



ACI NSW Agency
for Clinical
Innovation

REPORT

Care pathways for people with neurodegenerative and neuromuscular conditions

Summary report: diagnostic exercise

ACI Neurodegenerative and Neuromuscular Conditions Working Group



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The Neurodegenerative and Neuromuscular Conditions Working Group (the Working Group) was established to provide leadership and direction in developing recommendations on how to deliver and/or enhance current and developing models of care to improve outcomes (as defined by the Institute for Healthcare Improvement Triple Aim) for people with neurodegenerative (ND) and neuromuscular (NM) conditions. These recommendations are to be considered for implementation by the co-sponsoring networks. The group includes peak bodies and service providers, experts in provision of clinical service, and representatives of the NSW Agency for Clinical Innovation Clinical Networks. This report represents a significant body of work completed by the Working Group, supported by the ACI.

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Abbreviations

Abbreviation	Description
ACI	NSW Agency for Clinical Innovation
ADHC	Ageing, Disability and Home Care
CALD	Culturally and linguistically diverse
LHD	Local health district
MND	Motor neurone disease
ND	Neurodegenerative
NM	Neuromuscular
NDIS	National Disability Insurance Scheme
NIV	Non-invasive ventilation
PBS	Pharmaceutical Benefits Scheme
RACF	Residential aged-care facility

Executive summary

This diagnostic report draws together information about care and service issues for people affected by neurodegenerative (ND) and neuromuscular (NM) conditions in NSW. There are many different ND and NM conditions, which individually are quite rare but collectively affect many people. These conditions have a significant impact and cost, for individuals, their carers and communities, and the Australian health system.

Conditions	Areas affected	Diseases
Neurodegenerative	Primarily affects neurons in the brain, resulting in progressive degeneration of nerve cells, problems with movement or mental functioning.	<ul style="list-style-type: none"> Alzheimer's disease Parkinson's disease Motor neurone disease (MND) Multiple sclerosis.
Neuromuscular	Muscles or their control.	More than 40 different types including: <ul style="list-style-type: none"> Muscular dystrophy Motor neurone disease Myopathies.

It is estimated that 35,400 people in NSW have one of the higher prevalence ND or NM conditions.^{1,2,3,4,5,6,7}

Although, by definition, rare diseases occur infrequently, it is estimated that there are approximately 7000 different rare diseases and that they affect 6–10% of our population. This equates to 1.2 million Australians.⁷ A number of the estimated 400,000 people in NSW classified as having a rare disease have ND and NM conditions.⁸

People with ND and NM conditions have complex care needs throughout their lifespan, and require support across the continuum of care: primary care, acute care, specialist services, community care, residential care and social care. Little is known about how to prevent these conditions and treatments are limited, usually disease-limiting rather than curative. Diagnosis, treatment, therapy and research are far from established and therefore require close cooperation between specialists from a wide variety of disciplines.

The demand for multidisciplinary ND and NM services will continue to rise. There are increasing rates of neurodegenerative diseases, such as Parkinson's disease, associated with the ageing population. Likewise, the prevalence of muscular dystrophy is increasing as a result of improved clinical interventions, enabling people with this condition to live well into their adult years. Additionally, the prevalence and incidence of multiple sclerosis is increasing, especially among women.

The ACI Chronic Care Network is the lead network for the development of recommendations to deliver and/or enhance current and developing models of care to improve outcomes for people with ND and NM conditions. It is advised by the Working Group, which includes experts in provision of clinical services, peak bodies and service providers that represent patients, families and carers, as well as representatives of the ACI Transition Care, Rehabilitation, Palliative Care and Respiratory Care Networks.

This report represents a significant body of work by the Working Group, supported by ACI. The report considers:

- current arrangements for delivery of care
- aspects of care and support that are effective
- the challenges and gaps that are presented through the current arrangements in service delivery
- innovative models and approaches which will support the access to and delivery of improved care to this defined population.

Consultation with experts in clinical services, consumers and carers, peak bodies and a review of available data have identified many individual aspects that are relevant to each diagnostic group. However, the overriding theme impacting on care and quality of life of ND and NM conditions is the requirement for improved coordination of services. The following components of effective coordinated care found to be in common for all NM and ND conditions include:

- clear referral pathways across the system and local health districts (LHDs) including appropriate testing and diagnostics
- timely access to a range of affordable equipment appropriate to changing levels of need, for example, respiratory support
- timely access to affordable specialist services
- communication between and across providers and organisations
- access to appropriate allied health staff
- support for the transition from paediatric to adult services.

This work will continue towards a solution design phase, identifying key themes for improvement and examples of innovative practice, to support local improvement of care pathways for people with ND and NM conditions.

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Section 1

Background

Defining neurodegenerative and neuromuscular conditions

Neurodegenerative conditions primarily affect the neurons in the brain, resulting in progressive degeneration of nerve cells, problems with movement or mental functioning. ND conditions include Alzheimer's disease, Parkinson's disease, motor neurone disease and multiple sclerosis. Alzheimer's disease as a specific condition has not been included in this report because it is a key focus of the *Framework for the integration of care for the older person with complex health needs*⁹, however, the issues raised as a result of this report will have direct relevance to this population.

Neuromuscular conditions affect the muscles or their control. There are more than 40 different types of neuromuscular conditions, including muscular dystrophy, motor neurone disease and myopathies.¹⁰ Neuromuscular diseases may be inherited or acquired, and may be present at birth or manifest in childhood or in adulthood. Life expectancy varies by disease and severity, from very short to within the normal range. Quality of life however, regardless of life expectancy, is likely to be moderately to severely impacted for several years. This creates challenges on many levels: social, emotional, physical and financial for the person and their carer and family. There are also broader economic impacts on the community at large.

At present, little is known about how to prevent ND or NM conditions, and treatments are limited. Most treatments are directed towards controlling symptoms and slowing the progression or impact of the disease process on the individual. Treatments and therapies are varied, require interventions in a range of settings, and may be directed towards managing an acute episode or deterioration; a progressive deterioration; maintenance of health; wellbeing and function in the community; end-of-life; and prevention of sentinel events (for example, pressure areas, respiratory infections and urinary tract infections). At varying time intervals, these treatments will require access to a range, and sometimes a combination, of specialist and generalist clinicians, experts, carers and counsellors, and will require integration across government, non-government and private sector organisations. The variation in the course of each condition and within conditions raises challenges for the system in service delivery. However, there are underlying commonalities described through the report which will provide focus for the future body of work to be undertaken.

