020-2024	Aims to ensure accessible and inclusive healthcare, enhance support services, and promote the health and wellbeing of individuals with Disabilities.	
Western Australia	WA Health Promotion Strategic Framework 2022-2026	Aims to prevent Chronic Disease and injury and focuses on four main areas: <ul style="list-style-type: none"> • Reducing Tobacco Use: Efforts to make smoking history. • Healthy Eating & Active Living: Initiatives to halt the rise in obesity through better nutrition and increased physical activity. • Reducing Harmful Alcohol Use: Strategies to minimize alcohol-related harm. • Preventing Injury & Promoting Safer Communities: Measures to reduce injuries and promote safety. 	Features once as a chronic disease with associated risk factors listed.
	WA Disability Health Framework 2015-2025	Designed to improve the health care and health outcomes for people with Disabilities in Western Australia.	
	Western Australia Disability Inclusion Plan	Outlines a vision where people with Disabilities have the same opportunities as others to participate in all aspects of community life.	
Tasmania	Healthy Tasmania Five-Year Strategic Plan 2022-2026	Focuses on preventive health measures to improve the overall health of Tasmanians. It includes initiatives to reduce smoking rates, promote healthy eating and physical activity, and address mental health issues.	No
	Our Healthcare Future: Advancing Tasmania's Health 2021-2024	Includes strategies for improving healthcare delivery, investing in infrastructure, and enhancing workforce capabilities to meet the growing health needs of the population.	No
	Disability Health Strategy	Tasmania's first Disability Strategy - currently under development. It will aim to ensure that our public health services meet the needs of all Tasmanians living with a Disability.	
Northern Territory	NT Health Strategic Plan 2023-2028	Outlines a vision for providing high-quality, integrated healthcare services across the Northern Territory.	
	Strengthening Our Health System Strategy 2020-2025	Aims to integrate various health services and improve patient care through digital advancements.	
	NT Disability Strategy 2022-2032	Sets out five key outcomes: protecting rights and choices, creating inclusive communities, ensuring accessible communities, promoting employment and financial security, and supporting health and	



wellbeing.

**NT Disability
Strategy Action
Plan 2022-2025**

Includes actions like establishing an Aboriginal Disability Peak Body, conducting accessibility audits for correctional facilities, and enhancing NDIS support for Aboriginal Community Controlled Health Organisations.

The Neurological Alliance Australia (NAA) - Work To Bring Neurological Conditions to the Forefront.

Neurological Alliance Australia (NAA) is a collective of 21 not-for-profit organisations representing millions of adults and children living with progressive Neurological or Neuromuscular Conditions in Australia, their families, and carers. The NAA actively advocates for comprehensive strategies to address the needs of people living with Neurological and Neuromuscular Conditions, calling for a National Blueprint for Neurological Conditions.

The NAA's efforts include campaigning to secure funding for medical research, end age discrimination in the National Disability Insurance Scheme (NDIS), strengthen the NDIS, and ensure equal access to early interventions and tailored and responsive supports and services, including assistive technologies. The NAA is also lobbying hard to the Government to develop a national neurological dataset, which would help inform policy and improve care for Neurological Conditions Nationwide.

Overarchingly, the NAA argues that people with Neurological Conditions need swift detection, diagnosis, and access to treatment to prevent, reduce or delay disability. They also require a smooth "transition of care" through health, Disability, and aged care systems.

The NAA additionally emphasises the potential benefits of health-related technology, digitisation, artificial intelligence (AI), and the role of apps in improving detection and diagnosis, some treatment options, and better monitoring of disease progression.

Specific NAA Recommended Initiatives

The NAA has recently when recommended several key initiatives to help propel Neurological Conditions to the forefront of the public health agenda in Australia.

These include:

The inclusion of a specific question in the 2026 census to capture the diagnosis of a Neurological Condition, worded:

Have you been diagnosed with one of these Neurological Conditions, please tick:

- Acquired Brain Injury.
- Dementia



- Epilepsy
- Huntington's Disease.
- Leukodystrophy.
- Machado Joseph Disease.
- Mitochondrial Disease.
- Motor Neurone Disease.
- Multiple Sclerosis.
- Muscular Dystrophy.
- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome.
- Parkinson's Disease.
- Polio.
- Spinal Muscular Atrophy.
- Other.

Adding a list of Neurological Conditions (as above) to the current census questions relating to long-term health conditions. Presently; Mental Health Conditions, Arthritis, Asthma, Diabetes, Heart Disease, Cancer, Lung Condition, Stroke, Kidney Disease and Dementia are listed.

Establishing a new Neurological Mission within the Medical Research Future Fund.

Establishing a Neurological Working Group within the NDIA.

Allocating \$550,000 from the Australian Department of Health to the Australian Institute of Health & Welfare to address the current Neurological data gaps & opportunities, including:

- \$400,000 for a scoping study to develop a minimum data set for Neurological and Neuromuscular Conditions in Australia.
- \$150,000 for a data report on Neurological Conditions in Australia that would report the latest available data.

