



AUSTRALIA

**Multiple  
Sclerosis  
Specialist  
Nurses in  
Australia  
2017**

# Contents

<b>Foreword</b>	3
<b>Executive Summary</b>	4
<b>Introduction</b>	6
<b>1. DEFINING THE NEED AND DEMAND FOR SPECIALIST NURSING IN MS</b>	8
1.1 Multiple Sclerosis - A chronic disease	8
1.2 MS Prevalence rates in Australia	9
1.3 Disease Burden and Economic impact of MS	11
<b>2. DEFINING THE ROLE OF THE MS SPECIALIST NURSE (MSSN)</b>	13
2.1 Domains of MS Specialist Nursing Practice	13
2.2 Clinical Knowledge and Practice	14
2.3 Leadership, Teamwork and Collaboration	21
2.4 Professional Development and Research	23
2.5 Legal and Ethical Practice	24
<b>3. DEFINING THE CURRENT MS SPECIALIST NURSING WORKFORCE IN AUSTRALIA</b>	25
3.1 Models of Employment and Funding	26
3.2 Workforce Data	27
3.3 Key Responsibilities and Training	28
3.4 Defining a sustainable case load	29
<b>REFERENCES</b>	31
<b>ACKNOWLEDGEMENTS</b>	35

# Foreword



Multiple Sclerosis Specialist Nurses (MSSNs) are an established and essential part of the multidisciplinary team of specialist health professionals supporting people with multiple sclerosis (MS). They play a key role in information and advice to patients, family and carers, at the point of diagnosis and ongoing.

MSSNs provide holistic and specialist support in symptom management and are the key support that assists the patient and their family to navigate a complex number of service systems (health, disability, community and aged care), in order to access the right support at the right time. They work closely with medical staff in providing practical and individualised information for patients to make informed choices on treatment options best suited to their MS and lifestyle. They also assist with safety and monitoring reporting which is crucial to avoid serious adverse reactions especially in respect to several of the newer disease modifying therapies.

Employing specialist nurses to manage the requirements of patients living with chronic conditions makes economic sense. There is a strong foundation of international and Australian research to support this and it is no less true for MSSNs.

In 2017, a group of key stakeholders commenced a project, to establish an evidence base to support advocacy and lobbying efforts that hope to achieve increased funding for these specialist MS nurses in Australia. This report summarises the findings of the initial six month project phase, and highlights what we have learned so far about the current Australian MS Specialist Nursing workforce, what rigour exists internationally around these specialist roles, and how MSSNs currently meet Australian demand.

The report was a team effort. Our intended audience is first and foremost the people represented by our project advisory group: Neurologists, MS Nurses and other MS health specialists, MS Research Australia and people with MS who have asked us to prioritise this advocacy campaign. The report will also be provided to policy and funding bodies, to use the information within to inform their own future funding priorities and models of care.

It is our ongoing commitment, as the peak body for people with MS in Australia, to fully understand the needs of people with MS, and to continue to advocate and lobby for greater access to specialist services, knowing that the support provided by MSSNs makes a real difference to the lives of people living with this disease.

**Deidre Mackechnie**

Chief Executive Officer  
**Multiple Sclerosis Australia**

# Executive Summary

## BACKGROUND

### Key Issues:

- Stakeholders have reported a reduction in numbers of MS Nurses in Australia.
- Inequity of access to appropriate MSSN support is a key issue for people affected by MS but also within the multidisciplinary teams that support this cohort e.g. Neurologists.
- Initial investigations through a scoping project in 2016 confirmed no baseline information, other than anecdotal observations, to provide an evidence base to inform advocacy campaigns, funding policy changes or service improvements in Australia.
- International papers and studies highlighted the contribution of specialist nurses (i.e. breast cancer, diabetes, cardiac and importantly MS specialist nursing) within the health sector, but none within an Australian context.

The project, *'Multiple Sclerosis Specialist Nurses in Australia'* seeks to create an evidence-based business case to support a successful advocacy campaign for sustainable and increased funding for MSSNs in Australia by:

- Increasing our understanding of the current MSSN workforce data in Australia;
- Demonstrating the economic and consumer value of employing MSSNs;
- Developing and implementing a care pathway in emergency departments for patients presenting symptoms of MS, including exacerbation;
- Effectively lobbying and advocating for increased and sustainable funding for MSSNs in Australia; and
- Lobbying for the establishment of a national register for people diagnosed with MS that can be accessed and used by specialists, hospitals and general practitioners

Phase one of this project, aims to increase our understanding of the current MSSN workforce data in Australia, including national funding differences, service models, workload and the level of access for people affected by MS.

Stakeholder engagement resulted in the establishment of a project advisory committee, including:

- Multiple Sclerosis Australia (MSA) - Project Sponsor, MS Research Australia, MS Nurses Australia (MSNA), MS Health Professionals Network (MSHPN), Australian and New Zealand Association of Neurologists (ANZAN) and two consumer representatives.

# Results Achieved during this first phase of the project:

This Report, summarising the first phase of this project sets out the current demand and rationale for employing MSSNs in Australia. It refers to the prevalence of people with MS in Australia, the burden of this disease to both community and individuals, and highlights the extensive research available to demonstrate that MS specialist nurses are key health care professionals for people living with MS, within the multidisciplinary specialist network associated with this disease.

The Report also shares the results of the first ever MSSN survey completed in Australia that shows the MSSN prevalence, location, workforce data and possible variables to consider in estimating a sustainable workforce for this skilled profession.

The report consists of the following parts:

- A summary of the demand for MSSNs in Australia, referring to prevalence and burden of disease data.
- A review of the available and relevant international literature, to provide an evidence base that delineates the role of the MSSN from that of other more generic or neurology nurses, and make explicit the benefit of employing MSSNs as part of a multidisciplinary specialist MS Team.
- The outcomes of the first self-report Australian MSSN survey, completed by 88 nurses. Not all survey respondents are currently employed as MSSNs. Some either work directly with people with MS or are members of the respective peak organisations for MSSNs. This survey tool was distributed by MSNA and MSHPN from mid-March to 31 May 2017.
- Results show that:
  - 84% of respondents are based in metropolitan areas (population size >100,000) and 16% in rural areas (population size between 10,000 – 99,000);
  - The majority of respondents were employed in hospital settings and over 68% of all patients were seen within a hospital setting, and 20% within MS Clinics;
  - Two thirds of respondents were employed on a part-time basis managing a caseload of between 100-500 patients with MS, with about a third of respondents indicating that they responded to urgent patient issues after hours;
  - A third of respondents were employed within a research capacity;
  - 22 respondents have completed the MS Nurse International Certification Board (MSNICB) examination; and
  - There are currently no MSSNs in the ACT or the Northern Territory.

While the first phase of the project increased our general understanding of the potential MSSN workforce against prevalence data in Australia, it also shares a compelling rationale for employing MSSNs within a multi-disciplinary network associated with this disease. This message, with the aid of this Report, will be shared widely with those in decision making roles who could influence future policy and funding opportunities.

The case for greater MS specialist nurse services is strong. More data is however needed to provide a convincing, evidence-based economic value proposition to funding bodies that will highlight the value of training and employing additional MSSNs in Australia and how this benefits patient outcomes.

Our next suggested steps, reliant on funding availability, are to continue the following research activities:

- Development, user testing and administration of patient survey(s) to gauge patient expectations, satisfaction and perceived outcomes of support from MSSNs in Australia;
- Interviews and possible workshops with a MSSN working group in Australia to develop productivity and quality evaluation measurement tools for a nurse-led service evaluation project;
- Training and support to MSSNs to use a range of data tools developed in various health settings.
- Development, distribution and aggregation of a second follow-up self-reporting MSSN survey to all MSSNs;
- Information and education resources to improve access to specialist MS health care professionals; and
- Development and evaluation of a pilot agreed care pathway for people with MS presenting at an emergency department.

It is our hope that this document will lay the foundations for informed discussions with funding bodies about the critical value of MSSNs to patient outcomes of those living with MS.

# Introduction

The Multiple Sclerosis Australia (MSA) advocacy strategy, underpinned by our Strategic Goals, Principles of Best Practice and detailed in the *MSA Strategy 2016-2020*, rests on a core premise: to fully understand the needs of people affected by multiple sclerosis and to keep those affected by this condition at the very heart of our work – a focal point at every level of our organisation.

To this end, the Centre for Community-Driven Research (CCDR), Sanofi Genzyme Australia and MSA collaborated on a '*Multiple Sclerosis Program of Work*' (Holliday et al. 2016) to understand how clinicians' decision-making about treatment and care options relate to patient value and preferences. The study results suggested that patients noted overall that they were more comfortable talking with Multiple Sclerosis Specialist Nurses (MSSNs) about their treatment and care options, than any other medical professional or clinician. Based on these patient-identified needs, the report concluded that a key priority and patient-driven solution was to "investigate the role of the MS Nurse and models of care appropriate for MS patients", in order to improve access (p. ii).

Through feedback from people with MS directly to MSA, and via Multiple Sclerosis Research Australia, MSA also received a number of requests from key stakeholders throughout the MS community, including neurologists, MS Nurses Australia (MSNA) and people with MS to assist in securing or improving funding for MSSNs in Australia.

Over the last two decades, multiple sclerosis service delivery organisations based in Australian States and Territories, hospitals (public and private) and other health entities have funded and employed MSSNs to work in a range of settings, roles and service models. These include as research coordinators for clinical trials and research initiatives, community specialist nurses, specialist neurology MS Clinics and as nurse/consultants or coordinators within individual MS organisations.

MSA was made aware that previous funding for MSSNs had 'dried up' due to external changes in existing funding sources. These included the cessation of block funding, the National Disability Insurance Scheme<sup>1</sup> and changes to the funding relationship with pharmaceutical

companies<sup>2</sup>. State and Territory MS organisations have also had a previously high reliance on fundraising dollars to subsidise services and support offered in-kind. The fundraising space has become highly competitive and within the current economic climate, this funding source has substantially reduced for some MS organisations.

Over the past three years, these external factors have resulted in deficit cash flows and reserves for MS Organisations, and thus of overall funding available for service offerings. Transition to this new environment has driven subsequent service, model and workforce re-design and the ensuing loss of funded positions or changes to the responsibilities of the remaining MSSNs.

Anecdotal evidence indicates that there are resulting gaps in the provision of comprehensive access to MS specialist nursing services across Australia, for people with MS. People with MS directly approached MSA and MS Research Australia, sharing their own patient experiences, and their inability to cope with the complexity of MS treatments without access to and support from MSSNs. They also highlighted that some treatments require ongoing monitoring, close care and the involvement of a specialist multidisciplinary team of which the MSSN is a key part.

Neurologists highlighted that MSSNs are particularly valuable in trial coordination, patient advice and support, data collation, risk management and supporting MS clinics. With the advancements in disease modifying therapies, nurses now also assist with essential and required risk management/monitoring - especially in relation to new oral agents and the more potent monoclonal antibodies.

Significantly, MS Specialist Nurses also provide articulated pathways of diagnosis, treatment, care and support – providing both preventative and crisis interventions when episodic relapses may arise which often precludes the need for patients to present to emergency departments.

In summary, this feedback highlighted that people affected by MS are experiencing gaps in access to MSSNs and that anecdotally, more people are accessing emergency departments.

<sup>1</sup> Further details: <https://www.ndis.gov.au>

<sup>2</sup> Further details: <https://medicinesaustralia.com.au>

More broadly, the sector is experiencing a critical skills drain.

This project is the culmination and convergence of the needs expressed by the MS community, with the view that MSA will progress this issue as an advocacy priority.