Diagnostic process

In 2012, senior clinicians and the peak bodies that represent the interests of patients reported the need to improve outcomes for patients with ND and NM conditions. A scoping process supported by the ACI identified the need for a consistent approach to coordinated multidisciplinary care for adult patients with ND and NM conditions.¹¹

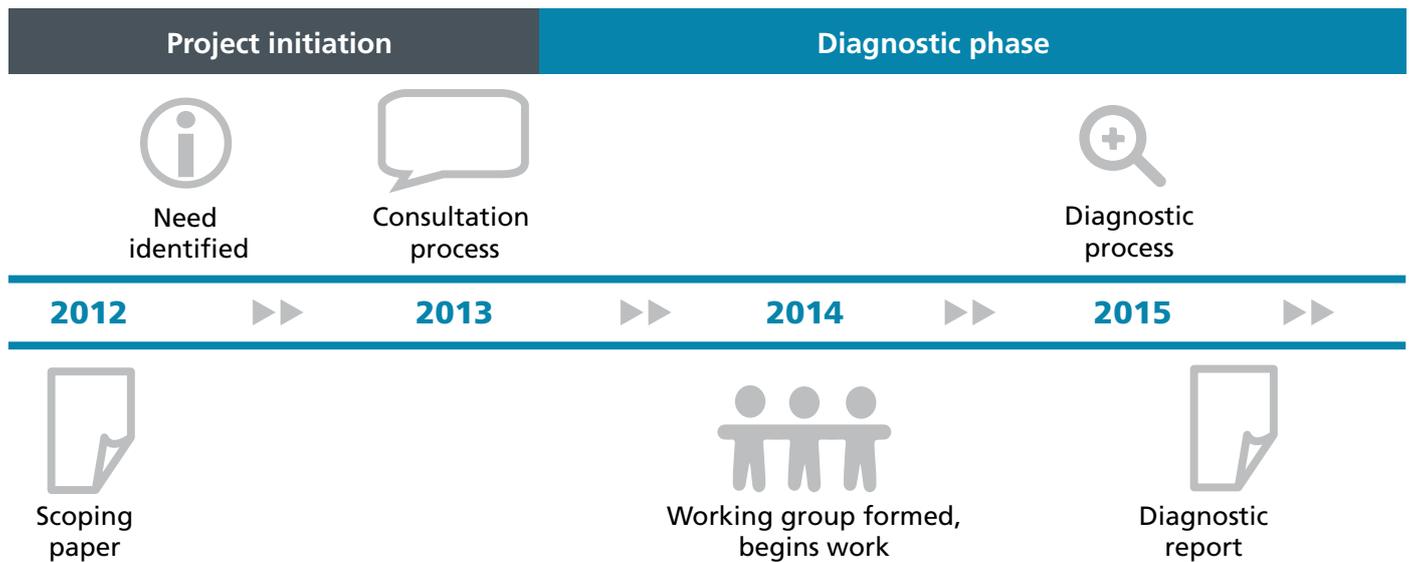


Figure 1. Neurodegenerative and neuromuscular conditions project stages

An internal scoping exercise within the ACI provided a high-level case for improving current practices for patients with ND and NM conditions. The exercise identified the key stakeholders and broadly described current services and areas of need. Challenges were identified, including:

- a lack of coordinated multidisciplinary care for adult patients with ND and NM conditions
- a lack of affordable and accessible multidisciplinary, community-focused adult services
- the need to coordinate support from specialised services.

As a result of the scoping findings, the ACI started an improvement process based on the Institute for Healthcare Improvement's Triple Aim (Figure 2). The Triple Aim describes three primary aims of healthcare: improving population health, improving patient experience and reducing per capita costs of healthcare. The Triple Aim can be used by implementation teams to ensure system interventions are cognisant of these three target outcomes of health system improvement, throughout design and improvement phases. The Working Group have referenced the Triple Aim in recognition of the complexity in designing system improvements for people with ND and NM conditions.

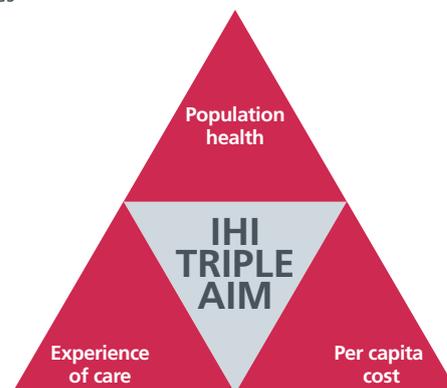


Figure 2. The IHI Triple Aim¹²

The diagnostic phase involves:

- defining and prioritising the issues and problems
- examining the underlying causes of any problems that are identified so that future recommendations to improve care address those core issues
- understanding current arrangements for the delivery of care and its impact on people affected by ND and NM conditions, their families and carers and care providers
- locating data and information sources
- reviewing evidence-based practice and innovation.

It is noted that while the Working Group is not developing a model of care, the stages outlined above of this document (Figure 1) relating to the ACI process for developing a model of care are applicable and will be followed for this project. This project is currently in its diagnostic phase.

ACI Networks

The ACI Chronic Care Network is the lead network for the development of recommendations to deliver and enhance current or developing models of care for people with ND and NM conditions and will work in close collaboration with key related ACI Networks including: Transition Care, Rehabilitation, Palliative Care and Respiratory Care. Other ACI Networks, including Nutrition, Neurosurgery, and Aged Health, have provided input to ensure a holistic approach.

Neurodegenerative and Neuromuscular Conditions Working Group

The Working Group was established to provide leadership and direction to deliver and/or enhance models of care to improve outcomes for people with ND and NM conditions. The group includes:

- peak bodies and service providers who represent patients and families affected by ND and NM conditions (Parkinson's, Huntington's, motor neurone, multiple sclerosis, muscular dystrophy, neurofibromatosis and rare diseases). Note that the Working Group's brief is not limited to these conditions. Many other conditions are included without formal representation
- experts in provision of clinical services (neurology, rehabilitation, clinical genetics, paediatrics, general practice and allied health)
- ACI Clinical Networks. The ACI Chronic Care Network is the lead network for the ND and NM conditions project. It works in collaboration with ACI's Transition Care, Palliative Care, Respiratory Care and Rehabilitation networks.

Section 2

Neurodegenerative and neuromuscular conditions in NSW

ND and NM conditions have a severe impact on the quality of a person's life, and also have profound impacts on their families. This diagnostic report draws together disease-specific information, the opinions and experience of clinicians and advocates, and information provided by people who are directly affected by ND and NM conditions, either as patients or as close family members. Further information on each of the conditions is available in the Addendum.

Parkinson's disease

Parkinson's disease is a chronic, progressive, incurable, complex and disabling neurological condition. It is a multisystem neuropsychiatric disorder in which motor and non-motor features contribute to morbidity. Patients experience tremor, rigidity and stiffness of limbs and trunk, sudden slowness and loss of spontaneous movement, and impaired balance, mobility and coordination. Parkinson's disease often leads to impaired speech and mental health issues, such as depression and anxiety. Cognition may be impaired. Other symptoms include sleep disruptions, difficulty with chewing and swallowing, respiratory infections, and urinary and constipation problems.¹³

Multiple sclerosis

Multiple sclerosis is a progressive, chronic disease of the central nervous system that affects a person's motor, sensory and cognitive functions. The cause of multiple sclerosis is unknown, but genetic and environmental factors play some role. The course is individually unpredictable. The most common form of multiple sclerosis is the relapsing-remitting type, which occurs in 85% of cases at onset. The primary progressive form of multiple sclerosis occurs in 10% of cases and is characterised by steady accumulation of disability from onset. Secondary progressive multiple sclerosis typically occurs 15 years after the onset of relapsing-remitting multiple sclerosis, with cessation or reduction of acute relapses and the commencement of steady accumulation of disability over time. Multiple sclerosis affects mobility, coordination and the respiratory system, and can have a significant cognitive impact. Other functions affected may include vision, swallowing and bladder and bowel function.

Motor neurone disease

Motor neurone disease refers to a group of diseases in which the nerve cells controlling the muscles that enable a person to move, speak, breathe and swallow undergo degeneration and die. It is a progressive, terminal neurological disease with no known cure and no effective treatment. People with motor neurone disease progressively lose the use of their limbs and their ability to speak, swallow and breathe, while their mind and senses usually remain intact.