Establishing a single National Assistive Technology Program to meet the needs of people with disability who do not qualify for the NDIS.

Adding Neurological Conditions to the existing Chronic Disease Conditions currently listed in the Chronic Conditions Framework.

This advocacy recently saw the Department of Health and Aged Care approve \$550,000 in funding for the AIHW to address existing Neurological data gaps.



The work is expected to include:

- Convening a Project Expert Advisory Group to inform the classification and grouping of conditions for ongoing monitoring.
- Establishing a dedicated topic page on the AIHW website highlighting the importance of monitoring the prevalence and impact of living with Neurological Conditions.
- Investing in developing a Neurological Condition dashboard for the ongoing monitoring of Neurological Conditions, including creating a system for future data updates.
- Publishing a factsheet / data set story alongside the data report highlighting interesting findings from the data.

The Neurological Condition dashboard will be incorporated into the National Centre for Monitoring Chronic Conditions (NCMCC) routine monitoring program. The data will be updated annually, or as new information becomes available.

The establishment of the Neurological Working Group within the NDIA is also underway.

Insights

- C6-I-1** Neurological conditions have been similarly neglected in Australia's public health and disability frameworks. They are often treated as isolated diseases rather than a collective concern, leading to a lack of comprehensive strategies to address their impact
- C6-I-2** An analysis of Australian state and territory health plans reveals that neurological conditions are rarely highlighted. Most plans focus on other chronic diseases like diabetes, heart disease, and mental health, with neurological conditions mentioned sporadically, if at all.
- C6-I-3** The gaps in the recent burden of disease findings by the Australian Institute of Health and Welfare (AIHW) and the WHO's Intersectoral Global Action Plan (IGAP) offers an opportunity where Queensland can take a leadership role in prioritising neurological conditions.

Opportunities

- C6-O-1** **Queensland Leadership in Neurological Care:** Develop a cross-government and sector Neurological care framework as a critical pillar of Queensland's Public Health and Disability Plans, involving careful co-design with key stakeholders and incorporating the lived experiences of individuals affected by Neurological Conditions.
- C6-O-2** **Leveraging NAA's Work & Insights:** To position Queensland as the leader amongst States and Territories in addressing the challenges imposed by Neurological Conditions, they can utilise the NAA's work to:
 - Recognise Neurological Conditions as Chronic Diseases to ensure appropriate attention and resources.
 - Develop a coordinated and co-designed response to Neurological care in Queensland.
 - Ensure quality data collection for informed decision-making and targeted interventions.

Component 7: Neuro Response Internationally



Overview

In 2006, the World Health Organisation (WHO) pronounced that “Neurological Disorders will be one of the greatest threats to Public Health.”¹⁴⁶

Sixteen years later, the 2022 release of the WHO’s Intersectoral Global Action Plan (IGAP) on Epilepsy and other Neurological Disorders showed that the dial had hardly shifted. The report emphasised that Brain health and Neurological Conditions globally were still not given the appropriate support and investment they needed.¹⁴⁷ In 2017, only 12% of countries reported having a dedicated budget for Neurological Disorders.¹⁴⁸ Only 24 per cent of countries Worldwide have stand-alone Neurological Health Policies.¹⁴⁹

The IGAP “aims to improve access to care and treatment for people with Neurological Disorders while preventing new cases and promoting brain health and development across the life course”.¹⁵⁰ It builds on many previous global resolutions, decisions, reports, and commitments that have identified the need for coordinated action at the country level to address the health, social and public knowledge implications of epilepsy and other Neurological Conditions.

Notably, the IGAP identifies that many preventive, pharmacological, and psychosocial approaches are shared by Epilepsy and other Neurological Disorders. While this alignment of approaches is consistent with Australia’s ‘National Strategic Framework for Chronic Conditions’ shared across States and Territories, Neurological Conditions are not explicitly listed.

Learnings From Other Countries

England

The UK’s Department of Health launched the National Service Framework (NSF) for Long-term Conditions in March 2005 with an implementation timeframe of 10 years to 2015. Previously published NSFs in the UK had set standards for Cancer, Coronary Heart Disease, Mental Health, Diabetes, older people, children’s services, and Renal Disease.

The 2005 NSF aimed to improve care and support for individuals with long-term Neurological Conditions such as Multiple Sclerosis, Parkinson’s Disease, and Spinal Cord Injuries.

The strategy set out 11 “Quality Requirements” focused on promoting independence and enhancing the quality of life for patients. Key objectives included ensuring prompt access to specialist care, providing comprehensive support for independent living, and improving the overall quality of health and social care services.

“The NSF ... is a very important step in delivering [a] strategic shift in the way in which health and social care organisations work together to support people with long-term conditions... in showing the difference which can be made by putting people with long-term Neurological Conditions at the heart of their own care, the NSF demonstrates the importance of the person-centred approach for everyone who uses health and social care services.” ¹⁵¹

John Reid, Secretary of State for Health.