To this end, the MSA Board endorsed the implementation of a project to support the ongoing role of the MS Nurse as an integral member of the multi-disciplinary team, as a key advocacy priority for 2017.

Initial investigations confirmed that there is no baseline information, other than anecdotal observations, to provide an evidence base to inform advocacy campaigns, to inform funding or policy changes or service improvements in Australia.

International papers and studies provided the evidence base and value proposition for the contribution of specialist nurses (i.e. breast cancer, diabetes, cardiac specialist nursing and MS Nurses in other countries) within the health sector, but none relating specifically to MS specialist nursing within an Australian context.

The subsequent, '*Multiple Sclerosis Specialist Nurses in Australia*' project, was initiated to create an evidence-based business case to support a successful advocacy campaign for sustainable and increased funding for MSSNs in Australia, in partnership with key stakeholders and partners<sup>3</sup>.

This Report aims to summarise the results of the first phase of this project, specifically looking at:

- The demand for such a role (prevalence and disease burden);
- The role of MSSNs (key activities and responsibilities); and
- The results of the first survey of MSSNs in Australia, highlighting our increased understanding of the current MSSN workforce data in Australia, including differences in funding and service models, workload and the level of access to MSSNs for people affected by multiple sclerosis.

This Report also considers what additional data is needed to complete a business case for increased funding of MSSNs in Australia.

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3 Multiple Sclerosis Australia (MSA) - Project Sponsor, MS Research Australia, MS Nurses Australia (MSNA), MS Health Professionals Network (MSHPN), Australian and New Zealand Association of Neurologists (ANZAN) and two consumer representatives.



# 1 ■ Defining the need and demand for Specialist Nursing in MS

## 1.1 Multiple Sclerosis - A chronic disease

A 2017 Galaxy poll commissioned by MS Research Australia, indicated that around seven million Australians know someone living with multiple sclerosis (MS), however the majority of people surveyed did not know exactly what MS was. The poll further suggested that misconceptions and a general lack of knowledge, especially about the signs and symptoms of the disease, might indicate that MS is still very much misunderstood (MS Research Australia 2017). This is most often the case for someone newly diagnosed, or awaiting a diagnosis of MS.

MS is an incurable neurological condition that is chronic, and for some progressive and degenerative (and therefore irreversible). It affects the Central Nervous System (CNS) that primarily consists of the brain and spinal cord. The disease is characterised by the body's own immune system attacking the fatty insulating myelin sheath, the conductive layer that surrounds these central nerve fibres, causing gradual loss or damage to some of the myelin and nerve cells it is meant to be protecting. Exactly what causes the immune system to attack the myelin sheath is unknown, however, some of the risk factors that make a person susceptible to developing MS are becoming much better understood (MS Research Australia 2017).

A number of epidemiological studies have investigated possible causes or triggers for MS, including:

- Possible genetic factors, predisposition or risks (International Multiple Sclerosis Genetics Consortium 2011);
- Possible environmental factors (Sloka et al. 2011) such as:
  - A decline in Vitamin D levels causing possible changes to the immune system (Simpson et al. 2010)
  - Latitude and longitude: the further away from the equator the more prevalent the disease (Koch-Henriksen & Sorensen 2010)
  - Smoking exposure (Wingerchuk 2012)

- Lack of exposure to sunlight (ultraviolet radiation) (O'Gorman, Lucas & Taylor 2012); and
- Exposure to viruses such as the Epstein Barr Virus or the Human Herpes Virus – 6 (HHV-6) (Simpson et al. 2012)

As the result of the demyelination process, lesions (scarring) and inflammation occur, and interrupt the nerve cells' ability to efficiently conduct signals to each other. Initially, the body can repair the damaged myelin and functioning might return to normal (relapsing remitting disease course), but repair is often incomplete and the capacity for repair declines with ongoing disease and ageing. Signals might also be re-routed via undamaged nerves or adapting undamaged areas in the CNS to take on new functions, which also helps with recovery from relapses. However, this capacity also declines over time with reduction in overall brain 'reserve' (Rocca et al. 2003). As the underlying pathology relates to an ongoing autoimmune response, episodes of exacerbation can continue to show up in any central neurological system of the body (motor, sensory and even cognitive functions after a relapse has resolved). Symptoms might also vary in severity and duration and eventually, cause permanent loss of function (progressive disease course).

The disease's pattern of expression in any person is therefore unique (Multiple Sclerosis Australia, 2012). Symptoms may be variable and unpredictable, depending on the individual's circumstances and the disease progression.

Some symptoms, or more often the interaction of a number of symptoms, can impact on a person's Quality of Life (QoL). Individual symptoms may present as: fatigue (90% of people experience this sensory disturbance)(MS Research Australia 2017), numbness and tingling or altered sensations or hyper sensitivity (40% reported this), blurred or poor vision or loss of sight (30%), pain, physical and motor function changes (39% experience weakness to loss of function), spasticity, bladder and bowel problems, sexual



dysfunction, changes in speech and swallowing and sometimes subtle cognitive and emotional disturbances (MSA 2017) (Multiple Sclerosis International Federation (MSIF) 2013).

Studies suggest that at least 50% of people with MS will experience depression in their lifetime (Siegert & Albernethy 2005).

As with other chronic diseases as defined by the Australian Health Minister's Advisory Council (Australian Health Ministers' Advisory Council 2017), MS is complex and may have multiple causes or triggers. It affects people of all ages (including their families and carers), for the majority, has a gradual onset marked by episodic relapses and acute stages, occurs across the life cycle and can eventually compromise someone's quality of life and create physical and social limitations, economic impacts and disability. It is long term, persistent and characterised by a gradual deterioration of health and loss of independence.

*"...it is possible for me to look the glowing picture of health while feeling disconnected from my body, meanwhile quietly wondering how socially acceptable it would be for me to lay down on the footpath and sleep. This makes it difficult for me to explain to family, friends and co-workers how I feel, and for them to understand how sick I am. This made me realize the extent to which the words that I use to describe how I feel no longer mean what they used to."*<sup>4</sup>

It is however, the diverse, episodic and unpredictable features of MS that makes it one of the most difficult

neurological diseases with which to cope (Serono Symposia International 2008). MS requires constant adaptation, transitioning and adjustments for the patient, their families and their professional support network (Silverman et al. 2017). With the arrival of disease modifying therapies (DMTs) in the early 1990s, the role of the MSSN has become even more important - in educating, managing and supporting the patient in direct treatment towards changing the disease course (Mynors, Perman & Morse 2012), as well as assisting with monitoring requirements, to mitigate against potentially serious side effects and risks of some DMTs.

As the Australian health system continues to face various challenges and struggles with the growing demand for services and rising health expenditure (Australian Institute of Health and Welfare (AIHW) 2016), certain strategies and policy responses will be needed, to increase the capacity of the health system and workforce to meet these increased needs – especially for those people living with a chronic condition such as MS.

More importantly and from a consumer perspective, patients living with chronic diseases with particularly complex health needs, who are under the care of various health professionals with little or no continuity of care, experience this health system as 'fragmented, uncoordinated, duplicating and generally feel disempowered, frustrated and disengaged' (AIHW 2016).

In a number of other chronic health conditions, disease-specific specialist nurses have been employed as part of a multiple disciplinary approach to chronic disease management, to enable a more seamless, coordinated and proactive care approach (Bodenheimer et al. 2005). Breast Cancer (National Breast Cancer Centre 2000), Diabetes (Australian Diabetes Educators Association (ADEA) 2013), Practice Nurses (Jolly 2007), Rheumatology (Ndosi et al 2013), Parkinsons Disease (Leary & Oliver 2010) and Cardiac Specialist Nursing (McDonald, Jones & Leslie 2016), to name a few, have evidenced the value and importance of these positions in a) providing optimal care and b) alleviating the cost on primary health services, by working in multidisciplinary or disease specific clinic models within the community.

## 1.2 MS Prevalence rates in Australia

The number of people living with MS worldwide has increased from an estimated 2.1 million in 2008 to 2.3 million in 2013 (MSIF 2013). Analysis of the 2009 Australian Bureau of Statistics (ABS) Survey of Disability Ageing and Carers (ABS 2012), estimates that approximately 23,700 (with a possible range between 21,150 and 26,250) people in Australia have MS.

There is also evidence suggesting that the incidence and prevalence of MS is increasing. Analysis of the national data collated in two Australian economic impact of MS studies (2005 and 2010), suggest an apparent increase in prevalence of approximately 4% per year since 2005 (Access Economics 2005) (Palmer 2010).

A recent Australian 50-year follow-up study of the east coast Australian city of Newcastle (Ribbons 2016), found a linear and marked increase in incidence from 1961 to 2011 in that particular geographical location, noting an aged-standardised MS prevalence of 6.7 per 100,000, higher than seen in 1961. In another regional prevalence study (Simpson et al. 2012) of the Greater Hobart region in Tasmania (1951-2009), the age-standardised prevalence of MS in Hobart increased threefold, and the incidence nearly doubled.

Prevalence rates are often based on a number of data sources and methodologies, as many countries, including Australia, do not have a central registry to monitor the number of people diagnosed with MS (MSIF 2013).

MS is the most common chronic disease affecting the central nervous system, and can be diagnosed in children and adults. Most people receive their diagnosis of MS between 20 to 40 years of age (The Brain Foundation 2017). This is generally in the most productive period of life when people are starting families, and establishing themselves in their careers and community life.

Epidemiological studies have identified that women are more likely to receive a diagnosis than men (Harbo, Gold & Tentore 2013). Seventy five percent of all people diagnosed in Australia are women (Palmer 2010). The Newcastle prevalence study (2016) mentioned previously, also suggests that this ratio of females to males has risen by 262% between 1961 and 2011, and by 123% since the 1996 survey (Ribbons 2016). Disease onset in women appears to be younger, however their disease and disability progression is likely to be less than in men who are diagnosed with the disease (Bergamaschi 2007).

Prevalence also varies considerably between Australian regions. The highest prevalence of MS is in Tasmania, followed by Victoria with Queensland having the lowest (Palmer 2010). Hobart is said to have six times the amount of people with MS than northern Queensland (McLeod, Hammond & Hallpike 1994). This was further supported by a Menzies Institute of Medical Research study in 2001 (Van der Mei et al. 2001) which concluded that ultraviolet radiation (UVR) exposure may reduce the risk of MS, and therefore has a close association with the actual prevalence rates in Australia.

For a state-by-state breakdown of the estimated prevalence of MS in Australia, please refer to table 1 below from the *Economic Impact of Multiple Sclerosis in 2010 Australian MS Longitudinal Study* (Palmer 2010). Data from the robust Newcastle region prevalence study (Ribbons 2016), suggests that this may be an underestimate. An updated prevalence estimate will be performed as part of the 2017/18 Economic Impact of MS in Australia report, expected in early 2018.

The author of the above study (Palmer 2010), found that the majority of people with MS reside in or close to major cities of Australia, followed by inner regional, outer regional, remote and very remote Australia.