Muscular dystrophy

Muscular dystrophy is a group of genetic and hereditary neuromuscular diseases characterised by progressive weakness and degeneration of the skeletal muscles that control movement, resulting in respiratory failure and premature death.

Huntington's disease

Huntington's disease is a hereditary neurodegenerative disorder that causes motor, cognitive and psychiatric symptoms, progressing over many years until the person dies. Each child of an affected parent has a 50% chance of developing the disease. There is currently no cure or treatment that can stop, slow or reverse the progression of the disease.

Neurofibromatosis

Neurofibromatosis is an umbrella term for a group of disorders in which tumours grow on tissue surrounding nerves. There are three different types of neurofibromatosis:

- Neurofibromatosis 1
- Neurofibromatosis 2
- Schwannomatosis.

Neurofibromatosis 1

Neurofibromatosis 1 is the most common neurological disorder caused by a single gene. Each child of an affected parent has a 50% chance of inheriting the gene and developing neurofibromatosis 1. The hallmark feature of neurofibromatosis 1 is the neurofibroma, a benign nerve sheath tumour which can appear on the skin (cutaneous), causing cosmetic disfigurement, or under the skin (subcutaneous), causing pain. Complex neurofibromas can become symptomatic and cause pain; there is also risk of malignant change. Clinicians need to be aware of differences in outcomes and management of tumours in people with neurofibromatosis 1 compared with those of tumours of similar appearance in patients without neurofibromatosis 1. For example, brainstem tumours in people with neurofibromatosis 1 are typically less aggressive than in those without neurofibromatosis 1, so may be more often conservatively managed. Also cranial radiation therapy is rarely used in people with neurofibromatosis 1 due to the high risk of secondary malignancy.

Neurofibromatosis 2

Neurofibromatosis 2 is a rare neurological genetic disorder. Affected individuals develop bilateral benign tumours (vestibular schwannomas) of the hearing nerve that cause hearing loss, balance problems and tinnitus.

Schwannomatosis

Schwannomatosis is a rare condition characterised by multiple schwannomas (benign tumours) that develop on peripheral and spinal nerves but not auditory nerves. Most cases are sporadic, with the main symptom in schwannomatosis being pain.

Rare diseases

In Australia, there is no single definition of a rare disease. A rare disease is any life-threatening or chronically debilitating disorder or condition, which, as the name suggests, is uncommon in the general population. Rare diseases typically exhibit complex symptoms and, as a result, frequently require special combined treatments.

Rare diseases are typically incurable, not preventable, life-threatening and degenerative, and they usually have no effective treatments. European data¹⁴ indicates that rare diseases as a group are characterised as follows:

- 80% have an identified genetic origin. Other rare diseases are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative
- 65% are classified as serious and debilitating
- 50% occur before the age of two years
- 50% are associated with motor, sensory or intellectual deficiency
- 30% lead to an incapacity that reduces autonomy.

Section 3

Prevalence of neurodegenerative and neuromuscular conditions in NSW

This section of the diagnostic report provides basic information and data about prevalence, mortality and morbidity rates. There is only very limited data available regarding costs and projections of caring for people with NM and ND conditions. Mostly this is limited to in-hospital care. Certainly, the costs of caring for individuals over the course of a lifetime are significant and will be borne by the individual and their family, and by all sectors of health and community services.

“ Neurological conditions affect young and old, rich and poor, men and women and people from all cultures and ethnicities... Some ND and NM conditions are life threatening, most of them severely affect people’s quality of life and many cause life-long disability... Neurological conditions are very poorly understood by the general public.

The Neurological Alliance⁸



Condition	Prevalence	People affected in NSW – estimate (NSW pop. 7,300,000)
Parkinson’s disease	283:100,000 ¹ 3400:100,000 over 55 years ¹	20,900
Multiple sclerosis ²	100:100,000	8000
Neurofibromatosis 1 ³ Neurofibromatosis 2 ³	33:100,000 3:100,000	3000
Muscular dystrophy ⁴	1:1000	7000
Motor neurone disease ⁵	7:100,000	500
Huntington’s disease ⁶	7:100,000	500
Subtotal		39,900 people

Table 1a. Prevalence of ND and NM conditions in NSW

Condition	Prevalence	People affected in NSW (estimate*)
Rare diseases ⁷ (*This data is based on European Commission data as Australian data is not available. It is unclear what % of rare diseases are ND and NM conditions.)	6000:100,000	400,000

Table 1b. Estimate of prevalence of rare diseases in NSW

An estimated 400,000 people in NSW have a rare disease; many of these are ND and NM conditions (Table 1b). The impact and cost of ND and NM conditions on the individual, the community and the Australian health system is significant.

People with ND and NM conditions vary in their length of life and intensity of care needs. Prevalence only indicates a snapshot at any one time. Some diseases, such as motor neurone disease (MND), have a rapid progression with complex needs and high rates of death, requiring intensive involvement by the healthcare team, especially allied health professionals. For example, while there may be 500 people living with MND at any one time, there are at least 233 people newly diagnosed each year and over 213 deaths.

Section 4

Perspectives of patients and carers

Living with neurodegenerative and neuromuscular conditions

Everyone in NSW who is affected by an ND or NM condition will require access to health services and necessary supports as they age. Health systems are currently better organised to address the needs of large groups of patients with similar conditions more effectively than they are to address the needs of small groups of patients with relatively rare conditions. The perspectives of a range of patients and carers are considered below to inform the diagnostic process.

ND and NM conditions create significant physical, emotional and financial burdens for patients, families and carers across the lifespan of the person with the condition. These conditions are often difficult to diagnose and complex to manage; they lead to significant disability and are incurable. The provision of timely support and clear navigation pathways through the system, whether from a specialist or non-specialist clinician or consultant expert, will help improve the experience of the person and their family as they negotiate the difficulties of living with, and managing, a chronic disability.

ND and NM conditions are typically progressive. The person with the condition will have ever-changing needs for care, assistance, equipment, investigations and, sometimes, hospitalisation. In the main, these needs are managed by the individual (and, with progression, increasingly the family or support person) and the general practitioner (GP) in consultation with specialist services. There is often insufficient support, education, equipment and respite available to assist family and carers who are looking after profoundly or progressively disabled people at home. Comprehensive care in the community is difficult to coordinate and access, with many inclusion and exclusion factors operating as barriers. For those aged under 65, respite and residential care services are not only difficult to access, but offer an inappropriate environment and staffing levels. Staff providing these services often lack specialised knowledge and skills for managing people with ND and NM conditions.

In-home care and residential respite services particularly lack the capacity to provide complex care, including palliative care, which is required as a disease progresses.

Minority and disadvantaged groups

Aboriginal population

Little is known about the Aboriginal population with NM and ND conditions. They may be cared for in the community with little access to financial and other resources to support them due to language and other cultural or religious barriers. Other options include residential aged-care facilities (RACFs) that may not have adequate cultural competence to manage this population.

The Australian Bureau of Statistics¹⁵ reports that Aboriginal people are:

- more likely than other Australians to need assistance due to a disability, health condition or ageing, and to have problems accessing services
- twice as likely to need assistance with core activities due to having a profound/core activity restriction.

Aboriginal people are more likely than other Australians to take on a caring role. Carers Australia identify the following barriers for Aboriginal carers who need access to services¹⁶:

- the carer not declaring themselves as a 'carer', based on cultural beliefs about the caring role
- lack of information about available support for carers
- socioeconomic factors that limit the capacity to seek help
- lack of availability of services
- reluctance to relocate to access services
- reluctance to use services that are considered culturally inappropriate
- over-complexity of service systems.