A central pillar of the NSF was to support NHS services in planning structured and systematic approaches for delivering treatment and care to individuals with long-term conditions. The aim was to ensure that care was efficient, supportive, and appropriate at every stage of life, from diagnosis to end of life. This included integrating specialist Neurological expertise, providing timely and accurate diagnoses, and ensuring consistent, high-quality support throughout the patient's journey to promote independence and enhance quality of life. The dissemination of an 'NSF Good Practice Guide' for care service professionals was an essential action.

A mid-way evaluation of the NSF for Long-term Neurological Conditions found that while it aimed to improve integrated care and support for individuals, its implementation faced significant challenges due to a lack of systematic monitoring and support structures.¹⁵²

Findings from the recent "Together for the 1 in 6: UK Findings from My Neuro Survey,"¹⁵³ indicate that gaps remain for people living with a Neurological Condition, with 50% of respondents experiencing delays in routine Neurologist appointments, some up to a year, nearly 40% believing information about their care was not effectively communicated among their health professionals and 67% indicating their mental wellbeing needs were not being met.¹⁵⁴

Scotland

Neurological Care and Support in Scotland – A Framework for Action 2020 – 2025 sets out a strategic vision “for driving improvement in the care and support for those with Neurological Conditions in Scotland”¹⁵⁵. The framework ensures equitable and timely access to high-quality, person-centred care Nationwide.

Key priorities include building a sustainable Neurological workforce, developing integrated care models, and effectively supporting people to manage their conditions. The Framework emphasises collaboration among National, Regional, and Local organisations to achieve these goals, aiming to improve the health, independence, and wellbeing of people with Neurological Conditions.

As Scotland’s first National Action Plan on Neurological Conditions, it seeks to centre lived experience at the centre of the framework.

The Framework makes a total of 17 Commitments under the pillars outlined below. The midpoint progress report, released in 2022, highlights achievements and challenges, emphasising the importance of continued efforts to meet the Framework’s goals. Progress to date has included a total of 35 projects funded since 2020 and innovative use of digital technologies for Neurology to support a range of conditions.

OUR VISION



Everyone with a Neurological Condition will be able to access the care & support they need to live well, on their own terms.



Source: *Neurological Care & Support in Scotland: A Framework for Action 2020-2-25*.



Specific projects have included:

Aim	Project
Ensure People with Neurological Conditions are Partners in their Care & Support	<p>Public-facing information about Neurological Conditions for the NHS Inform website to support education and self-management.</p> <p>Neurological Alliance of Scotland (NAoS) funded to produce three new 'What to Expect' information guides for carers on Anticipatory Care Planning, advocacy services, and becoming a new carer.</p> <p>Tailored Talks: An innovative digital presentation platform that delivers comprehensive information to patients and carers with a wide range of Neurological Conditions.</p> <p>MS Society: Wellbeing Hub: Provides virtual activities to help support the people with MS with their emotional and physical health.</p> <p>The MS Centre Mid Argyll: Specialising in support for people with MS in rural and remote areas.</p> <p>The Pain Association: Received funding to deliver online carer sessions.</p> <p>Spina Bifida Hydrocephalus Scotland: Healthy Ageing Hub: A Wellbeing Matrix that incorporates 'health personas' as a tool for decision support, focusing on wellbeing rather than ill health.</p>
Improve The Provision Of Coordinated Health & Social Care / Support for People with Neurological Conditions	<p>Five funded projects supporting statutory bodies to develop collaboration across sectors to improve integrated care and support for people with Neurological Conditions.</p>
Ensure High Standards of Effective, Person-Centred, Safe Care & Support	<p>A multi-disciplinary cross-agency working group recruited to develop and implement a quality assurance programme for the General Standards for Neurological care and support.</p>

Source: *Neurological care & support - framework for action 2020-2025 midpoint progress report.*¹⁵⁶

Canada

The Neurological Health Charities of Canada (NHCC) has called on the Canadian Government to partner in the development of a National Neurological Strategy, emphasising that:



“It is time to tackle one of the twenty-first century's most challenging but ultimately solvable health issues: the prevention, treatment and cure of Neurological Conditions. It is time for unprecedented collaboration and resolve.”¹⁵⁷

The NHC has published a *Framework for National Neurological Strategy for Canada*, emphasising the need for coordinated efforts to address Neurological health issues.

The framework aims to ‘finally address the patchwork approach to Neurological health that has a profoundly negative impact on quality of life for millions of Canadians living with Neurological Conditions’¹⁵⁸. It focuses on preventing, treating, and curing Neurological Conditions and advocates for collaboration within the Brain Health community, building on existing National strategies and Global initiatives.