**Table 1. Prevalence of MS in Australia, 2010**

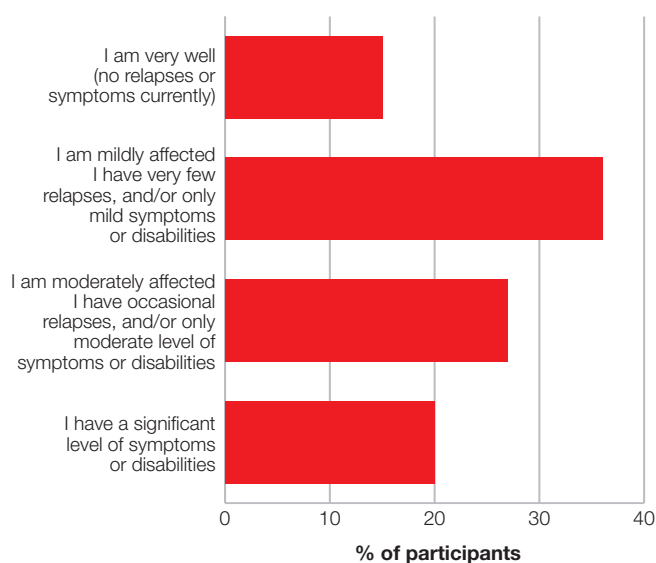
	NSW	VIC	QLD	SA	WA	TAS	ACT	NT	TOTAL
Penetration of Immuno-modifiers	45.0%	45.0%	44.9%	46.0%	45.0%	42.0%	55.0%	46.0%	
Number of people with MS based on prescriptions	6,268	6,637	3,179	1,760	2,313	718	360	49	<b>21,283</b>
MS Society clients	5,717	5,400	3,020	1,507	1,964	690	496	39	<b>18,833</b>
Number of People with MS based on MS clients, assuming only 92% of true MS population are clients of MS societies	6,214	5,870	3,283	1,638	2,135	750	539	42	<b>20,471</b>
Prevalence of MS (per 100,000) by prescription	86.8	120.0	70.7	107.2	101.2	141.6	100.6	21.2	<b>95.6</b>
Prevalence of MS (per 100,000) by MS society numbers unadjusted	79.2	97.7	67.1	91.9	85.9	136.1	138.7	17.1	<b>84.6</b>
Prevalence of MS (per 100,000) by MS Society number adjusted assuming only 92% membership rates	86.1	106.2	73.0	99.8	93.4	147.9	150.7	18.6	<b>89.3</b>

Abbreviations: ACT, Australian Capital Territory; NSW, New South Wales; NT, Northern Territory; QLD, Queensland; people with MS; SA, South Australia; Tas, Tasmania; Vic, Victoria; WA, Western Australia.

In many countries, MS is the leading cause of non-traumatic disability in young adults (MSIF 2013). Australian census data suggests that approximately 11,400 (48%) have a profound or severe core-activity limitation (ABS 2012). Data from the 2016 MS Research Priorities Survey conducted by MS Research Australia (see Figure 1), indicates that approximately 50% of the highly representative sample of people with MS who responded to the survey, were either very well or mildly affected. Just over 27% had occasional relapses and/or a moderate level of disability. 20% had a significant level of disability and/or symptoms (MS Research Australia 2016).

**Figure 1. The degree of disability and symptoms experienced by people with MS who responded to the MS Research Australia survey**

<https://msra.org.au/wp-content/uploads/2017/04/ms-research-priorities-survey-full-report.pdf>



## 1.3 Disease Burden and Economic impact of MS

*“..the simple “head count” approach does not allow policy-makers to compare the relative cost-effectiveness of different interventions, for example the treatment of conditions such as acute stroke versus the long-term care of patients with chronic disorders such as Parkinson’s disease or multiple sclerosis” (World Health Organisation (WHO) 2006).*

Economists tend to use three methods to measure the economic impact or the disease burden on individuals and society: 1) the cost-of-illness approach (direct, indirect and other costs associated with the disease), 2) the value of lost output (the economic growth approach) and 3) the value of statistical life (‘population’s willingness to pay to reduce the risk of disability or death’ (p.14)) approach (Bloom et al. 2011).

To date, two Australian studies have looked at the economic impact of MS, in 2005 and 2010 and, together with a number of other Australian and international studies, the results indicate that the impact on people with MS, their families and the Australian community is staggering:

- In 2005, the total financial cost of MS was estimated “as over \$600m (0.07% of GDP) and \$37,333 per person with MS, or \$30 per Australian, each year” (Access Economics 2005);
- The total cost of MS to Australian society has increased 58% between 2005 and 2010 (Palmer 2010); and
- In 2010, MS was conservatively estimated to cost Australia over \$1.042 billion each year -based on a conservative prevalence estimate of 21,283 people with MS in Australia (2010 figures). This represents an average annualised cost per person with MS of approximately \$48,945 (based on the 2010 Consumer Price Index) (Palmer 2010), which is compared globally and found to be greater than other long-term chronic conditions such as asthma, chronic obstructive pulmonary disease and diabetes, and most other brain disorder cost estimates (mental and other neurological disorders) (Giovannoni et al. 2017). These findings seem to be consistent with the World Health Organisation’s *Global Initiative on Neurology and Public Health and the Global Burden of Disease (GBD) Studies* and subsequent reports (WHO 2006). The WHO Neurological Disorders Report (2006) particularly highlighted how “rehabilitation may mitigate the effects of disease and thereby prevent it from resulting in impaired social and occupational functioning” (p.10).

*MS is conservatively estimated to cost Australia over \$1.042 billion each year based on a conservative prevalence estimate of 21,283 people with MS in Australia (2010 figures).*

- Loss of productivity as a result of MS accounts for 48% of the overall cost of MS, suggesting that MS costs the Australian economy over \$494 million a year– the largest indirect cost associated with this disease (Palmer 2010);
- Australians with MS spend a combined \$78 million a year in out-of-pocket expenses (Palmer 2010);
- MS is the leading cause of non-traumatic disability among young and middle-aged people (MSIF 2013);
- The care provided by family and other informal carers to Australians with MS would cost \$145 million a year to replace (Palmer 2010);
- Of the number of people living with MS, 15,800 (66.7%) needed assistance with at least one of the 10 everyday activities considered in the 2009 Survey of Disability, Ageing and Carers (SDAC)(ABS 2012);
- Notably, 46% of people with MS needed assistance with mobility tasks (ABS 2012);
- Of the 20,400 people with MS aged 15-64 years, an estimated 9,800 were employed, with 5,900 of those people employed part-time (Palmer 2010);
- People with MS have lower employment participation i.e. are less likely to be in paid employment compared to those with other chronic diseases (Simmons, Tribe & McDonald 2010);
- However, the outlook for people with MS in employment is improving, with the gap in employment between people with MS and the general population having substantially reduced from 2010 to 2013. This is in part related to employers responding positively to requests for work role/ environment adjustments (Van Dijk 2016).

*“So what did I do? Nothing. Because there’s nothing to be done. And that’s part of dealing with multiple sclerosis. Working out what you can control and what you can’t. When to worry and when to save your energy. It’s taken me a while (and I’ve had a few false starts) but I’ve moved towards working out*

*what I can comfortably do and what won’t fit for my lifestyle with the MS any longer. I haven’t allowed myself to grieve the things that are going to be too difficult in the future. I’ve instead decided to use my energy working out what I do want to do. It’s actually created some great opportunities.”<sup>5</sup>*

Health care decisions and allocation of resources should be based on not only how many people are affected, but on how different diseases or health conditions impact someone’s quality of life (Ashcroft 2005). Cost-effectiveness evaluation studies often utilise a measure of disease impact, based on various patient-reported domains of quality of life relating to health, psychology, social interaction and environment, known as ‘utility’. This is expressed between the value of 1 (full health) and 0 (death). The 2010 Economic Impact report (Palmer 2010) summarised the following:

- The utility for Australians aged 50-59 (average age of people with MS) is 0.8;
- The mean utility for people with MS is 0.65 (a 20% reduction);
- There is a 50% reduction in utility as MS becomes more severe; and
- Reduction in quality of life associated with advanced MS is equivalent to stroke and end stage cancer.

Even in the early stages of the disease, the utility value of people affected by MS is lower compared to the general population and as the above data demonstrates, this figure worsens during the more progressive part of the disease course, when there is a marked increase in disability acquisition (Giovannoni et al. 2017).

Investment in proactive interventions or therapeutic strategies that slow disease and disability progression (that will improve outcomes for people with MS), and therefore reduce societal costs, should be seriously considered. Unless a comprehensive and holistic approach to the funding of MS health, allied health and care and support services (Giovannoni et al. 2017) is developed, the growing long-term cost, burden of disease and the economic impact of MS will continue to be felt in Australia. A core part of this approach is the role and value of the MSSN as part of an integrated chronic health care framework across primary, community and acute health settings for people with MS in Australia.

5 Quote provided by Jillian Kingsford Smith for the book ‘Taking Control.’ Used with permission from Jillian Kingsford Smith (author).



# 2. Defining the role of the MS Specialist Nurse (MSSN)

Although research nationally and internationally has highlighted the economic argument for employing specialised nurses in the management of chronic diseases (Mynors, Suppiah & Bowen 2015), no evidence base exists yet for MSSNs within an Australian context.

A desktop review conducted as part of the scoping phase of this project (2016), highlighted the existence of several international literature reviews, papers, reports and books that aimed to determine, evaluate and affirm the role and benefit of the MSSN.<sup>6</sup>

There are some research articles that demonstrate a clear economic argument to employ MSSN. For example the 2015 10-year retrospective evaluation study conducted in the UK, found that the introduction of a proactive nurse-led management and rapid response service of MSSNs in one health area - including the implementation of a care pathway in the emergency department for patients who present with MS - was associated with a reduction from a mean of 2700 bed-days per year to a mean of 198 bed days per year (Leary, Quinn & Bowen 2015).

There is certainly clear evidence of patient preference for the use and perceived value of MSSNs (Holliday et al. 2016). However, role expectations differ from what the neurologist (or other health professionals) expect from the MSSN and might differ again to the expectations of the person and often their family members or carers living with this disease. In-depth literature reviews have highlighted that the role of the MSSN in its entirety is still not well understood amongst other health care professionals (Smrtka et al. 2010).

The second part of this Report will look at the role of the MSSN, referencing the domains or conceptual models and also looking at various international studies that provide the academic rigour and evidence base for the professional framework already existing, as well as those that have been developed over the past two decades for this specific role.

## 2.1 Domains of MS Specialist Nursing Practice

The complex and unpredictable nature of MS necessitates the input of a specialised multi-disciplinary professional network (Giovannoni et al. 2017), of which the MSSN is a key partner (as both non-leading and leading team member).

The role is fluid, intuitive and dynamic and its impact spans across the lifespan of the disease trajectory (from first diagnosis to palliative care). The role is constantly evolving, as a greater understanding of the pathogenesis of MS evolves and the need for new and improved treatment options are researched, trialled and approved for use (Burke et al. 2011).

It is worth restating that no person with MS presents in the same way. Something similar can be said for MSSNs. Patient needs determine the skills of the MSSN: The MSSN will acquire disease-specific knowledge and experience by providing the care and support needs to the patient with MS.

<sup>6</sup> Main sources: (De Broe, S 2001), (Johnson 2003), (Forbes et al. 2003), (Halper & Harris 2017), (Corry, McKenna & Duggan 2011), (Mynors 2012), (Ward-Able et al. 2014), (Mynors 2015) including several publications from the International Organisation of Multiple Sclerosis Nurses (IOMSN) established in 1997<sup>9</sup>

*We respond to the gaps in service provision and needs within the various employment settings, creating particular interests and sub specialities. One MSSN might for example become a subspecialist in pain, because the local pain specialist decides to no longer refill Baclofen pumps for the local MS patients. Another might specialise in bladder and incontinence assessment and support as there are no continence nurses available; or a MSSN might become skilled in employment advocacy by being asked by employers to assist in adapting the work environments for employees with MS. Needs determine skills. I guess we just fill in the gaps there are and pick up the slack. (Interview with MSSN 2017)*

MSSNs may have various educational levels, qualifications, employers and role variations but in essence, also some foundational clinical acumen, training and experience that will delineate them from other health professionals or more generic neurological nurses (Mynors, Suppiah & Bowen 2015).