Culturally and linguistically diverse population

It has not been possible to isolate information about the prevalence or effects of ND and NM conditions among people from culturally and linguistically diverse (CALD) populations in NSW. However, between 25% and 30% of carers in Australia are from CALD backgrounds, with 3% of carers unable to speak English well.¹⁷ Carers Australia¹⁸ identifies the following key issues for CALD carers:

- different interpretation, or lack of awareness, of the term 'carer' and available support for carers
- lack of identification as a 'carer' by professionals, and subsequent lack of referrals, due to perceptions about the carer's role in their family
- lesser uptake of Centrelink carer payments, benefits and concessions
- problems with the cultural appropriateness of assessment processes and eligibility criteria
- lack of choice between mainstream and culturally specific carer services, such as respite, carer counselling and support groups
- concerns about the cultural appropriateness and competency of services
- lack of individual and systemic advocacy
- lack of involvement in service planning, implementation and evaluation
- lack of availability of bilingual and culturally and linguistically diverse staff
- lack of carer information and resources that have been translated into different languages
- issues relating to the quality or appropriate use of interpretation services.

Rural and remote populations

There is limited information about the prevalence of ND and NM conditions and health service usage patterns of people living outside urban centres. However, the diagnostic process and anecdotal reports suggest that access to specialist services is more challenging; the financial and other barriers associated with living in rural areas serve to amplify the experience of metropolitan people.

The lack of clear referral pathways, access to necessary allied health services, and affordable transport, aids and equipment, compounds the difficulties imposed by the condition itself, for people who live away from major centres. Specialist ND and NM services are limited or unavailable in most regional, rural and remote areas.

Many patients with ND and NM conditions travel long distances to seek care at specialist centres. The care of these patients is further complicated by restricted access to certain specialty services that exist only within a limited number of local health districts (LHDs).

People with rare diseases

The extent of health needs of patients and families living with rare diseases is not well understood or recognised by the health sector or the wider community. Difficulties in the diagnosis of rare diseases, cost and unavailability of treatment and the burden of disease all exacerbate the problems in the patients' journey.

Young people transitioning from paediatric care

Specialist neurological services for people with ND and NM conditions are generally available to the adult and paediatric population. There is insufficient support, and gaps in the services provided, for young people aged between 14 and 25 years old. The lack of holistic case management leads to preventable health problems and an increased burden for younger patients with complex needs. There is also a shortage of age-appropriate respite care and longer term disability housing.

Paediatric neuromuscular multidisciplinary clinics are well established, however, there are no multidisciplinary transitional care clinics for young people with NM disorders. Patients and their families have difficulty coordinating the complex, interrelated components of care from a range of specialist services that are often located at different sites.

Improving survival rates have increased pressure on the adult medical system. Adult physicians lack experience in caring for young adults with disorders traditionally known only to the paediatric community. Young patients often disengage from services at this point, only to return when in crisis and requiring acute care.

Section 5

Settings and types of care

Primary care

Most healthcare provided to people with ND and NM conditions starts in the primary care setting. GPs are frequently responsible for initial diagnosis, guiding access to specialist services, coordinating care, supporting the patient's journey and enabling carers. The role of GPs outside urban centres is particularly vital due to difficulties accessing specialist services and clinics. GPs require support and guidance to effectively manage a person with NM and ND conditions as they progress. Primary care providers need access to current evidence-based care pathways as well as specialist advice to implement best practice guidelines when the need arises.

People with ND and NM conditions generally first visit their GP with symptoms. GPs are frequently responsible for:

- carrying out the relevant preliminary tests and investigations to enable a diagnosis
- recognising deviations from common patterns of disease
- facilitating access to specialist services
- coordinating multidisciplinary aspects of care
- providing and interpreting information about the condition and healthcare choices
- providing holistic healthcare for other unrelated health issues
- supporting the patient's journey, enabling carers and linking to available support and community organisations.

The Working Group identified the following challenges for GP's in managing the care of patients with ND and NM conditions:

- maintaining knowledge of emergency presentations, diagnosis and management of the wide range of rare ND and NM conditions
- gaining timely access to evidence-based pathways for providing care
- obtaining specialist advice and support to implement current best practice guidelines
- gaining the breadth and extent of knowledge required
- gaining access to best practice approaches
- coordinating services.

Specialist services

People with ND and NM conditions require timely and often coordinated access to multidisciplinary specialist services that are generally provided in outpatient hospital clinics. This particularly applies to those living outside of metropolitan areas.

Clear referral pathways and patient eligibility information may not be readily available. A patient in one LHD may be unable to access specialist services that are available in another LHD. This applies to neurology, clinical genetics, surgery, respiratory, allied health, rehabilitation, pain management, oncology and palliative care services.

LHDs boundaries complicate the development of areas of clinical subspecialist expertise for rare conditions (for example, surgical and oncology management of neurofibromatosis, psychiatric support for people with Huntington's disease).

There are also issues that affect the effectiveness and sustainability of these services, including:

- a lack of holistic case management and linkage of patients to available support
- a limited pool of specialist nurses with the capacity to deliver the growing demand for specialist treatments.

Specialist multidisciplinary care

People with ND and NM disorders require multidisciplinary care to:

- maintain their quality of life
- prevent and manage early complications related to the illness
- prevent unnecessary emergency admissions to hospitals
- avoid premature/inappropriate placement in residential aged-care facilities
- prolong their life.

Significant input is required from specialist medical teams and also from allied health practitioners, including occupational therapists, physiotherapists, dieticians and speech pathologists. Clinic coordinators are also important to the provision of specialist multidisciplinary care. Lubomski's 2013 analysis of services provided to people with Parkinson's disease in Victoria found a strong positive association between the use of allied health services and patients' quality of life. Patients who could not access allied health services had a significantly lower quality of life than those who had available services.¹⁹