Key pillars include:

Strengthening Government Leadership Of Neurological Health

- Supporting human rights-based laws, policies and programs for people living with Neurological Conditions.
- Ensuring budgets are proportionate with the human and other resources needed to maximise Neurological health.
- Adopting Global Neurological health initiatives including the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders.

Investing In & Improving Accessibility To Early Diagnosis, Comprehensive Treatment & Care

- Working with provinces and Territories to lead the coordination of equitable access and delivery of health and social care services across the life course including transitioning from one stage of life to the next, palliative care and mental health.
- Making essential medicines accessible and affordable equitably across the country, including drugs for rare disorders.
- Expanding caregiver supportive programs and financial assistance.

Investing In Capacity Building Of Neurological Health Care Workforce

- Investing in training, support, retention and capacity-building of the Neurological health care workforce.
- Investing in digital education and online learning programs to accelerate workforce training to enhance equitable access to



care.

Reducing Stigmatization & Discrimination

- Improving public attitudes and protecting the rights of people with Neurological Conditions by raising awareness and promoting a better understanding of Neurological Conditions.
- Empowering individuals from all cultures to identify their health needs, participate in the planning and delivery of services and play an active role in maintaining their own health and wellbeing.
- Promoting Neurological development and health across the life course including mental health aspects.

Strengthening Health Information Systems

- Building national capacity to collect, monitor and report on population and health care system data related to Neurological Conditions.
- Supporting development of electronic medical records with appropriate access for individuals living with Neurological Conditions.

Fostering Strategic Approaches to Research into Neurological Conditions

- Increasing the attention given to Neurological Conditions in National and Global research agendas, including access to clinical trials for treatments for Rare Disorders.
- Encouraging the use of innovative technologies such as artificial intelligence and precision medicine to consolidate currently fragmented research approaches and identify new treatment options.
- Supporting the development of the Canadian Brain Research Strategy Network long-term.

Source: *National Neurological Strategy For Canada*¹⁵⁹

The Strategy highlights the importance of reducing stigma and discrimination, promoting autonomy, and ensuring comprehensive support for individuals and caregivers. Implementing the Framework is essential to mitigating the rising burden of Neurological Conditions and improving outcomes for Canadians affected by these disorders.

While the Strategy has garnered support and outlined key steps, formal adoption and implementation by the Canadian government is still pending. If adopted, it will strongly align with the WHO's IGAP.

Ireland

Ireland developed a three-year *National Strategy & Policy for the Provision of Neuro Rehabilitation Services* from 2019 to 2021. The Strategy & Framework were aimed at enhancing Neuro Rehabilitation services by:

Outcomes

Benefits



Improving Patient Outcomes

More efficient, joined up care.

Improving Access to Specialist Rehabilitation Services

Consistent care, regardless of location.

Limiting Variation in Patient Pathway / Experience

Service designed with patients' needs at the centre understanding of how to re-access the services as the condition requires.

Decreasing The Length of Stay (LOS) In Acute Hospital Setting

Care delivered in the appropriate setting and as near to home as is family from a holistic perspective practicable.

Source: National Strategy & Policy for the Provision of Neuro-Rehabilitation Services.¹⁶⁰

To ensure that care was patient-centred, integrated, and accessible, the Strategy & Policy plan focussed on:

- Enhancing service delivery by mapping a population needs assessment and identifying gaps to inform service development needs.
- Emphasising the importance of interdisciplinary teams and coordinated care across community health organisations, acute hospitals, and rehabilitation centres.
- Building capacity within the Neuro Rehabilitation Services to ensure they could meet the demands of patients requiring individualised, goal-focused rehabilitation.
- Aligning Neuro-Rehabilitation Strategy with other National Health Policies.
- Establishing local implementation teams to oversee the development of Neuro Rehabilitation Services at the community level to ensure services were tailored to local needs and circumstances.

Other Countries

While the USA has several targeted initiatives and strategic plans addressing Neurological health, such as the National Institute of Neurological Disorders and Stroke (NINDS) Strategic Plan and National Plan to Address Alzheimer's Disease, it does not appear to have a single comprehensive national neurological strategy.

Countries in South America and Africa have integrated Neurological health into broader public health and healthcare strategies but do not appear to have adopted any standalone national frameworks.

Likewise, most European countries, outside the UK, Ireland, and Scotland, do not have dedicated national neurological care frameworks, generally incorporating neurological care into their broader healthcare policies.