MSSNs have demonstrated ability and skill to individualise the provision of:

- Information and education;
- Case management and clinical care;
- Symptom assessment and management;
- Monitoring, safety and risk management of disease modifying therapies (DMTs); and
- The provision of psychosocial support for the patient and their family (Ward-Able et al. 2014).

The International Organisation of Multiple Sclerosis Nurses (IOMSN) defines a MSSN as:

*“...a competent expert who collaborates with those affected by MS and shares knowledge, strength, and hope.” (Harris & Halper 2016)*

## 2.2 Clinical Knowledge and Practice

The first domain relates to the MSSN's competency around clinical knowledge and practice. In this domain, the MSSN's role is centred on the competencies of communication, clinical assessment and the provision of education and counselling to patients and their families.

*“‘The diagnosis is multiple sclerosis.’ Being told you have MS is a life changer. An MS Nurse is one of the first health professionals on the scene and the one with whom an important nurse-patient relationship is established, often lasting for many years. Being an MS Nurse is a privilege, rich and rewarding, sharing times of sadness and also times of gladness – being part of our patient’s lives is where we want to be.”<sup>7</sup>*

The MSSN has to establish a therapeutic partnership and, after a comprehensive assessment, formulate a collaborative treatment plan. Most often, the MSSN will also be the person to initiate and facilitate a treatment regime while constantly monitoring outcomes and change (Harris & Halper 2016).

### 2.2.1 Diagnosis, prognosis and disease course

The initial onset of symptoms suggestive of MS, diagnostic testing and ultimately the reaction to the diagnosis of a chronic, incurable disease have been described as traumatic, devastating, disruptive, isolating and ‘powerfully evocative and unforgettable’ (Solani et al. 2007). Perceptions formed during the diagnostic phase of the disease and the meaning of such a significant health-related event can have a lasting effect on the ability of the individual to cope, and on the quality of relationship with members of the health care team (Johnson 2003).

Research has also established that anxiety or unregulated and negative emotions were strong predictors of depression, and that treatment approaches

<sup>7</sup> Quote provided by Kaye Hooper in the foreword she wrote for the book ‘Taking Control.’ Used with permission from Jillian Kingsford Smith (author).

to target anxiety should include sharing disease-specific knowledge that addresses both individual and social factors to support resilience (Gay et al. 2017).

*“‘They think I have MS,’ my daughter stuttered in shock. I had no idea what MS was. I’d heard of it before – Jillian had grown up participating in the MS Readathons – but I really had no idea what type of condition it was or what it would mean. I really never had much reason to think about it. No one in our family has ever lived with MS. At the time, I confused MS with Parkinsons and a few of those conditions.”<sup>8</sup>*

Effective communication prior to, and at the time of diagnosis, is critical to improve the patient’s journey to acceptance of the diagnosis of MS or CIS (Clinically Isolated Syndrome)<sup>9</sup>, as well as compliance with therapeutic treatment plans and ultimately achieving optimal quality of life outcomes (Messina et al. 2015). Helping the patient and their family navigate the confusing period during diagnosis and post-diagnosis is a key role of the MSSN.

In relation to diagnosis acceptance, a second function of the MSSN is ensuring that patients receive prompt access to appropriate information on disease management and treatment options, thus ensuring that the disease is treated and managed as effectively as possible from the outset. This includes accessing information on other allied health services, including those relating to diet, rehabilitation, lifestyle choices, physical activity and the holistic support needed to manage this disease effectively. The MSSN also takes into account these individual factors when discussing therapeutic options proposed by the prescribing neurologist.

A recent international consensus report on improving diagnosis, management and treatment access in MS strongly recommends early intervention and treatment initiation by actively promoting a shared decision-making process. This is recommended to preserve and maximise the patient’s neurological reserve, cognitive and physical function by reducing disease activity. (Giovannoni et al. 2017). The same report also

recommends that ideally, people should be referred for diagnosis to an experienced team specialising in MS. Such a specialist team, including a MSSN, has specific expertise and follows an integrated approach, based on best practice, to achieve timely diagnosis, individualised treatment plans and optimal long-term care.

*We receive more and more referrals to our MS Centre from other Neurologists. Particularly for patients with more complex MS related health needs. We are better equipped, more experienced and skilled, and our MS Centre has MSSNs that can comply with safety monitoring, reporting and data recording requirements (Interview with MSSN 2017).*

The mandate for competency, professional practice and safe quality care, coupled with the knowledge explosion in MS research and therapies therefore supports differentiation and specialist practice in the field of neuroscience nursing (MSNA, 2016)

A specialist MS nurse understands the importance of timing, patient expectations, individualised information needs (diagnosis, symptoms and treatment options), and the value placed on the information shared during this crucial period of diagnosis.

During the time of completing an initial comprehensive and systematic nursing assessment, the effectiveness of sharing information is based on trust and relationship and can result in better patient outcomes (Kopke et al. 2014). International MS guidelines such as the European Union’s ‘Code of Good Practice’ (European Multiple Sclerosis Platform (European Multiple Sclerosis Platform (EMSP) 2014) and the subsequent UK National Institute for Health and Care Excellence (NICE) clinical guideline, ‘Multiple sclerosis in adults: management’ (NICE 2014) recommend a client-centred approach.

*“The news is initially overwhelming and it is not until a few weeks after diagnosis – often longer – that the reality of having MS sinks in and a myriad of questions about MS come to the fore. It is a steep learning curve in the early days.”<sup>10</sup>*

8 Quote provided by Geoff Kingsford Smith for the book ‘Taking Control Together.’ Used with permission from Jillian Kingsford Smith (author).

9 “Clinically Isolated Syndrome is diagnosed when a person has only experienced a single episode of neurologic symptoms (such as visual blurriness, numbness, tingling and weakness of the limbs). It is caused by inflammation and/or loss of the myelin sheath that covers the nerve fibres. It can be associated with future development of MS, but is not always associated with the development of MS. A diagnosis of MS can only be made if a person has experienced two or more attacks separated by time (for example 2 months) and affecting different parts of the central nervous system.” (Multiple Sclerosis Research Australia 2017).

10 Quote provided by Kaye Hooper in the foreword she wrote for the book ‘Taking Control.’ Used with permission from Jillian Kingsford Smith



Most people receive their diagnosis after one or two brief consultations with a neurologist. With the changes to the MS diagnostic criteria now allowing for an earlier and more expedient MS diagnosis, DMT options might already be discussed during the second follow-up appointment to the neurologist. Practicalities and time pressures often limit the amount of information and discussion during visits to neurologists (Holliday et al. 2016). MSSNs tend to be more involved with initial screening, treatment discussion and initiation and ongoing monitoring (Remington et al. 2013).

The MSSN role is to assist the patient in regaining control by accessing relevant, good quality information, reducing anxiety, creating realistic expectations and promoting self-care (Perrin Ross 2013).

*“Some of the common questions include: what causes MS, will the children get MS, queries on employment, who should be told about the diagnosis, what is a relapse, who to contact for advice when something new happens, what about travelling with MS medications, is it necessary to move house, what about taking complementary medicines, is there a special MS exercise regime and diet?”<sup>11</sup>*

A MSSN plays an important role in improved patient acceptance of the diagnosis, psychological outcomes, treatment compliance and DMT adherence through:

- **Prompt and effective diagnosis communication:** patients placed high value on being seen quickly, having problems and symptoms identified accurately, and in being diagnosed as soon as possible. They valued health professionals being able to interact with them in a responsive and efficient manner – with the availability and provision for follow up appointments (Messina et al. 2015);
- **Sufficient emotional support, privacy, adequate time and individually tailored information:** that allows for questions, current and up to date knowledge, specific information needs (not general information) and not being left with any unanswered questions (Messina et al. 2015). This ensures that patients fully understand their diagnosis and treatment options;

- **Providing the patient with informed choice that promotes self-management or self-efficacy and autonomy:** allowing the patient to inform the agenda and treatment decisions (Perrin Ross 2013);
- **Information on changing symptoms ('MS over time');** the disease course and what to expect, look out for (relapses and pseudo relapses) and how to respond (Soundy et al. 2016);
- **Providing accessible information of current research, developments and treatment options** (Burke et al. 2011);
- **Continuity and coordination of care** (Solani et al. 2007); and
- **Provision of support for family and carers and where appropriate, other health professionals** (National Institute for Health and Care Excellence (NICE) 2014).

A MSSN's clinical practice is based on evidence-based discussions and assessment driven by patient values and goals that form the foundation of the patient-clinician relationship and communication (Rieckmann et al. 2015).

Care decisions that are achieved through a shared decision-making process and a patient-centred care system achieve greater patient engagement and autonomy (Remington et al. 2013). Similar to other nurse specialisations, the MSSN is able to build their relationship with patients and their families throughout the MS journey, thus also providing psychosocial care as part of the development of this clinical relationship (Legg 2011).

There is growing evidence that specialist nurses' clinical and emotional support to people with MS and their families, from the time of diagnosis and throughout the disease trajectory, are invaluable (Burke et al. 2011). Although a neurologist plays a central role in diagnosing MS, the expertise of other specialist health professionals such as MSSNs are needed to provide continuity of care and support (Johnson 2003).

The field of neurology is so broad and dynamic, that sub-specialisation and a specialist clinic approach has become best practice and is welcomed by patients. This ensures that the patient can access the latest in specialist knowledge and equipment and a cohesive care plan developed by a specialist multidisciplinary team who have in-depth knowledge of the latest techniques and treatment options, but can also have effective safety and monitoring protocols in place (Giovannoni et al. 2017).

<sup>11</sup> Quote provided by Kaye Hooper in the foreword she wrote for the book 'Taking Control.' Used with permission from Jillian Kingsford Smith

## 2.2.2 Relapse Management

*“Right away I noticed that the top of my left hand had no sensation. I tried tapping it with the fingers on my right hand but felt nothing. By the time I was pulling up at my office that morning, I felt overwhelmingly exhausted. As I locked the car, I felt like I was getting the flu; by the middle of the day my ‘flu’ had gotten to the point where I couldn’t handle it any more. This didn’t feel good. I tentatively walked towards the elevators and when I was sure I was out of sight of everyone, started using the walls to prop myself up....the world felt like it was tilting.”<sup>12</sup>*

Even with the marked advances in DMTs, relapses cannot be eliminated completely (Halper & Harris 2017). The episodic nature of relapses is possibly one of the most frustrating things about the disease (Saunders 2011).

Over 85% of patients with MS are diagnosed with relapsing-remitting multiple sclerosis (RRMS) which is often associated with a step-wise worsening in patients, even though it precedes the progressive phase of the disease. As the name suggests, patients will therefore experience relapses<sup>13</sup> (also referred to as attacks, exacerbations or flare-ups) separated by periods of full or partial recovery (MS Research Australia 2017). A relapse must include one or more neurological symptom, must last more than twenty-four hours and must not be secondary to an infection, fever (Saunders 2011) or other precipitating factors (Halper & Harris 2017).

True relapses – and depending on the location of the attack (CNS), the disability or its impacts – can evolve over several days, plateau over weeks and slowly resolve over months (Multiple Sclerosis Australia 2012).

During the period of repair, individuals will however always be symptomatic in some form i.e. experiencing symptoms associated with their individual disease course. MSSNs therefore firstly educate patients to recognise symptom changes, often suggesting a symptom journal (noting onset, location and duration

of changes) to assist the specialised care team in providing the right treatment and management strategy (Halper & Harris 2017).