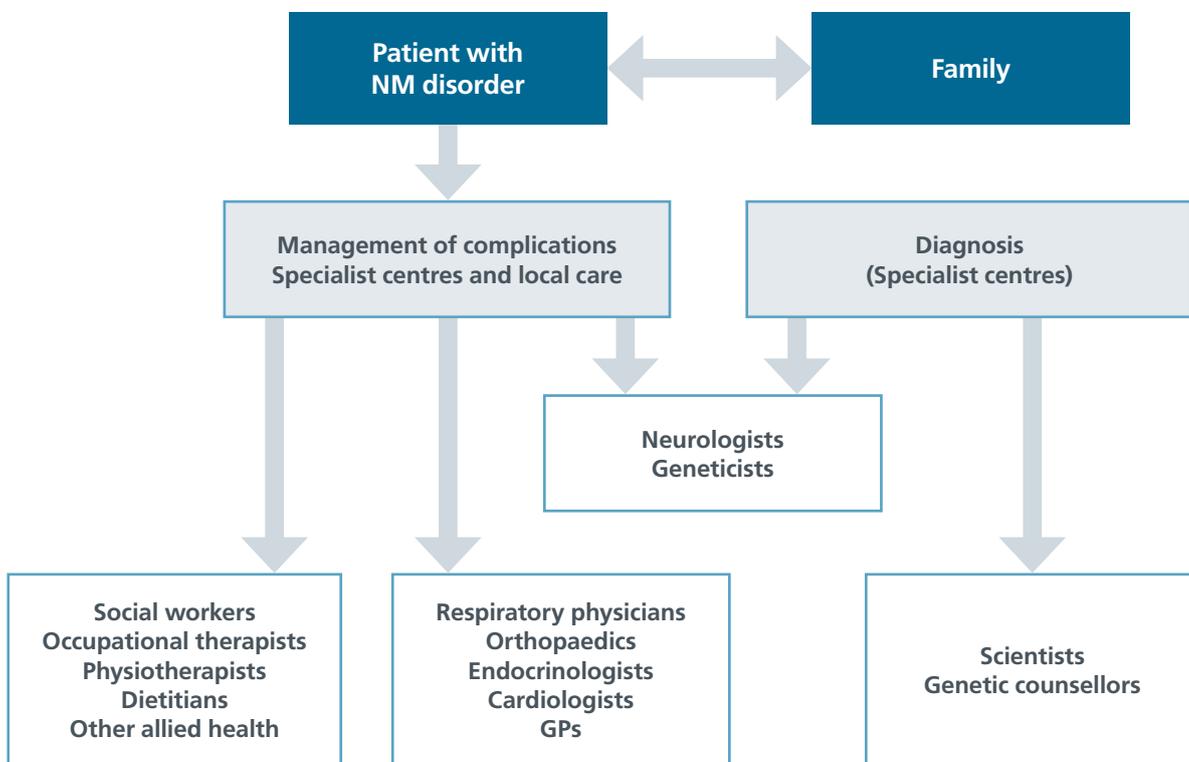


Figure 3. Clinicians involved in the care for a patient with NM disorder²⁰

Allied health services

Limited access and long delays to essential and publicly available allied health services can reduce the quality and the length of patients' lives. A specific example is lack of access to speech pathology services as a person experiences increasing difficulty with swallowing. There is a lack of holistic discharge planning after hospital stays, with not all clinicians being aware of, or referring patients to, the appropriate support teams at handover of care. Patients are frequently not referred to existing support groups, rare disease groups or genetic support services.

Acute care

ND and NM conditions represent a small portion of the primary diagnoses for admissions to acute care in NSW. Many more patients in acute care have ND and NM conditions as a secondary diagnosis.

ACI's Health Economics and Evaluation and Chronic Care teams examined NSW service use data for patients admitted in 2009–10 with a principal diagnosis of 'other' ND and NM conditions, including:

- G10 Huntington's disease
- G11.0 Early onset cerebellar ataxia
- G12.2 Motor neurone disease
- G35 Multiple sclerosis
- G60.0 Hereditary motor and sensory neuropathy
- G70.0 Gravis myasthenia
- G71.0 Muscular dystrophy
- G72.4 Inflammatory myopathy, not elsewhere classified
- M33.1 Other dermatomyositis
- M33.2 Polymyositis.

These episodes of care represented 0.2% of inpatient separations in 2009–10. The number of patients with these ND and NM conditions admitted for treatment grew by approximately 26% over the period 2007–08 to 2011–12. Half of the separations where a NM and ND code appeared in the top five codes were multiple sclerosis. Interestingly, the average length of stay fell from 6.5 days to 4.5 days over that period. This is slightly higher than the NSW acute length of stay of 3.1 days.²¹

Further details are included in the Addendum (available upon request from the ACI).

Patients admitted to acute care with a primary or secondary diagnosis of Parkinson's disease have:

- significantly longer average length of stay than controls (median seven days)
- more likelihood to be discharged from acute care to other hospitals or to nursing homes.

These patients can have protracted hospitalisations resulting from complications, difficulty accessing necessary follow-up clinic appointments, or changes in care and equipment required for discharge. Significant discharge delay can be encountered in waiting for the coordination of essential services.

Patients with Parkinson's disease, as an example, are more likely to experience serious health problems while hospitalised with the median length of stay being seven days. In addition, they are:

- five times more likely to experience delirium
- three times more likely to have adverse drug reactions and syncope
- more than twice as likely to suffer falls and fractures, dementia, gastrointestinal complications, genito-urinary infections, reduced mobility and other trauma
- less likely to be discharged to their usual place of residence, with more being transferred to other hospitals or to nursing homes.

Ensuring ND and NM patients have access to specialist outpatient clinics, essential equipment, community-based services, and in-home support will reduce the greater cost of lengthy, preventable admissions to acute care and premature admission to residential aged-care facilities.

Community and outpatient care

The bulk of services provided to people with ND and NM conditions occur in primary care and outpatient hospital clinics. Aggregated data is not available about services provided in non-admitted settings.

Community outreach team

Multidisciplinary allied health teams providing community support are available in only a few LHDs. Most of these services are not available to people with chronic ND and NM conditions and disability, and most are only provided on a time limited basis.

Residential aged care

When the person with the condition can no longer be managed at home, or is not able to access the necessary care and support requirements at home, the usual option, though often premature, is to provide that support in a residential aged-care facility.

“I'd like to highlight the plight of people who are in their 20s, 30s, 40s and 50s who are diagnosed with degenerative neuromuscular conditions.

For these people, the support and funding networks are appallingly limited, if not non-existent. Many of these people have known all their lives that there was something not quite right. They have known that they were a bit weak, couldn't run, but didn't really know what the problem was, and they have soldiered on with their lives, studying, working, marrying and so on. Now they're faced with an almost certain premature death, drastically diminishing physical capabilities, limited employment options and so on. They need advice on how to perhaps retrain into a different job or career pathway. They need advice on equipment and housing options and they need counselling about the genetic consequences of their condition. What they get instead is waiting lists and not much else.”

Ms Lesley Murphy, whose son has Duchenne muscular dystrophy²³

The complex care needs of people with many ND and NM conditions are difficult to address in RACF settings, leading to preventable admissions to acute care and reduced quality of life for patients.

Access to neurologists and other specialists is often limited in this environment. Improvements in RACF systems are needed to reduce the numbers of preventable admissions to acute care.

Information is not currently available about the full extent of ND and NM conditions in RACFs. However, 5% of permanent residents in aged-care facilities have Parkinson's disease.²²

The Working Group identified the challenges involved in providing care to ND and NM patients in RACF settings (Table 2).

Issue	Challenges
Complex needs are hard to manage in RACF	Motor neurone disease patients' complex needs cannot be met in mainstream aged care. RACFs have limited capacity to manage percutaneous endoscopic gastrostomy and non-invasive ventilation (NIV) services. RACFs lack capacity/skills to manage the feeding problems and movement disorders that occur with people with advanced Huntington's disease. Some ND and NM patients in RACF are not receiving correctly timed medications. Some patients have challenging behaviours.
Access to specialist services	Neurologists and other specialists do not provide services for people living in RACFs.
Coordination	There is insufficient coordination between specialist ND and NM services, RACFs, disability services, allied health and palliative care.
Avoidable admissions	RACFs require systems and additional workforce capacity to reduce preventable admissions to acute care.
Young people in RACF	10% of all people under the age of 50 in residential aged-care facilities have Huntington's disease. RACFs are not equipped to provide suitable care for young people. The needs of younger patients who are not cognitively impaired are different to the needs of elderly people with cognitive impairment.

Table 2. Challenges in providing care to ND and NM patients in RACF settings

“Over the past five years, Children's Hospital Westmead has transitioned fifty four complex neuromuscular patients to adult care with varying and limited success. Sydney Children's Hospital has transitioned similar numbers.”