Insights

- C7-I-1** There are consistent common themes throughout England's, Ireland's, Scotland's, and Canada's National Neurological Care Frameworks and similar publications.
- C7-I-2** Plans are co-designed with lived experience.
- C7-I-3** Plans emphasise a patient-centred approach, where care is tailored to patients' individual needs through shared care planning and decision-making.
- C7-I-4** Integration of services across different levels of care is key, including coordination between primary care, secondary care, specialist services, and community health services. This enables seamless care transitions and comprehensive treatment plans.
- C7-I-5** Improving access to Specialist Neurological Services is a common component. This includes increasing the availability of Neurologists, enhancing Telehealth Services, and ensuring timely referrals to Specialists for early diagnosis and treatment.
- C7-I-6** The use of interdisciplinary teams, including Neurologists, Nurses, Therapists, and Social Workers, is a priority for responding to the multifaceted needs of Neurological patients.
- C7-I-7** Investing in training and education for healthcare providers to build a skilled workforce is essential.
- C7-I-8** Raising public awareness about Neurological Conditions and reducing stigma is critical.
- C7-I-9** Ensuring equitable access to Neurological care for all population groups, including at risk and vulnerable populations and rural communities is a must.
- C7-I-10** Implementing robust data collection and monitoring systems to track outcomes, measure effectiveness, and inform policy decisions is essential.
- C7-I-11** Despite having a National Plan in place since 2005, there still significant room for improvement in the UK's response to Neurological Conditions. This is not a good sign for jurisdictions that have not yet considered a plan.

Opportunities

- C7-O-1 Dedicated Queensland Neuro Taskforce:** Form a taskforce with key sector and Government Stakeholders and people with lived experience to drive Neuro-specific actions across Queensland.
- C7-O-2 Develop Neuro Care Framework:** Provide a comprehensive approach to Neurological care across the state, focusing on enhancing diagnostic communication skills, integrating services, improving access to specialist care, developing centralised resources, and using interdisciplinary teams.

**Component 8: Benefits Of Awareness, Early
Diagnosis & Targeted Response**



Overview

While some Neurological Conditions, like Epilepsy and Multiple Sclerosis, can in some cases, be effectively treated, most have chronic, episodic, static, or progressive courses. The severity of these conditions varies from minimal to debilitating impairment, profoundly affecting individuals, their families, caregivers, and communities.

Living with a Neurological Condition is challenging enough without the added difficulty of siloed health support, facing months-long waits for brief specialist appointments, or lacking crucial information at diagnosis.

Benefits of Raising Awareness

Raising awareness about Neurological Conditions has multifaceted benefits. From improving public knowledge and reducing stigma to encouraging early diagnosis, targeted awareness campaigns have been shown to improve health outcomes and, in turn, save money.¹⁶¹

Greater awareness can lead to minimising potential modifiable risk factors.

Table 32: Benefits Of Awareness Raising

Raising Awareness of Neurological Conditions Can...

Improve health literacy and patient empowerment: by leading to better health literacy among patients and the general public. This knowledge empowers patients to take an active role in their healthcare, make informed decisions, and advocate for their needs.

Enhance early detection and diagnosis: by increasing awareness and facilitating earlier consultations and interventions, which can prevent the progression of diseases to more severe stages that require hospitalisations.

Reduce stigma: by improving the social acceptance of affected individuals and encouraging them to seek help without fear of discrimination.

Enhance quality of life: by leading to better management of symptoms and overall improved quality of life for individuals with Neurological Conditions. Knowledgeable patients and caregivers are better equipped to handle the challenges associated with these conditions.

Foster community and social benefits: by creating a more inclusive environment for individuals with Neurological Conditions.

Studies have highlighted **the potential to prevent or mitigate some Neurological Conditions**. For example, literature shows that Cardiovascular risk factors like smoking and Diabetes are linked to Stroke, Alzheimer's Disease, and

other Dementias. Brain injury, itself a Neurological Condition, is a risk factor for Alzheimer's in men and Epilepsy in both sexes. Additionally, addressing falls in the aging population can reduce the risk of Traumatic Brain and Spinal Cord Injuries.¹⁶²

While further research is needed to identify preventable risk factors for some Neurological Conditions, raising awareness has the significant potential to minimise their future impact.

Case Study

Migraine Australia recently emphasised the risks of low awareness about migraines, even among sufferers. They argue that stigma prevents many from seeking care, with over half relying solely on over-the-counter medications and unaware of the risks of medication overuse headaches (MOH). Awareness is also lacking among medical professionals, leading to non-adherence to treatment guidelines. 2022-2023 Pre-Budget Submission: *Out of the Dark*.

Benefits of Investing in Data, Information & Technology

Potential Cost Saving Benefits

Numerous research studies highlight the enormous savings to the government, communities, individuals, and families when diagnosis, treatment, rehabilitation, and care are early, effective, and timely.

A report by Economist Impact demonstrates the importance of increasing access to prevention, treatment, and rehabilitative services for Neurological Disorders² bringing significant social and economic benefits. Analysing Neurological Conditions in 11 countries (Brazil, China, Colombia, Germany, Italy, Japan, Kenya, Lebanon, Romania, United Kingdom and The United States of America), the report highlighted that the total potential savings across all countries if prevention, treatment and rehabilitation were scaled up would be:

- \$727 Billion in rehabilitation costs.
- \$911 Billion in treatment costs.
- \$2.4 Trillion in prevention costs.