Relapses should not be confused with that of pseudo-relapses, characterised by a temporary worsening of symptoms as a result of environmental factors such as overexertion, heat exposure or infections (Perrin Ross 2013). The MSSN will usually take a symptomatic history, screening for these factors and trying to ascertain the cause of the symptoms, by asking the patient some exploratory questions (Halper & Harris 2017). This triaging process allows for streamlining of new neurological symptoms to the most appropriate review platform (i.e. GP, MSSN clinic, neurological review in outpatient department or Emergency Department presentation (ED)) and often forms part of key strategies to reduce unnecessary ED presentations.

The MSSN, as part of a holistic clinical assessment, also takes into account any existing comorbidities (particularly vascular diseases, anxiety and depression) that might adversely impact on the overall outcomes of any given MS management strategy and subsequent quality of life outcomes. Recent research into MS has found that comorbidities may adversely impact on diagnostic delays, disability progression, cognition, health-related quality of life and ultimately mortality (Marrie 2017). Such an integrated model of care approach requires highly developed clinical assessment skills, knowledge of how to improve the efficacy of therapies, and experience in managing MS symptoms and comorbidities and thus specialisation in MS nursing practice.

MSSNs, in contrast with a more generally trained nurse, understand and have expert knowledge, skills and experience in the pathophysiology and immunology of MS and can guide the patient through:

1. The identification of actual exacerbations vs pseudo relapses or comorbidity;
2. Assess how the effects of the relapse impacts on the person’s overall functioning;
3. Educate the patient on often complex pharmacological treatment options proposed by the neurologist and advise the patient on nonpharmacological options/strategies to manage ongoing symptoms;
4. Evaluate any safety concerns; and
5. Assist in coordinating an integrated treatment strategy or plan of care, including rehabilitation care (MSNA 2016).

Treatment options are individual and decisions are based on how acute the relapse episode might impact

<sup>12</sup> Quote provided by Jillian Kingsford Smith for the book ‘Taking Control.’ Used with permission from Jillian Kingsford Smith (author).

<sup>13</sup> The McDonald criteria for the diagnosis of MS defines a relapse as a “patient-reported or objectively observed events that are typical of an acute inflammatory demyelinating event in the CNS, current or historical, with a duration of at least 24 hours, in the absence of fever or infection.” (Polman et al. 2011)

on daily living. Options may include a high-dose of corticosteroids (intravenously or orally administered such as methylprednisolone). These medications are given to decrease inflammation in the area of demyelination and to assist in neurotransmission and recovery (Saunders 2011).

Dosing is administered over a 3 to 5-day period, sometimes with a planned tapering oral dose. Patients and carers are educated by MSSNs on what to expect, and as like with most medications, what short and long-term side effects might occur (mild to acute) and to understand that sometimes these side effects might, in their own right, require medical and dietary intervention to mediate their impacts (Saunders 2011).

Patients are guided on how these episodic treatments impact on their current use of DMTs (and any considerations to change or switch to another therapy) and the need for additional or alternate treatments specifically to deal with presenting symptoms. The support required goes well beyond the skills and expertise of an emergency or neurological nurse or general practitioner and requires the expert clinical knowledge and skills of a MSSN (Harris 2016).

The main goals of MSSN management are always to maximise the patient's self-management and autonomy though a shared decision-making approach that focuses on:

1. Delaying disability progression and minimise disease impact;
2. Avoiding complications by effectively managing and treating relapses;
3. Managing and recognise the accumulation of symptoms and co-morbidities; and
4. Maintain and optimise Quality of Life (QoL) outcomes, promote wellbeing and optimal functioning (Perrin Ross 2013).

The MSSN is achieving these goals through specialist care coordination of symptom management, providing clinical support of disease modification, neurorehabilitation and strengthening of informal supports as part of a specialist multidisciplinary team (Croft 2016).

The patient may experience a change of their functional status as the result of a relapse and this can cause high states of trauma, anxiety and depression, distress (Halper & Harris 2017) and concern to both the patient and their families and carers that can substantially and adversely affect an individual's quality of life (Trisolini 2010). The role of nurse 'educator, counsellor, patient and family advocate' during this time is vital. It is therefore imperative that a MSSN continuously update

their specialist knowledge of advances in treatment, management strategies, rehabilitation and research, which will ultimately assist the patient and their family members in coping through this difficult time of adjustments (Halper & Harris 2017).

Not having the continuity and access to a MSSN during this crucial time, who can deliver a specialist proactive case management approach to manage the exacerbation (Leary, Quinn & Bowen 2015), and who can provide expert guidance on symptom management and the possible need for other interventions (such as temporary adaptive equipment), may lead to an increased burden on emergency department admissions for people with multiple sclerosis<sup>14</sup> (MS Trust 2017).

The MSSN is able to respond effectively to the patient symptoms of a relapse prior to presenting to the emergency department and is able to work out a care plan to prevent the need for admission. The MSSN can also coordinate a care approach that encapsulates access to neuro-rehabilitation, psychological support and specialist intervention and therefore reduce the likelihood of a crisis and potential hospital re-admission (Mynors, Perman & Morse 2012).

### 2.2.3 Disease modifying therapies, symptomatic therapies and non-pharmaceutical interventions

*"One night, shortly after being transferred into the neurology ward, I got a bit of a fright when the dinner tray came around. (And no, it wasn't because of the hospital food.) I went to pick up my knife and fork and couldn't grip the fork properly in my left hand. On top of that, trying to coordinate to have the knife and fork work together proved too much. I looked at mum and was really alarmed. She could see the panic in my face as I broke into tears. I felt like the simplest tasks were starting to become impossible. Already walking was difficult, thinking hurt my head and now eating was the new challenge."*<sup>15</sup>

14 Also see summary here: <https://www.ms-trust.org.uk/ms-admissions>

15 Quote provided by Jillian Kingsford Smith for the book 'Taking Control.' Used with permission from Jillian Kingsford Smith (author).



MSSNs facilitate both treatment and symptom management that promotes enhanced functioning, self-efficacy and quality of life outcomes.

The MSSN employs a number of assessment tools through patient interviews to enable the completion of a baseline comprehensive assessment that can be compared with future assessments (AANN, ARN and IOMSN 2011). During such assessments, people living with MS can present with a complex range of symptoms (Harris & Halper 2016), co-morbidities and individual prognostic factors that include age at disease onset, current age, their current MS disability scale score<sup>16</sup>, and various social and environmental factors (MSA 2009). Any developed treatment regimen starts with understanding the patient's needs and preferences, based on their lifestyle and support needs (Smrtka et al. 2010).

## Disease modifying therapies

The two main aims of the drugs that are available for people with MS are to either ease specific symptoms (symptomatic therapies), or reduce the risk of relapses and disease progression known as 'disease modifying drugs' or 'disease modifying treatments' - DMTs (MSA 2017). These DMTs have been shown to effectively limit the frequency and severity of relapses, acquisition of disability progression and thus functional impairment (Trojana et al. 2011).

MS treatment was essentially symptomatic until new DMTs became available in Australia after 1995, including interferon beta(β)1B, interferon beta(β)1A, glatiramer acetate, fingolimod and natalizumab (Medicare Australia 2011). DMTs are either immunomodulatory or immunosuppressive drugs that act by modulating and/or suppressing the immune system at various levels and with different mechanisms of action. Most DMTs are available to treat relapsing forms of MS (currently 12 available in Australia), and clinical trials are underway to increase the availability of DMTs for the more progressive forms of MS.

The efficacy, tolerability and safety of each DMT is variable, ranging from modest efficacy and excellent safety (new generation therapies) to high efficacy but increased adverse reactions and events (second and third line treatments of therapies). DMTs can be administered through IV infusion (e.g. natalizumab, alemtuzumab), injection (e.g. interferon- β, glatiramer acetate, daclizumab) or orally taken (e.g. fingolimod, dimethyl fumarate, ocrelizumab, teriflunomide). Medication frequency varies from being taken daily to bi-annually. Side effects may include low level discomfort such as headaches, flu like symptoms,

injection site reactions, rash, insomnia, nausea, gastrointestinal irritation, and UTIs to more severe adverse effects or risks such as effects on the heart and liver, viral brain diseases, impaired sight, thyroid problems, skin infections i.e. herpes, problems with blood clotting and kidney failure. Changes in therapies may be recommended when relapses persist, pregnancy is likely or in case of safety concerns arising during treatment (Gojofatto 2015).

In more recent years MSSNs have been contributors to local protocols for screening, administration and management of the new-to-market therapies in the absence of therapy-specific, governance mandated protocols. Specialist therapy knowledge, local infrastructure and services capacity knowledge are all used by MSSNs to enhance practical roll out of these therapies and protocols. MSSNs have been vital in assisting in the treatment of patients with 'next generation' DMTs. These DMTs require augmented monitoring protocols to be established and ensuring ongoing compliance by patients with monitoring regimes.

Australians with MS are fortunate that the Pharmaceutical Benefits Scheme (PBS) allows patients to access all of the current MS therapies available (MSA 2017). Greater choice also comes with more complexities for patients and their specialist team. After the patient has consulted their neurologist, who might have suggested a few DMT options, the MSSN has to effectively communicate to patients how a range of considerations may inform DMT options available. These include (but are not limited to) the outcomes of any initial screening process, previous use of DMTs, unique health needs, lifestyle considerations, likely pregnancy, employment factors, travel, issues around tolerability and adverse side effects. This is not a discussion that a general nurse or even a neurological nurse will be able to have effectively, due to the specialist knowledge, skills and experience required.

MSSN nurses provide an individually tailored, proactive, practical and evidence-based approach for the patient and their carers in navigating and selecting DMTs (Sanchez & Porter 2015) or switching between DMTs, as suggested by their prescribing neurologist or treating physician (Colhoun et al. 2015).

The MSSN offers more practical information and strategies to understand the unique mechanisms of action of each MS DMT (Singer et al. 2008). During this shared decision-making process, the patient is also well-informed about the likely adverse reactions and risks associated with each DMT treatment strategy and any associated consequences of inadequate or suboptimal treatment outcomes (AANN, ARN and

16 The Kurtzke Expanded Disability Status Scale (EDSS) is a method of quantifying disability in multiple sclerosis. The EDSS quantifies disability in eight Functional Systems (FS) and allows neurologists to assign a Functional System Score (FSS) in each of these. (Multiple Sclerosis Research Australia, 2017)

IOMSN 2011) (Clanet et al. 2014). Patients are given the opportunity to make informed decisions based on the expected benefits and adverse effects of each medication therapy, how the DMT best suits the patient's lifestyle and individual health needs, which ultimately facilitate patient efficacy and improved treatment adherence (Remington et al. 2013).

A recent survey of patients with MS (Holliday et al. 2016), highlighted that there are a number of factors that are important in the patient's decision-making process. The highest ranking factors were 'how safe the medication is and weighing up the risks and benefits' closely followed by the 'severity of side effects' and 'impact of treatment on my quality of life'.

Once an immunomodulatory agent has been selected, the patient needs to learn how to self-manage their medication schedule, notice possible side effects and tolerability (Harris & Halper 2016). A recent consensus paper on the use of DMTs (Costello & Halper 2017) highlights the range of options now available, the importance of early and ongoing access to DMTs, and perseverance and creative options that should be explored to address barriers to treatment adherence and improved long-term clinical outcomes.

Safety and monitoring starts before a treatment is initiated. MSSNs take baseline measurements that can be tracked across the period of treatment with the specific DMT. Some treatments may require structured monitoring, supervision, tracking and tests after treatment initiation as prescribed by the Therapeutic Goods Administration (TGA) and the protocol stated in the Consumer Medical Information (CMI) Guidelines. These may include minimum and long-term monitoring such as injection site reactions, changes in white cell count and liver enzymes by regularly taking bloods, mandatory first dose monitoring (6 hour monitoring of blood pressure and heart rate followed by repeated Electrocardiography (ECGs) to testing for viruses such as the presence of John Cunningham virus (JCV) antibodies, Magnetic resonance imaging (MRI) and cerebrospinal fluid analysis.