Helen Young, Senior Staff Specialist,
Westmead Childrens' Hospital



Palliative care

Despite medical advances, many ND and NM conditions are life-limiting and patients would benefit from involvement of specialist palliative care services based on assessed need throughout the course of the disease. Specialist palliative care services support and complement the care provided across all settings, and are an essential component of a high quality and safe system of care for people who are approaching and reaching the end of their life. These specialist palliative care services provide care for patients with complex or unstable symptoms or meet other high-level needs associated with a life-limiting illness.²⁴

Working to address these assessed needs can support people and their families to remain in their preferred place of care for as long as possible. The delivery of needs-based care reduces unnecessary burden and distress on patients, their carers and families. Earlier recognition that a person may be approaching the end of their life provides patients and their families, and their clinicians, with opportunities to establish their goals of care and to plan for their changing care demands into their future.

Intersectoral approaches

The interface between the different sectors involved in the management and care of people with ND and NM conditions is unclear. Patients' access to reasonable and necessary support can be improved by better coordination between health specialties, community agencies and disability, aged-care and palliative care services.

For example, a lack of protocols and assessment processes for the interface between the National Disability Insurance Scheme (NDIS) and aged-care service providers means that older patients (over 65 years) with rapidly progressing neurological disease lack access to necessary support and services.

Transition from paediatric to adult services

ACI Transition Network collects data on children with neuromuscular conditions who are being transitioned to adult services. Transition coordinators collate an annual summary of referrals received, which indicate that approximately 30 children with neuromuscular conditions transition from paediatric services provided by Sydney Children's Hospital Network to adult services each year. At the Children's Hospital at Westmead Neurogenetics clinic, 57 neurofibromatosis 1 patients are due to transition this year. These young people have complex, multisystem problems and will have difficulty accessing limited adult services. There is no clear path or linkages for these patients at this time.

Respiratory care

Delays in assessing and initiating respiratory services lead to preventable presentations to acute care facilities for ventilatory failure. This creates additional pressure on family and carers. In addition, there is some evidence suggesting that, in some conditions, the use of non-invasive ventilation may reduce mortality. Eagle et al.²⁵ aimed to determine whether survival in patients with Duchenne muscular dystrophy had improved between 1967 and 2002, and whether the impact of NIV altered the pattern of survival. This study found that better coordinated care probably improved the chances of survival from 1960s to 1980s, but the impact of NIV has further improved this chance for those ventilated since 1990.

There are lengthy delays to access NIV support, even when patients are referred by their specialists. Bilateral positive airway pressure machines, which allow patients to leave home, are often not available. In-home provision and regular use of mechanical exsufflation/insufflation devices could have a dramatic impact on respiratory health and prevent of acute care admissions.²⁶

Section 6

Barriers to effective care and service delivery

Equipment and assistive technology

Significant delays and limited access to aids, equipment and assistive technology, including NIV and enteral feeding equipment and consumables, lead to adverse health outcomes, preventable accidents and other harms for people at home and in RACFs.

Lack of prompt, affordable access to wheelchairs and other essential aids reduces the capacity for independent living and creates unnecessary burdens on patients, caregivers and other support services. Lack of timely access to equipment and assistive technology is particularly relevant in rural and regional areas.

Pauline is 67 and has had MND for three years. She has been in a wheelchair for two years and is having trouble accessing assistive technology to assist with opening doors and cupboards. What she requires is 'smart technology', on loan until this is no longer a feasible option. The independence she would gain would let her husband leave her for a few hours at a time.

In-home care

Lack of prompt access to personal care, respite, end-of-life care and domestic help leads to preventable admissions to tertiary healthcare and increases burdens on carers. There is growing inequality in access to in-home community support services. For the people aged over 65 years, the inability to access necessary services to remain at home become more pronounced.

Joseph is 69 and has Parkinson's disease. He has significant rigidity and is difficult to move. His wife is not able to access sufficient care to assist her to manage morning and evening activities of daily living, including dressing, bathing and toileting. She is considering nursing home admission, as she can no longer cope without support.

Specialist clinics

Delays between the onset of symptoms and access to specialist assessment and treatment lead to preventable harm to patients and avoidable admissions to tertiary care facilities.

There is almost no dedicated funding for specialist ND and NM clinics, case coordination or multidisciplinary teams. Specialist ND and NM clinics rely on resources provided from other sources, including research grants, pharmaceutical companies, non-government organisations and charitable groups. Service coordination remains unfunded. Coordinators may be sourced and funded through non-governmental organisations.

The funding available to support specialist services, such as for Huntington's disease at Westmead Hospital, is rare and frequently relies on advocacy and service usage data to justify the ongoing need for the service.

Future funding for ND and NM conditions is currently unclear. The implications of NDIS funding arrangements and ongoing eligibility to services for patients with episodic conditions (such as multiple sclerosis) are uncertain. There is also doubt about the ongoing funding of peak bodies that represent the interests of people affected by ND and NM conditions, casting uncertainty on the ongoing viability of core services provided for patients.

John has multiple sclerosis and has recently experienced difficulty with swallowing. He has lost several kilos and has developed pressure ulcers on his buttocks. He urgently requires review by a specialist multidisciplinary team to address seating, swallowing, and bladder and bowel aspects, which are confounding the development of his pressure area.

Access to regular assessment and monitoring in hospital or outpatient settings

Early identification and management of ND and NM inpatients who are at risk of complications will improve patient outcomes and reduce length of stay. This includes gait and balance assessments, falls prevention strategies, respiratory monitoring, pressure area prevention and management, swallowing and speech therapy reviews, nutritional and dietary support, education on common adverse drug events and timely administration of medication.

Francis is 35 and has muscular dystrophy. He has been troubled recently by increasing difficulty breathing. He requires immediate respiratory monitoring to determine his respiratory support requirement to keep him out of hospital.

Transport

The lack of accessible, affordable transport reduces patients' capacity to access treatment services and live independently. Disability access can be an issue on public transport and on hospital campuses, which often have limited access for patient drop-off and pick-up. Problems are compounded when health services are dispersed across different locations.

Workforce capacity and capability

Significant knowledge and skills gaps exist across all disciplines in the continuum of care. Clinicians and care workers require support, training and knowledge to be able to provide the best care to people with NM and ND conditions.

GPs, in particular, would benefit from: an improved knowledge of emergency presentations, diagnosis and management of the wide range of ND and NM conditions; access to evidence-based pathways for providing care; specialist advice; and support to implement current best practice guidelines.

Treatment affordability

Treatments and services for ND and NM conditions are increasingly costly, and may be prohibitive for patients and families, for example:

- the cost of additional care at home is prohibitive for many
- drugs listed on the Pharmaceutical Benefits Scheme (PBS) can be inaccessible when the consumables required to administer those medications, such as injections and pumps, are not also listed
- medications such as corticosteroids are not listed on the PBS
- orthopaedic surgical procedures to correct complications such as scoliosis and spinal fusion for people with muscular dystrophy and neurofibromatosis are expensive and frequently only available to the privately insured
- specific treatment for disfiguring neurocutaneous manifestations of neurofibromatosis 1, or deep brain stimulation for Parkinson's disease, are examples of treatments that are often unavailable in the public system
- an electric wheelchair with modifications to enable independent living may cost in excess of \$10,000.