Examples cited included: ¹⁶³

Neurological Condition Cost Benefit

² This was based on ten Neurological Disorders including; Stroke, Alzheimer's & other Dementias, MS, Migraine, Parkinson's Disease, Spinal Muscular Atrophy, Epilepsy, Spinal Cord Injury, Traumatic Brain Injury & Brain / Nervous System Cancers.



Multiple Sclerosis

Mainly impacting individuals during their most productive years (30's & 40's), MS causes a 15-30% decrease in employment rates, productivity, and income compared to those without the condition. Depending on the country, enhancing treatment efforts can also result in annual savings of \$1 Billion to \$12 Billion by reducing productivity losses from the baseline.

Parkinson's Disease

Expanding treatment and rehabilitation services for Parkinson's Disease in the US is projected to save \$2 Billion through treatment and \$31 Billion through rehabilitation by 2030.

Alzheimer's

40% of Parkinson's cases may be prevented or delayed with appropriate intervention. Scaling up prevention in the US would save \$863 Billion from baseline by 2030.

The use of advanced technology and the development of biomarkers and diagnostic tools are increasingly being seen as critical tools for improving early diagnosis.¹⁶⁴

- Technologies, such as Internet of Things, wearable devices, next-generation sequencing, metabolomics, and AI techniques, are seen to enhance the accuracy and efficiency of early diagnosis.
- Developing and utilising biomarkers, advanced imaging techniques, and AI-based diagnostic tools for early detection provide precise and reliable diagnosis, facilitating early intervention

Benefits of Early Diagnosis

Acting early & consistently over time holds tremendous value.

Early diagnosis offers significant personal and cost-saving benefits, as does effective, targeted, and timely treatment. One of the most powerful levers to pull is enhancing public awareness about Neurological Conditions. A practical and targeted campaign can galvanise people to seek a diagnosis, prompt them to modify how they take risks and alter their perspective on a condition that might carry a cultural stigma.

Numerous studies have highlighted the benefits of diagnosing Neurological Conditions early, from improving the effectiveness of treatments to tailoring personalised care plans.¹⁶⁵

Table 33: Key Benefits Associated with Early Detection

Early Diagnosis Can Lead To...

Improved Treatment Outcomes: By allowing for timely intervention, which can significantly enhance the effectiveness of treatments. Early-stage treatments can slow Disease progression, improve patient outcomes, and enhance the quality of life.

Better Management of Symptoms: By helping to manage symptoms more effectively. Early intervention can reduce the severity of symptoms and delay the onset of more severe stages of the Disease.



Economic Benefits: By helping prevent disease progression to more severe and costly stages. Early diagnosis can reduce overall healthcare expenses.

Enhanced Patient Care: By allowing healthcare providers to tailor treatment plans to the specific needs of patients at an early stage. This personalised approach can lead to better adherence to treatment and improved patient satisfaction.

Benefits of Effective Models of Support & Treatment

A 2021/22 My Neuro Survey of over 8,500 adults, children, and young people in the UK revealed significant support and treatment challenges faced by people with Neurological Conditions.¹⁶⁶ Key findings included:

- **Mental Wellbeing:** There is a substantial lack of mental health support for those living with Neurological Conditions.
- **Delays In Treatment:** Many patients experience delays in receiving life-changing therapies and care.
- **Information & Support At Diagnosis:** Patients often do not receive adequate information and support at diagnosis.
- **Workforce & Service Gaps:** There are insufficient workforce and services to meet the needs of the Neurological community.
- **Healthcare Professional Awareness:** Medical professionals' awareness and adherence to treatment guidelines are low.

“Living with a Neurological Condition can be a daily battle. That battle shouldn’t be made harder by a system that can mean you are turned away for mental health support, experience waits of more than a year for a few precious minutes with a specialist or don’t get the information you need when diagnosed. Forward, Together for the 1 in 6.”

Some providers, such as MND Australia, have highlighted the challenges Australians over the age of 65 with a neurological condition experience within the aged care system. They argue the system is underfunded, means-tested, and primarily



designed for age-related issues rather than disabilities. This leads to inequitable treatment, lengthy wait times, and insufficient support, often forcing seniors into financial hardship or premature residential care.

Other studies highlight problems when treatment plans focus more on the disease than the person living with it. This approach often excludes patients from important decisions about their care.¹⁶⁷

Conversely, when people are empowered to participate in service planning, they can better make more informed decisions. Additionally, when they have interdisciplinary care coordination and integrated neurological care pathways as their condition progresses, they are more likely to experience greater health outcomes.¹⁶⁸

Table 34: What Effective Models of Care Can Look Like

Effective Models of Care...

- Foster effective collaboration across public, private, and nongovernmental actors.

- Create interdisciplinary health and social care teams and networks and integrated Neurological Care Pathways across the continuum, including prevention, diagnosis, treatment, rehabilitation, and palliative care.

- Enable people with neurological conditions and their carers to make informed choices and decisions about care that meets their needs.