MSSNs are often the first point of contact for any safety concerns and most are also a named delegate to receive pathology reports for some DMTs; many also provide after-hours accessibility, if required. Recording the monitoring of adverse events is another critical responsibility of the MSSN.

## Symptom management and complementary therapies

Each individual's clinical features and symptoms vary, depending on which part of the CNS is affected. MSSNs can establish whether secondary causes exist or if symptoms relate to medication side effects. Symptoms and the interactions or triangulation of symptoms can be complex. They may be managed in a variety of ways and might involve a number of other members of the interdisciplinary health-care team to improve quality of life and functional capabilities (Frohman et al. 2011). This includes a wide range of pharmacologic and non-pharmacologic treatment strategies (Halper & Harris 2017), complementary and alternative medicine and surgical interventions with which a MSSN is familiar with (AANN, ARN and IOMSN, 2011).

*"Nurses should use an evidence based and wellness-focussed approach to educate and counsel patients with MS and their families to adhere to the treatment regimen, manage their symptoms, and cope with their chronic disease." (AANN, ARN and IOMSN 2011, p.41)*

Specialist clinical knowledge and skills are particularly necessary when managing the progressive disease course where the MSSN has to discriminate between primary (directly caused by MS), secondary (complications arising from primary symptoms) and tertiary symptoms (social, psychological and vocational consequences) (Hooper 2015).

The hierarchy of needs and patient choice are key to finding a treatment regimen and individualised and dynamic care plan that is designed to achieve optimal comfort during this time (Reitman 2010).

As part of this coordination role, the MSSN (as part of a multi-disciplinary team approach) ensures increased communication between healthcare staff, increased access to MS specialists and faster referral to specialist review and treatment. The MSSN thus provides the continuity of care and assists the patient and their family or carers to negotiate effectively the often complex services systems of the disability, health, community and aged care sectors.

## 2.2.4 Support for family and carers

*"It can be so hard in those times that Jillian telephones and I can hear the anxiety or distress in her voice. I feel so worried that I'm going to say the wrong thing to her because all I want to do is find some words of wisdom that will make it all better."<sup>17</sup>*

"Upon diagnosis individuals with Multiple Sclerosis (MS) must cope with both day-to-day and disease-related stressors in addition to unpredictable, fluctuating and confusing symptoms. Furthermore, disease progression may interfere with employment, family life, relationships and social activities" (Malcomson 2007).

Life expectancy of people with MS is only reduced on average by 5-10 years and as the disease progress, about 80% of a person's care and support is provided by their informal carers (Giovannoni et al. 2017). Living with a chronic disease does not only hold direct consequences for the patient, the personal costs of MS can also include the impact on the quality of life of the caregiver or family's life on both a physical and emotional level (McKeown, Porter-Armstrong & Baxter 2004). As MS is often diagnosed in early adulthood, it may also affect experiences such as raising a family, building a career and may especially have

consequences for the partner or main caregiver and children of the patient (Cheung & Hocking 2004).

The caregiver burden is described as a 'multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience' (Buhse 2008). The MSSN's key role is thus to coordinate an integrated care approach that may also reduce the caregiver burden. Often this involves the provision of individualised information and education to the caregiver and family, mindful of their educational level, age and their relationship with the patient (Smrtka et al. 2010). An Irish study looking at the experiences of support by caregivers, suggests that support needs change over time (not only in relation to the episodic and uncertain nature of this disease), and that these often fit into four phases: 'rejecting', 'resisting', 'seeking' and 'accepting support' (McKeown, Porter-Armstrong & Baxter 2004). MS is a chronic disease that affects a person and their family over the course of their lifetime. The MSSN is a key member in providing the continuity of care needed to manage the disease trajectory.

A review of literature around the value of the role of the MSSN highlighted the lack of research-based evidence that recognises the invaluable role these nurse specialists play in providing individualised support to family and carers of people living with MS (Corry, McKenna & Duggan 2011).

## 2.3 Leadership, Teamwork and Collaboration

A recent Australian public consultation process of people living with chronic conditions and/or multiple chronic conditions, found that patients often experience a fragmented service system resulting in a feeling of "disempowerment, frustration and disengagement" (Department of Health (DoH) 2015). This occurred where providers worked in isolation from each other, lacked coordination or a collaborative approach, and resulted in experiences of delays, service duplication or barriers to access the correct supports.

Individuals with chronic and complex health conditions such as MS, are more likely to require services from a range of sectors. These include community services, as well as complex health care systems (primary care, allied health, mental health and acute specialist interventions), disability supports, welfare and long-term

care settings (i.e. aged care providers). The accessibility and quality of service provision varies considerably across the country, especially for Australians living in rural and remote locations. Australia's health report found that people living in remote, rural locations experience 'lower life expectancy, higher rates of disease and injury, and poorer access to and use of health services than people living in major cities' and therefore poorer health outcomes (AIHW 2016).

People living with MS have individual, variable challenges and needs that fluctuate over time. More than ever, MSSNs are required to work in partnership and collaboration with other health care professionals and need to establish successful networks to provide support to patients. MSSNs are valuable in providing the leadership in managing the care coordination for

<sup>17</sup> Quote provided by Vicki Kingsford Smith for the book 'Taking Control Together.' Used with permission from Jillian Kingsford Smith (author).

patients, especially when the primary care practitioners feel ill-equipped to deal with MS. As a practice competency, the MSSN understands and values the roles, knowledge and skills of members of the multidisciplinary health care team in relation to their own responsibilities. The MSSN is able to use this knowledge of effective inter- and intra- professional working practices to strategically advocate and negotiate outcomes for the MS patient from a commissioning level.

Through effective brokering and coordination of support, the MSSN is able to refer to other skilled health care providers and disciplines to ensure people with MS have access to the best available intervention, resulting in improved health outcomes coupled with the economic benefit of people with MS remaining in employment (Mynors, Suppiah & Bowen 2015).

As part of this referral process, the MSSN also imparts their clinical expertise and knowledge to other health professionals. By raising greater awareness about the disease, MSSNs build community capacity, knowledge and understanding of MS and convey the importance of key treatment goals i.e. preserving brain health and neurological reserve through early diagnosis and treatment, regular monitoring of disease activity, prompt referrals to specialist MS health care professionals (Giovannoni et al. 2017), and thus ensuring an integrative approach to patient care (Affara 2009).

While advances in therapies, technology and specialist services offer improved outcomes and longevity, there's an increased reliance on a 'patient's skills and motivation to optimise all the benefits available' (Burke et al. 2011). The MSSN is often the key contact person for people with MS providing ongoing information and education about the best strategies to manage their disease (Giovannoni et al. 2017). This role extends to the patient's family and carers, as the MSSN continually builds individual capacity and autonomy through shared decision making (Perrin Ross 2013), and their also aims to strengthen the existing informal support network (Halper & Harris 2017). This ongoing dialogue between people with MS and the MSSN achieves proactive collaboration, which is vital to the successful management of the disease (Giovannoni et al. 2017).

During the proceedings of an international MS Nurse symposium, attended by over 300 participants from 30 countries in September 2011, MSSNs were asked to participate in a poster survey. 85% of participants stated that they take a leadership role in coordinating the multidisciplinary management of MS patients and 92% thought that this role should be increased (Chrysovitsanou, Thomas & Duddy 2012).

The UK GEMSS study patient survey (n=1208) as part of the MS Specialist Nurse Evaluation project, asked patients the number of times they had seen a

health professional about their MS in the preceding 12 month period. 95% of respondents confirmed that they had seen a health professional and the average number of consultations were 9.5 per respondent. 78% of respondents stated that they had seen their MS specialist nurse. MS Specialist nurses were by far the most consulted professional of patients regarding their MS and therefore the best placed to coordinate their care (Mynors, Suppiah & Bowen 2015.) In the same study, topics covered during consultations ranged from medication management, understanding of diagnosis and conditions to physical ability, balance and mobility, bladder and bowel function, mood and mental health, fatigue, care activities of daily living, roles, relationships and social integration to various other symptomatic topics (cognition, spasticity, swallowing and nutrition, skin, communication, sight and hearing, end of life and respiratory and cardiac function). This not only highlights the extent and range of topics covered but also indicates the increasing complexity of managing MS as a speciality.

From an economic point of view, respondents to the GEMSS patient survey confirmed that in the absence of a MSSN, they would have struggled on their own (37%) potentially delaying timely intervention and treatment, that they would have had to see their GP more regularly (39%), or would have had to see their neurologist (19%) or attend the emergency department (5%) instead. This study compared the various unit costs, suggesting that employing a MSSN on a full-time basis, would contribute to significant cost savings.

The objective and benefit of the MS nurse-led clinic is multi-dimensional. A guiding principle of MS care is that MS treatment should be delivered in the context of the physical and psychological impact of the diagnosis on individuals, with the patient at the centre of a therapeutic team. The therapeutic team incorporates the patient, the physician and the nurse into long-term treatment and disease management. The nurse-led clinic, as an adjunct to the physician-led clinics, enhances this team approach.

The first MS Nurse-led clinics commenced simultaneously in August 2011 at Austin Health in Victoria and at Flinders Medical Centre in South Australia, following interstate collaboration between two specialist MS nurses, Jennifer Coleman and Sharon Barlow. They have since been implemented at a number of MS centres across the country as they provide a structure to efficiently consolidate and streamline the nursing workload, enhancing patient management in an era of increasingly complex MS treatments.



The MS Nurse-led clinic provides a designated space and an opportunity for focused MS nursing care to support patients in a variety of challenging situations, including those in crisis; those faced with a new diagnosis, requiring information and support; those making complex and difficult treatment decisions; those at risk of loss of employment or in financial distress; and those on treatments which require careful monitoring over many years.

The MS Nurse-led clinic also achieves economic and clinical management efficiencies, including avoidance of presentations to Emergency Departments, avoidance of hospital admissions, and enabling swift and successful management of MS relapses, MS symptoms and treatment side-effects. The MS Nurse-led clinic serves

as an adjunct to the physician-led clinics, and thus can be helpful in providing support, assessment and management on those occasions where the patient does not necessarily need to see a clinician.

However, responsibility for diagnostic and treatment decisions ultimately rests with medical staff. The role of the nurse in the MS Nurse-led Clinic remains within the scope of practice of an advanced nurse, but clinical matters beyond the scope of the specialist MS nurse are brought to the attention of medical staff or referred on, with the level of urgency dictating the nature and timing of referrals.

## 2.4 Professional Development and Research

Another key reason for initiating this project was to recognise the immense benefit of the MSSN in coordinating research trials. These 'research nurses' perform a range of roles, not always limited to that of the clinical trial requirements i.e. recruiting, selecting and screening, arranging consent, assessing and coordinating the collection of specimens, logistics, documenting research activities, data management, monitoring and risk evaluations. More often, MSSNs also provide information, education, and psychological, psychosocial and case coordination support to research participants. Nurses specialising in clinical research make important contributions to research integrity, patient care, care coordination, and provide the practical application and clinical translation for research science. Another study also suggests the value of having 'real world' observational data to influence contemporary treatment outcomes research (Kalincik & Butzkeuven 2016). That is certainly the case when a MSSN translates their clinical trial expertise derived from emerging DMTs into practical, logical protocols in safety and monitoring procedures, or routine care requirements for patients. MSSNs in this research capacity also demonstrate a capacity to support the uptake of newer therapies on site, because of their previous experience of the DMT during the clinical trial period.<sup>18</sup>

*"The complex, unpredictable nature of MS necessitates input from a range of health and social care professionals. Although these individuals may affect the experiences of people with MS, the MS nurse remains the central key worker responsible for coordinated care and support. Thus it is essential that they receive ongoing education and are appropriately skilled to work effectively with all members of the multidisciplinary team."* (Ward-Able et al. 2014)

Training and education opportunities are essential for MSSNs to keep up with the rapid and changing landscape of MS therapies. The emergence of new MS treatments and the resulting changes in the 'treatment paradigm will cause the skill set required of an MS nurse to expand and evolve to ensure appropriate care of the patient, both physically and psychologically, and to meet the monitoring needs specific to each therapy' (Burke et al. 2011).