Section 7

Common issues

The diagnostic process identified a number of issues with care and the experiences of people with ND and NM conditions. Common themes extend across all the diagnostic groups; they relate to the necessity to improve the coordination and availability of services and support. People with ND and NM conditions need:

- accessible and affordable care and support that is tailored to the individual regardless of their diagnosis, and is respectful of the person's needs, values and preferences, including the transition years between 14 and 25
- coordinated care across all levels of the health and community sector
- access to equipment appropriate to the person's needs, for example, an electric wheelchair or non-invasive ventilation as the requirement for respiratory support changes
- access to appropriate specialist and allied health support in the community
- respite, clinical and emotional support integrated with palliative care options, as required
- clinicians to access accurate information about the disease process and available support
- their carers and family members to be supported as part of the process of delivering care to the person with the condition
- appropriate information, training and support to be provided to clinicians and carers working with this group of patients
- the difficulties of receiving age-appropriate and condition specific care in residential aged-care facilities to be addressed
- easy access to services across and between local health districts.

Section 8

Approaches that strengthen coordinated care

The Working Group has identified services or trial approaches that strengthen holistic care and have been successful in overcoming some of the challenges identified.

Multidisciplinary specialist care/clinics

There are several, though isolated, examples of successful multidisciplinary specialist services established within hospital settings. The services have usually been established historically, located within an LHD where there is a specialist, or group of specialists with an interest in that area. They may or may not have the full team of allied health members required as part of the team. Table 3 identifies a range of such clinics.

Hospital/Facility	Clinic	Service
Concord Hospital	Parkinson's and Movement Disorders Clinic	Multidisciplinary service accessed via GP referral. The waiting list for new patients is 6–8 months.
War Memorial Rehabilitation Hospital	Parkinson's Disease Clinic	Conducted monthly by a geriatrician. Allied health staff are also available.
Westmead Hospital	Parkinson's Disease Clinic	Conducted by neurologists and Parkinson's disease specialists. There is limited access to allied health.
	Multiple Sclerosis Clinic	An MS Complex Care Clinic for new patients (run in conjunction with St Joseph's Hospital) and a Neuroimmunology Clinic.
	Huntington's Disease Clinic	Multidisciplinary with outreach support.
Royal North Shore Hospital	Movement Disorders Clinic	Monthly clinic that includes medical, nursing and counselling services to optimise and coordinate treatment; provide advanced therapy options, support and make referrals to appropriate allied health and community services. The waiting list for new patients is 13 months.
	Neuromuscular Clinic	There is a 6 month waiting list for new patients to attend the weekly NM Clinic.
	Clinical Genetics Neurofibromatosis Clinic	Service provides diagnostics, genetic testing, reproductive planning, surveillance and management.
Gosford Hospital	Movement Disorders Clinic	Staff specialist, Parkinson's NSW counsellor on staff.
	Community Outreach Team	Community-based allied health team working within the Central Coast LHD.
John Hunter Hospital	Movement Disorders Clinic	Run by Parkinson's disease nurse specialist.
	Newcastle Huntington's Disease Service	Has one full-time social worker based at Hunter Genetics who is responsible for people with Huntington's disease and their families and for predictive testing in the Hunter New England LHD. He has a very large case load. People with Huntington's disease can also see a neurologist, who has a neurology clinic at John Hunter Hospital and a psychiatrist at John Hunter.
	Rankin Park Centre Day Hospital	Conducts a multidisciplinary education program.
	Royal Newcastle Centre, Multiple Sclerosis Clinic, Department of Neurology	Operates three days per week. Multiple sclerosis clinical nurse consultants (CNCs) are available throughout the week. Bulk billing is available for all clinic appointments.

Hospital/Facility	Clinic	Service
Dubbo Medical and Allied Health Group	Multidisciplinary Neurology Clinic	Runs for two days every six weeks.
St Joseph's Hospital, Auburn	Multidisciplinary Motor Neurone Disease Clinic	The Inpatient Unit includes six state hospital inpatient beds: two beds in Medical Rehabilitation Unit and four beds in Huntington's Disease Behavioural Management Unit. It also has a 14-bed residential care facility for Huntington's disease patients.
	Medical Rehabilitation Unit	Provides assessment, rehabilitation and respite. Upon discharge, there is a handover back to the person's Huntington's disease keyworker. These beds: <ul style="list-style-type: none"> • provide rural patients with access to specialist services • free-up acute hospital beds (for example, admission following multiple falls) • prevent other acute health service usage by improving the functional status of people with Huntington's disease.
	Behaviour Management Unit	Admission is via the psychiatric team. Acute psychiatric ward admissions can last as long as 6–24 months, due to the complex interplay of psychiatric, behavioural and physical problems and lack of local medical input specific to Huntington's disease. The behavioural unit aims to prevent acute psychiatric ward admission, and to relocate people with Huntington's disease and behavioural problems from acute psychiatric wards to a more appropriate setting.
	Residential Care	This facility caters for only a fraction of people with Huntington's disease. Due to the high demand, whenever a bed becomes available, priority is given the youngest person with Huntington's disease who is able to move into the bed immediately.
Royal Prince Alfred Hospital	Multiple Sclerosis and Motor Neurone Disease Clinic	The weekly clinic is a multidisciplinary bulk billing service; a joint venture between the Brain and Mind Research Institute and Multiple Sclerosis NSW. Staff includes neurologists, multiple sclerosis CNCs, continence advisors and a multiple sclerosis physiotherapist.
Prince of Wales Hospital	Multiple Sclerosis Clinic	Weekly clinic, bulk billing for all clinic appointments.
Liverpool Hospital	Multiple Sclerosis Clinic, Neurology Department	Available throughout the week. Medical clinics operates on Wednesday and Thursday mornings. Bulk billing is available for all clinic appointments. Motor Neurone Clinic also offered.
Calvary Health Care, Kogarah	Motor Neurone Disease Service	Has dedicated palliative care and rehabilitation staffing (inpatient and outpatient). No neurologist available.
Children's Hospital at Westmead	Neurogenetics and Neuromuscular Clinic	Services for children and young people with disorders affecting nerves and muscles. Operated in conjunction with the CHW Rehabilitation Department.

Table 3. Multidisciplinary specialist services

Community information providing care pathways

Patient advocacy groups, including Multiple Sclerosis Australia, Parkinson's NSW, the Motor Neurone Disease Association NSW, Huntington's NSW, Muscular Dystrophy NSW and Children's Tumour Foundation, provide information services that link people to available services, crisis supports and information for that specific condition. There is no centralised source of information about ND and NM conditions in NSW, and many services are only provided to those people having the identified condition. Consumers and clinicians have identified that a centralised information centre would be helpful. The Neurological Council of WA²⁸ service is an example of a service that does provides information about the full range of services for a wide range of neurological disorders. This includes hospital services and patient and carer support.

The European Project for Rare Diseases²⁷, funded by the European Commission, has recently developed a plan that will establish a single overarching advocacy group for rare diseases and facilitate collaboration between patient advocacy groups in European countries, the pharmaceutical industry and academic researchers.