- Facilitate the promotion, implementation and scaling up of digital health solutions and technologies.

- Recognise and responds to the impact and complexities of comorbidities in individuals with a neurological condition and their caregivers.

- Address the extra challenges faced by at risk groups and rural patients in accessing care.

- Encourage health promoting behaviour by raising awareness of diet and exercise and removing perceived barriers that prevent people with Neurological Conditions from undertaking regular physical activity.

Effective holistic models of care and support provide benefits from better symptom management and improved mental and emotional wellbeing to reduced hospitalisation.

Case Study

Australia's first Clinical Practitioner Specialist in Multiple Sclerosis (MS), funded by MS Australia – Qld, marks a significant advancement in MS care. This role, inspired by successful models overseas and interstate, offers numerous benefits:

- **Early Intervention:** From diagnosis, the specialist initiates and maintains patients on immunotherapy, improving compliance and continuation of therapy.
- **Central Care Coordination:** Acting as a crucial link between patients, Neurologists, inpatient wards, and the community, including MS Australia – Qld, the role enhances patient care, continuity, & outcomes.
- **Expert Support & Education:** Providing timely support and education to patients, their families, and hospital staff, the specialist ensures ongoing MS-specific education, improving inpatient care and discharge planning.
- **Enhanced Case Management:** By strengthening connections between patients and health and community services, the specialist enhances case management.
- **Symptom Management:** Offering an accessible service for timely advice on symptom management and troubleshooting, the role reduces delays and the need for neurologist contact. The specialist facilitates nurse-led clinics for prompt assessment of potential relapses and symptom management.
- **Professional Leadership:** Serving as expert role models, specialists improve the knowledge and skills of healthcare workers in managing MS across the disease continuum.

MS Specialist Nurses work holistically, often at the centre of the multidisciplinary team in MS care. They require high levels of judgment, discretion, and decision-making in clinical care. They monitor and improve care standards through supervision and audits, provide skilled professional leadership, and develop MS management through teaching, research application, evidence-based practice, and support for colleagues in other disciplines.



Insights

- C8-I-1** Given the broad impacts of Neurological Conditions, the prevention and early detection are crucial for reducing the burden on individuals, communities, and healthcare systems.
- C8-I-2** If individuals do not receive timely and effective interventions from diagnosis, the impact felt on the health care system is significant.
- C8-I-3** A more holistic approach to primary care for patients that unites general practitioners, specialists, and allied health, along with access to assistive technology, is crucial for maintaining quality of life, social engagement, and independence.
- C8-I-4** Specialist planning and coordination of care, including a proactive decision-making framework, are essential components in achieving health outcomes.
- C8-I-5** Barriers to accessing care such as lack of access to specialists and lack of training for GPs exist in rural areas, make it challenging to receive specialist care and support.
- C8-I-6** Awareness campaigns for Neurological Conditions save money. By educating the public about symptoms and encouraging timely medical consultations, campaigns can reduce the burden on healthcare systems, lower emergency care costs, and improve management of Chronic Conditions.
- C8-I-7** The lack of a large-scale National or State Neurological survey makes it difficult to fully map the current gaps in the neuro service landscape.

Opportunities

- C8-O-1 Invest In Data Collection & Research:** Conduct a large-scale Neurological survey to identify current gaps and inform service delivery and planning.
- C8-O-2 Targeted Public Awareness Campaigns:** Educate the public about symptoms and encourage early diagnosis and better management of Neurological Conditions.
- C8-O-3 Innovative Communication Tools:** Develop user-friendly interfaces for interaction and support, such as a centralised gateway, to significantly enhance the quality of life for people with Neurological Conditions, and their family / carers.

10. Opportunities For Action



10. Opportunities For Action

Component 1: Prevalence Of Neurological Conditions By Condition & Cohort

- C1-O-1 Data Collection Improvement:** Prioritise financial investment, resource allocation, and coordinated data collection strategies to address gaps in gender and ethnic- specific research on the profound difference between men and women and CALD and First Nations populations living with Neurological Conditions.
- C1-O-2 Targeted Messaging:** Implement early awareness and intervention campaigns tailored to the specific needs of different demographic groups, ensuring messages resonate with all gender identities, First Nation people, and CALD groups.
- C1-O-3 Tailored Approaches:** Develop gender-specific medical treatments and preventive strategies requiring different diagnostic procedures or therapeutic approaches for men and women.
- C1-O-4 Disparity Awareness:** Plan support services with a greater understanding of the disproportionate impact on caregiver burden, loss of productivity, and higher healthcare costs across different cohorts.

Component 2: Impact Of Neurological Conditions

- C2-O-1 Coordinate Efforts:** Establish a dedicated Queensland Neuro Taskforce led by key sector and government stakeholders and people with lived experience to provide timely advice and co-designed solutions for enhancing the quality of care and support.
- C2-O-2 Develop A Neuro Care Framework:** Create a comprehensive approach to Neurological care throughout the state, focusing on providing timely, integrated, and effective responses tailored to the specific needs of different patient groups.
- C2-O-3 Educate, Promote, & Raise Awareness:** Launch a targeted collaborative campaign to educate the public about the impact of Neurological Conditions, highlighting real stories, providing critical information, and encouraging proactive steps towards better Neurological health.