A research culture should be embedded in every aspect of MS care to enable better understanding of the disease mechanisms, treatment options (including pharmacological and non-pharmacological), specialised services and therapies for progressive forms of MS. Evidence-based practice that is guided by secondary end points are needed to increase treatment efficacy and only improve patient outcomes (Rieckmann et al. 2013).

<sup>18</sup> From informal interview with MSSN in Australia.

## 2.5 Legal and Ethical Practice

Currently, MSSN practices are only endorsed by a voluntary, periodic certification by examination through the Multiple Sclerosis Nursing International Certification Examination delivered through the Multiple Sclerosis Nurses International Certification Board (MSNICB). This certification established a measure of baseline knowledge in MS nursing and therefore assists employers in the standard of knowledge required for practising in MS care. While highly regarded, this qualification, to date, has not been a prerequisite for new positions in Australia, rather a measure of skill and specialist knowledge ascertainment for career development.

Board certification in MS nursing is highly valued and provides formal recognition of basic MS nursing knowledge. Eligibility requirements include registration as a Registered Nurse and a minimum of two years of experience in MS Nursing. The registered designation of MSCN (Multiple Sclerosis Clinical Nurse) can be used after a nurse's name and the certification can be renewed every five years.

Outside this international examination, encouragement of ongoing professional development in Australia is guided by the Nursing and Midwifery Board of Australia who require a minimum of Continuing Professional Development (CPD) hours depending on the type of registration. The Australian Health Practitioners Regulation Agency (AHPRA) requires nurses to meet several standards, which include criminal history checks, English language skills, length of time of most recent is their practice, CPD, professional indemnity arrangements and a number of endorsements relating to nurse practitioners and scheduled medicines.

Although Professional and Practice Standards for MSSNs in Australia exist (MSNA 2016), this is seen as a guide to nurses seeking to enhance their practice rather than an enforceable quality framework or standard.

# 3. Defining the Current MS Specialist Nursing Workforce in Australia

MSSNs already exist and work within a number of different health and community settings in Australia. This project is the first time in over two decades that attempts have been made to quantify the number of MSSNs in Australia and to look at the demographic factors of this highly specialised workforce.

As part of this project's initial phase, a self-report survey was distributed to all MSSNs and other nurses affiliated or known to the two peak bodies in Australia for MSSN's: MS Nurses Australia (MSNA) and via MS Health Professionals Network whose membership covers other MS health professionals (including nurses). The survey was distributed between March 2017 and May 2017.

The survey was loosely based on the UK's MS Trust's MSSN Supplementary Survey (Mynors 2014), which was kindly shared with MSA. The UK MS specialist nurse evaluation project through GEMSS (Generating Evidence in MS Services)<sup>19</sup> was a national program of work funded through the UK MS Trust from 2012-2016.

In total, 88 Australian nurses who were members of, or known to, the two peak Australian MS organisations, MSNA and MSHPN and identified themselves as either MSSNs or nurses who are working closely with people with MS completed the survey. The survey was emailed using two distribution lists (17 March 2017) and an extended response time was provided to increase participation rates. The last completed survey was received on 29 May 2017. Of the 96 survey requests distributed, 88 (92% of respondents) completed the survey.

The respondents represented the following states and territories<sup>20</sup>:

**Table 2. MSSN Survey 2017 - respondents by state**

STATE OR TERRITORY	PERCENTAGE OF COMPLETED RESPONSES	NUMBER OF COMPLETED RESPONSES
New South Wales	20%	18
Australian Capital Territory	0%	0
Victoria	31%	27
Queensland	7%	6
South Australia	10%	9
Northern Territory	0%	0
Western Australia	26%	23
Tasmania	6%	5
<b>Total responses</b>	<b>100%</b>	<b>88</b>

<sup>19</sup> Evidence for MS Specialist Services: Findings from the GEMSS MS Specialist nurse evaluation project (Mynors 2015)

<sup>20</sup> At time of publication (August 2017) several MSSNs who have completed this survey have either lost their positions, had significant changes to their roles or accepted redundancy.

## 3.1 Models of Employment and Funding

### 3.1.1 Employers of MS Specialist Nurses

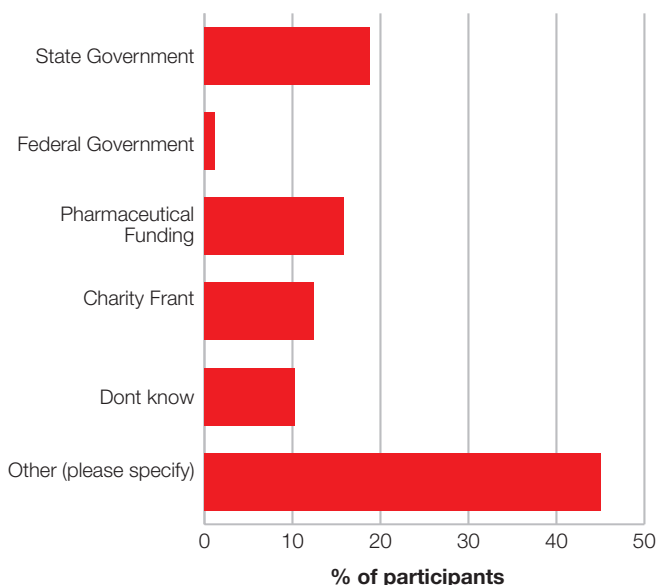
The majority of MSSNs were employed within hospital settings (47%) while the next largest cohort (36%) reported MS State Societies as their employer. Less than 5% of MSSNs were employed directly through a research project alone.

Due to the variations in models of practice and funding across State/territory MS organisations, the actual number of MSSNs working within hospitals might be significantly higher as, anecdotally, Western Australia's MS Society supplies MSSNs through a number of health settings.

### 3.1.2 Changes in external funding sources

Funding for these positions is mostly sourced from State Government (20.99%) and Pharmaceutical companies (17.25%). The self-specified answers included a various number of combinations of sources i.e. hospital (public and private), state/territory MS organisation, clinical research trials, pharmaceutical, neurologist or fundraising dollars.

**Figure 2. MSSN Survey 2017 - Funding Sources**



Historically, many State/territory MS organisations received their main funding from state and territory governments who all had their own systems of funding or frameworks for contracting of services.

This purchasing relationship changed significantly with the introduction of the NDIS.<sup>21</sup> One of the core tenets or premise of the scheme is that funding relationships will be with the individual rather than with a provider. In effect, this individualised funding approach created choice and control for the consumer. In contrast, MS organisations, like many other not-for-profit providers, were historically funded through state and territory disability departments to provide information, coordination and support services to people with MS as a specialist provider. Some organisations also received resources from health and aged care services. The state governments (as the purchaser) would set the funding levels, targets and outcomes and often allocate the service users, either individually or through the creation of target outputs in funding agreements.

However, in order to fund the NDIS, state and territory governments and the Australian Government combined some new funding, along with numerous existing disability program funding sources (that would have previously provided upfront block funding to not-for-profit organisations) into one large national fund.

In response, disability organisations had to reshape and redesign their business models to survive in this new market-style disability service system.

Within the previous block funding approach, a state/territory MS organisation was able to employ MSSNs to provide information, advice and support, case coordination<sup>22</sup> and services to people with MS. Some organisations had the flexibility to decide in what setting to provide such a service (i.e. in-kind support to a MS clinic or local neurology clinic) as long as they met the funding requirements of their contract with the respective state or territory department. These state MS organisations could also provide seamless support across the whole lifetime trajectory of disease - from early diagnosis to end of life support. In effect, the previous funding culture inadvertently allowed for cross subsidisation across a variety of service systems, including health, disability and aged care, even though the original funding came from disability services. The funding was attached to providing a specific type of support (say information and advice) to a specific audience or consumer (people affected by MS) as a specialist disability provider. No separation or distinctions were drawn between, for example, the provision of information and advice to someone who was first diagnosed and mainly accessing health services, to someone requiring information and advice around their relapse or symptom management or to

<sup>21</sup> See [www.ndis.gov.au](http://www.ndis.gov.au)

<sup>22</sup> See <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129555638>

someone who might be over 65 years and still requiring support in managing their day-to-day functioning.

The NDIS initially set a unit pricing and support type<sup>23</sup> policy that provided consumer protection and assisted the sector with transitioning into the new scheme. They also re-distributed funding into three separate tiers<sup>24</sup> and required organisations who would like to offer services within the NDIS to meet a registered provider criteria<sup>25</sup>.

Most disability providers, especially smaller ones, simply do not have the funding reserves to make the necessary strategic changes (IT, HR, marketing, strategy<sup>26</sup>) and transition seamlessly from a secure, recurring block funding relationship to an individualised 'payment in arrears' environment that would enable them to survive within such a competitive market place (NDS 2014). If a provider's staffing costs were already high, (for instance, the MSSNs were paid as allied health professionals) and those staffing costs no longer fit within the set unit cost calculations for their registered NDIS support service types, the provider either has to decide to continue to subsidise that expense through a fundraising model (which are highly competitive in Australia) or recruit a different staffing cohort and improve efficiencies and resources utilisation to remain financially viable. Many state/territory MS organisations have subsequently made some strategic changes to their business models while one has merged with another organisations in order<sup>27</sup> to continue a viable service offering.

## 3.2 Workforce Data

Although funding sources have reduced the number of MSSNs available in Australia, the survey showed that the commitment to the role of the great majority of MSSNs remained high. The survey showed that a high percentage of MSSNs have been working in this specialist role for over 8 years with the mean number of years worked as a specialist nurse in MS between 5-8 plus years (70%).

From 1 October 2015, the Code of Conduct for Australian pharmaceutical companies<sup>28</sup>, called *Medicines Australia*, changed its transparency measures and reporting obligations for sponsorships and grants to health entities or health care professionals. The new Code requires Medicines Australia member companies to publicly report when a company pays a healthcare professional for their service or when a pharmaceutical company provides financial support for a healthcare professional to engage in education activities. This is designed to avoid the risk of such sponsorships being characterized as 'inducements'<sup>29</sup>. Given the increase in competition as more DMTs became available and the correlating decrease in market share for pharmaceutical companies, some of the previous funding sources ceased for MS and health entities which previously enabled them to employ MSSNs through pharmaceutical grants.

In summary, despite an annual increase in MS incidence, there is a contrary trend in availability and funding of MSSNs.

**Table 3. MSSN Survey - Period of Employment**

ANSWER CHOICES	RESPONSES	PERCENTAGE (%)
0-1 years	19	22
2 years	3	3
3 years	4	5
4 years	3	3
5 years	3	3
6 years	7	8
7 years	8	9
8 plus years	40	46
<b>Total Responses received for this question</b>	<b>87</b>	

23 See: <https://www.ndis.gov.au/providers/pricing-and-payment>

24 See: <http://www.pc.gov.au/inquiries/completed/disability-support/report>

25 See: <https://www.ndis.gov.au/providers/info-new-providers>

26 See: <https://www.readiness.nds.org.au/>

27 See: <https://www.ms.org.au/attachments/ms-tas-annual-report-2015-16.aspx>

28 See: <https://medicinesaustralia.com.au/code-of-conduct/>

29 See: [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Finance\\_and\\_Public\\_Administration/Completed\\_inquiries/2010-13/therapgoodsamendbill2013/report/c01](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Finance_and_Public_Administration/Completed_inquiries/2010-13/therapgoodsamendbill2013/report/c01)

The greater majority of MSSNs were employed on a part time basis (58%), on a permanent employment contract, while only 6.9% responded that they are employed on fixed term temporary arrangements.