Systems that strengthen primary care

Intersectoral collaboration across the disability, aged-care, primary care, rehabilitation and acute care sectors is a key element that can facilitate improved service provision for people with a NM and ND conditions. The NSW government has recently introduced a \$120 million strategy to integrate care. *The Integrated care strategy 2014–2017 information sheet*²⁹ has coordination of care as its overarching objective. Integrated care can be achieved through a number of mechanisms including the following:

1. GP support and development is provided through several of the NGOs. For example, there are a number of online training tools available for GPs and allied health staff working in the community. Some of these are:
 - Motor Neurone Disease: *MND aware* training modules
MNDcare offers training in capacity building for health and community care professionals including community, home care, disability and aged-care workers, case managers, allied health and palliative care professionals
<http://www.mndcare.net.au/Home.aspx>
 - Motor Neurone Disease: *Aspects of care for the primary health care team*
This publication provides guidance for general practitioners who have a patient with MND in their care.
<http://www.mndaust.asn.au/Documents/Information-resources/MND-Aspects-of-care-for-the-primary-health-care-te.aspx>
 - Motor Neurone Disease Australia
<http://www.mndnsw.asn.au>
 - The *General practitioners guide to Parkinson's disease*
This is a six hour online educational course designed to help GPs address the issues of most concern when confronted with a patient with Parkinson's disease. This training is promoted through Parkinson's Australia and the Australian College of Rural and Remote Medicine.
<https://www.acrrm.org.au/subscribers/parkinsons/login>

- Therapeutic guidelines and best practice standards are helpful in guiding care for rare conditions. Some examples include:
 - The *Australian neurological therapeutic guidelines 2011*. This guideline includes flow charts for managing neuromuscular disorders.
<https://tgldcdp.tg.org.au/guideLine?guidelinePage=Neurology&frompage+books>
 - The Australasian Neuromuscular Network provides standards of clinical care for a range of NM conditions. It aims for excellence in diagnostic methods and clinical management, access to clinical trials and new therapies.
<http://www.ann.org.au/standards-of-care/>
2. E-health secure messaging facilitates communication and a common approach to care across all aspects of the system. However, this technology is now only sporadically available across the state.
 3. Community outreach teams, as available through the Central Coast LHD, provide specialist follow-up for neurological conditions, including physiotherapy, occupational therapy and speech pathology. The Central Coast Community Outreach Team provides responsive support to people with NM and ND conditions, and supports the person to manage the condition in their own home.
 4. A Parkinson's specialist nursing program is available in the Shoalhaven. This is a trial program, but has provided evidence that community-based Parkinson's disease nurses can work well with this client group. These nurses provide follow-up in the home and liaise with appropriate health professionals, especially as the disease progresses and further and ongoing management and intervention are required (particularly for people in rural/remote areas where access to services is limited).
 5. Telehealth has been available for many years but has not been well adopted. This is because the systems available do not facilitate point-of-care access to specialist services in an accessible format. Telehealth has the potential to address many of the barriers, but would require service agreements and innovative funding models. An successful telehealth example is the multiple sclerosis project in which the Brain and Mind and Research Institute is providing telehealth support to the Dubbo School of Rural Health.
 6. Multiple Sclerosis NSW provides specialist programs to people with multiple sclerosis, their families, carers, friends and healthcare professionals through a network of centres, support groups and health services. The range of services available address many of the aspects outlined in this report. Services include:
 - MS Connect: tailored information and education on living with multiple sclerosis, diagnosis, treatment options, digital library and peer support
 - MS Advisor: links to local services, crisis supports, symptom management, clinical hotline
 - MS Wellbeing: early interventions to maintain or regain employment, wellbeing consultation, financial planning, webinars and conferences
 - MS@Home: practical support to remain at home, attendant care, in-home respite and advanced care planning
 - MS Residential: around the clock care, permanent shared accommodation and out-of-home respite.

Systems that promote access to essential aids and equipment

Timely access to essential equipment (including assistive technology, mobility aids, respiratory and nutrition equipment) is critical for the person living with NM and ND conditions. An example where this has been successfully implemented is the Victorian Respiratory Support Service. This organisation provides services to adults with a chronic respiratory failure including home visits around the state and provision of equipment including batteries and second machines in case of breakdowns.

FlexEquip is funded by Motor Neurone Disease NSW with some non-recurrent funding from Ageing, Disability and Home Care (ADHC). FlexEquip assists adults with rapidly progressive neurological conditions, including motor neurone disease, multiple sclerosis and muscular dystrophy, to access equipment to meet their short-term needs.

Enable NSW is an equipment loan and provision service available to residents of NSW, however, there are long waiting times and many exclusion criteria.

Access to respite

FlexiRest NSW funds a range of respite-related services either in or out of the home for people with progressive neurological disorders including multiple sclerosis, motor neurone disease and muscular dystrophy. It is funded by ADHC.

For Huntington's disease, periodic or crisis admission to the Behavioural Management Unit is possible and accessed through the St Joseph's and Westmead Hospital psychiatric team. Acute psychiatric ward admissions are possible for 6–24 months. The complex interplay of psychiatric, behavioural and physical problems, combined with a lack of local medical input specific to Huntington's disease, make lengthy admissions a necessity. The behavioural unit aims to prevent acute psychiatric ward admission, and to relocate people with Huntington's disease with behavioural problems from acute psychiatric wards to a more appropriate setting.

Specialist residential care

People with Huntington's disease may become very complex and difficult to manage in the home environment, and even within a residential aged-care facility. Specialist units where the staff are trained to manage these patients are important. The RACF at St Joseph's caters for only a fraction of people with Huntington's disease. Due to the high demand, whenever a bed becomes available, priority is given the youngest person with Huntington's disease who is able to move into that bed immediately.

Peer and carer support

It has been identified that the carers of people who have NM and ND conditions require ongoing support. Some examples that have been successfully implemented follow.

- Brainlink Victoria provides programs for families and friends of people living with progressive neurological diseases including multiple sclerosis, Parkinson's disease, muscular dystrophy, motor neurone disease and Huntington's disease.
- Motor Neurone Disease Family Support Regional Advisor service has nine part-time advisors who provide people with MND with information, support, coordination, advocacy and education. They liaise with GPs, MND multidisciplinary clinics/services and assist with access to other available services. Each regional advisor has a case load of 50–60 people, so there is limited capacity to provide case coordination.

Adult retreats and support groups are available through the organisations such as Northcott and are particularly relevant for parents in regional areas who lack access to other services.

Transition from paediatric care

Transition support for those aged between 14 and 25 is difficult to access across the system. In the last 10 years, the Spina Bifida Adult Resource Team has been introduced to provide case management and coordination to assist in the transition from paediatric to adult care. Specific recreation and other services are offered to this age group through a range of organisations. One example is the Duke of Edinburgh's Award program run by Muscular Dystrophy NSW, which provides support to young people aged 14–25 with muscular dystrophy to achieve the Duke of Edinburgh Award.

Palliative care

The Victorian Motor Neurone Disease Pathway Project provides facilitated access to palliative care.

Section 9

Next steps in the diagnostic process

The diagnostic stage has:

- defined key issues and problems affecting services for people with ND and NM conditions, their families and carers
- located data and information sources
- reviewed evidence-based practice and innovations
- identified current arrangements for the delivery of care.

Setting priorities

The Working Group will prioritise the issues and problems affecting people with ND and NM conditions in the next phase. Priority-setting will involve examination of aspects related to coordination of care in the following areas for people with ND and NM conditions:

- clear referral pathways across the system and LHDs, including appropriate testing and diagnostics
- timely access to a range of affordable equipment appropriate to changing levels of need
- timely access to affordable specialist services, including allied health and nursing
- communication between and across providers and organisations
- access to appropriate allied health staff
- support to transition from paediatric to adult services.

Section 10

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