Component 3: Financial Support Systems & Participation by Cohort

- C3-O-1 Improve Access to the NDIS:** Improve access to the NDIS for people diagnosed with certain Neurological Conditions to ensure early intervention support is applied at the earliest possible stage of the Disease course.
- C3-O-2 Enhanced System Integration:** Mandate the integration between aged care, healthcare, and Disability care systems to ensure coordinated service delivery and improved outcomes for people affected by Neurological Conditions, regardless of the system they access.
- C3-O-3 Enhance Data Collection:** Invest in comprehensive data systems that track detailed information on service usage and patient demographics to improve decision-making and targeted healthcare interventions.

Component 4: Map Support Gaps & Unmet Needs

- C4-O-1 Enhanced Diagnostic Communication:** Establish clear guidelines and training programs for healthcare providers to improve their communication skills and ensure patients fully understand their diagnoses and treatment options.
- C4-O-2 Integrated Mental Health Support:** Incorporate mental health services into Neurological departments by employing specialists and training staff to blend care approaches, providing comprehensive care for psychological and physical health needs.
- C4-O-3 Centralised Support Platform:** Create a digital gateway listing all Neurological support services in Queensland to simplify patient access to necessary care, make information more accessible, and reduce fragmentation.
- C4-O-4 Community-Centric Neuro Wellness Hubs:** Establish community-centric hubs, especially in rural and remote areas, to provide comprehensive resources and support services, enhancing access and community engagement while reducing service fragmentation.
- C4-O-5 Rural Neurologist Incentives:** Provide incentives for Neurologists to work in rural areas and support the adoption of Telehealth technologies, improving access to Neurological Services in underserved regions.
- C4-O-6 Navigating Support:** Establish a personalised centrally led but locally focused service that provides critical and timely over the phone or virtual support and advice for people at the point of diagnosis to help simplify the complex maze of health and support systems.



Component 5: Demographic Considerations

- C5-O-1 Improved Research & Data:** Boost investment in research that maps the similarities and differences across diverse demographic and social determinants to understand the prevalence and impact of Neurological Conditions in Queensland.
- C5-O-2 Enhanced Data Linking:** Link existing data to better identify and understand the specific needs of all populations, informing more effective and equitable healthcare strategies.
- C5-O-3 Preventative Policies:** Focus on preventive health policies, health promotion, and education that address the different burdens of Neurological Conditions across age groups and sexes.
- C5-O-4 Overall, Health Approach:** Explore interventions for Neurological Conditions that combine treatments for Comorbid Conditions, particularly for First Nations peoples.
- C5-O-5 User-Friendly CALD Supports:** Invest in culturally accessible entry points and navigation support for CALD people in Queensland with Neurological Conditions and their families.
- C5-O-6 Making Family Caregivers Visible:** Recognise caregivers' significance as part of the healthcare team and provide them comprehensive support for their mental, physical, and overall well-being.

Component 6: Neuro Response in Other States / Territories

- C6-O-1 Queensland Leadership In Neurological Care:** Develop a cross-Government and sector Neurological Care Framework as a critical pillar of Queensland's Public Health and Disability Plans, involving careful co-design with key stakeholders and incorporating the lived experiences of individuals affected by Neurological Conditions.
- C6-O-2 Leveraging NAA's Work & Insights:** Utilise the NAA's work to:
- Recognise Neurological Conditions as Chronic Diseases to ensure appropriate attention and resources.
 - Develop a coordinated and co-designed response to Neurological care.
 - Ensure quality data collection for informed decision-making and targeted interventions.



Component 7: Neuro Response Internationally

- C7-O-1 Dedicated Queensland Neuro Taskforce:** Form a taskforce with key sector and Government stakeholders and people with lived experience to drive Neuro-specific actions across Queensland.
- C7-O-2 Develop Neuro Care Framework:** Provide a comprehensive approach to Neurological care across the state, focusing on enhancing diagnostic communication skills, integrating services, improving access to specialist care, developing centralised resources, and using interdisciplinary teams.

Component 8: Benefits Of Awareness, Early Diagnosis, & Targeted Response

- C8-O-1 Invest In Data Collection & Research:** Conduct a large-scale Neurological survey to identify current gaps and inform service delivery and planning.
- C8-O-2 Targeted Public Awareness Campaigns:** Educate the public about symptoms and encourage early diagnosis and better management of Neurological Conditions.
- C8-O-3 Innovative Communication Tools:** Develop user-friendly interfaces for interaction and support, such as a centralised gateway, to significantly enhance the quality of life for people with Neurological Conditions, and their family / carers.

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