Depending on the model of service, some MSSNs also worked across a number of other conditions such as Parkinsons Disease (5%), Epilepsy (5%), Motor Neurone Disease (11%), Huntingtons (2%) and other neurological conditions (27%). Of the total number of respondents, 58% stated that they worked exclusively as a MS specialist nurse.

### 3.3 Key Responsibilities and Training

Although different models of employment exist, the key responsibilities for all MSSNs are listed below.

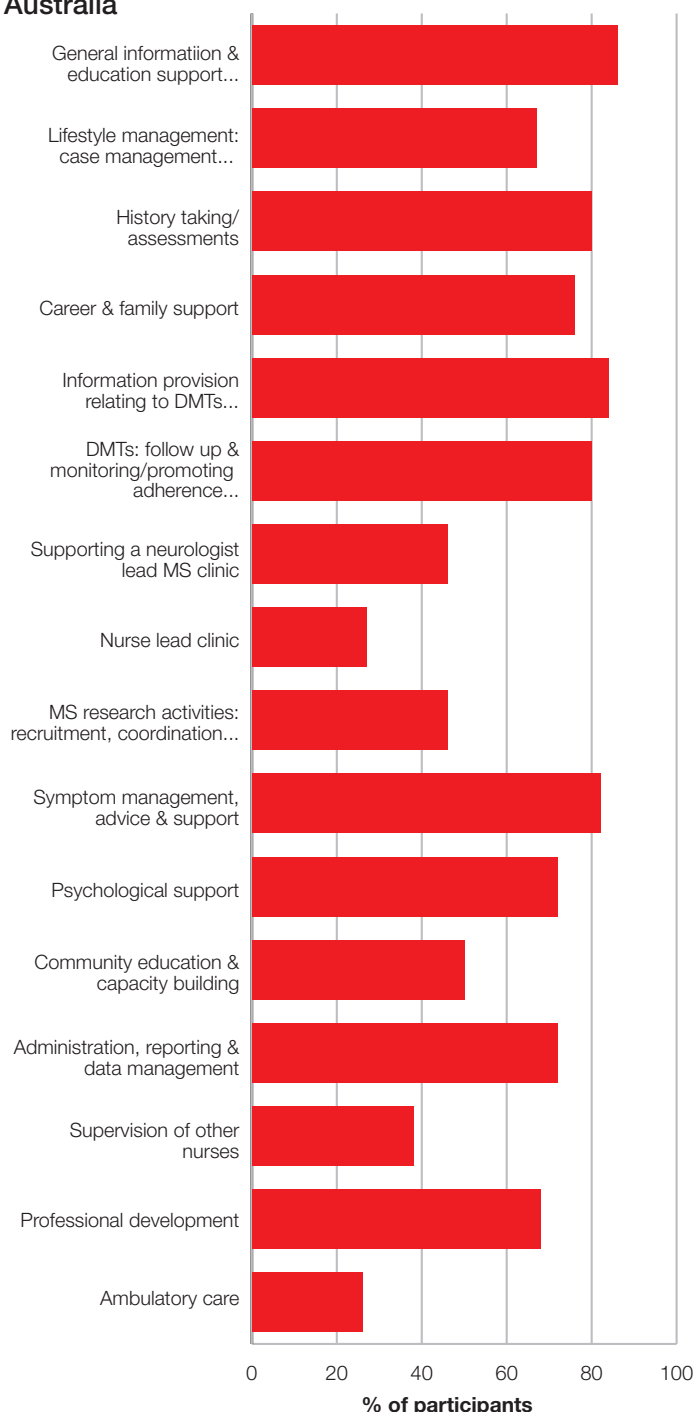
The most cited roles include:

- General information and education support;
- History-taking and assessment;
- Information provision around DMTs; and
- Symptom management and advice.

Only two MSSNs who completed the questionnaire were trained as Enrolled Nurses while nearly half (48%) noted a minimum qualification as a Registered Nurse.

18% of MSSNs were employed as Clinical Nurse Specialists; 16% as a Clinical Nurse Consultants while 19% were employed as a Research Nurse or Research Coordinator (15%). Twenty two MSSNs have completed the MS Nurse International Certification Board (MSNICB) examination.

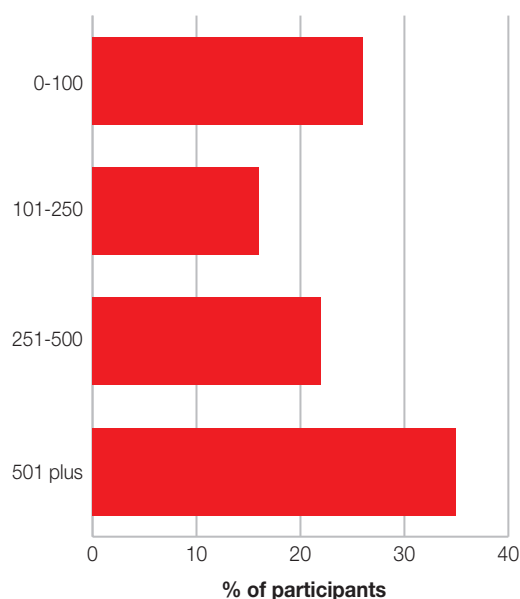
**Figure 3. MSSN Survey 2017 - Roles of MSSNs in Australia**





## 3.4 Defining a sustainable case load

Figure 4. MSSN Survey 2017 - Average Case Load per MSSN respondent



The average case load per survey respondent results did not have specific qualifiers attached, so a number of possibilities exist in interpreting case load. This could include total number under active management, or those subject to annual reviews at their MS clinic or even a broad estimated patient case load based on the number of people living in the area the MSSN is located.

This is to be seen in the context of MSSNs who stated that they:

- They mostly work on a part time basis (61.36%);
- They are employed as a Research Nurse (19%) or Research Coordinator (15%); and
- Worked with patients with MS only (66%).

Conducting a specific case load survey in the future would be helpful to provide greater clarity.

Table 4. Average number of patients managed by MSSNs

RESPONSE RANGE	RESPONSES	%	MIDDLE NUMBER IN RESPONSE RANGE	RESPONSES X MIDDLE NUMBER = NUMBER OF PATIENTS MANAGED BY MSSNS
0-100	20	26%	50	1,000
101-250	12	16%	175	2,100
251-500	17	22%	375	6,375
501+	27	36%	600	16,200
<b>TOTAL</b>	<b>76</b>	<b>100%</b>		<b>25,675</b>

From the above table, the survey results may indicate that:

- MSSNs each manage a wide range of patient numbers, from less than 100 patients to over 500 patients;
- 36% of those surveyed indicated that they manage over 500 patients; and
- Using the middle number of the range of patients managed as a proxy for the exact number of patients managed by each MSSN, we are able to estimate that MSSNs manage, on average, 338 patients.

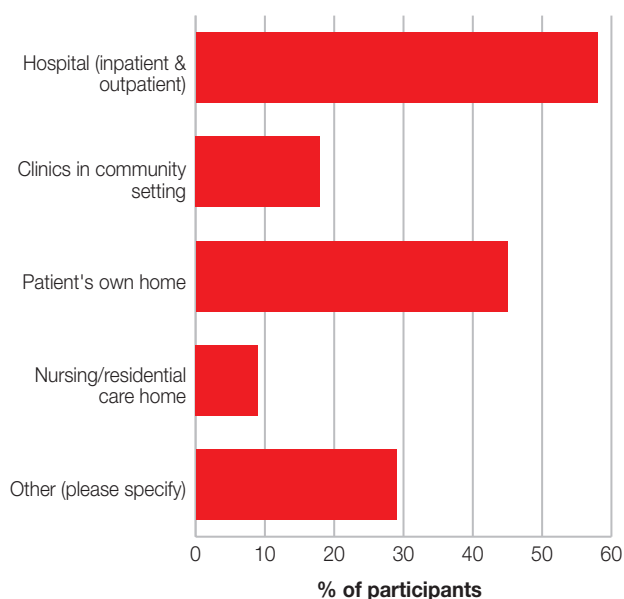
In the survey, MSSNs were asked what the number of actual contact hours with people with MS would be if rounded to a typical full time equivalent. The results suggest that:

- 31 MSSNs (41%) provided an average of 11-20 contact hours in their work week to people with MS;
- 23 MSSNs (30%) provided an average of 20-30 contact hours in their work week to people with MS;
- 12 MSSNs (16%) suggested less than 10 contact hours (which might include MSSNs working solely in research roles);
- 10 MSSNs (or 13%) suggested an average of over 30 plus contact hours with people with MS; and
- Variations in case load can also occur in relation to the health or geographical setting in which patients are regularly seen.

In the UK GEMSS study (Mynors, Bowen & Doncaster 2016), 62% of the MSSNs surveyed stated that they had less than a day a week of non-clinical support to help with administration and coordination of services, and 25% stated that they had no administrative support at all. Promoting role diversification is essential, where MSSNs have the capacity to focus on clinical tasks rather than administrative tasks that could be performed by a separate administrative resource.



**Figure 5. MSSN Survey 2017 - Routine setting in which patients are regularly seen**



According to the MSSN survey results, 68% of all patients are seen within a hospital setting (in or outpatient) while nearly 20% were seen through MS clinics within community settings. 38% of patients receive home visits or are visited in their respective nursing or residential care home (10.47%).

Methods of communication also varied, as 33 respondents identified phone/Skype and telehealth as the most used method of communication, closely followed by face-to-face contact and other types of communication such as email/letters and text messages.

Only 21 respondents i.e. 28% stated that as part of their role, they respond after-hours to calls and/or emergencies. Of those respondents, the average after-hours responses were:

- 70% for less than one hour per week;
- 14% for up to two hours a week;
- 5% for 3 hours a week;
- 3% of less than five hours; and
- 8% responded more than 6 hours per week.

The majority of MSSNs (84%) were based in metropolitan areas with a population size >100,000 and only 16% of MSSN respondents were in rural areas with a population size of between 10,000 and 99,999. None of the respondents stated that they are based in remote areas with a population <10,000.

The location and current provision of specialist MS services is demonstrated in the following figure. However this reflects the location of survey respondents (by post code) and not actual MSSNs currently in positions. This resource will be updated in late 2017, once a more current prevalence study of people with MS (to estimate how many people with MS lives in Australia) is completed by the Menzies Institute of Medical Research.

**Figure 6. Post code data were used to map the prevalence and geographical location of Survey Respondents in Australia.**



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## About Multiple Sclerosis Australia

MS Australia is the national voice for people with multiple sclerosis. We work in advocacy and communications, and collaborate with our stakeholders to benefit thousands of people affected by MS across the country.

We work closely with MS Research Australia, who fund research into better detection, treatments and a cure.

We also advocate and communicate on behalf of all our state/territory member organisations who work tirelessly providing services, programs and support to the MS community.

For further information on this report and the work of Multiple Sclerosis Australia on MS Specialist Nursing and other services, please contact Deidre Mackechnie, CEO.

If you would like further information about MS or how to connect with your local MS organisation for information about treatments, support and services please contact us.

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