## **MS Nurse Education & Information Provision:**

Information Needs	Delivery Method/Activity	Benefit
Diagnosis: From the first symptom onset Diagnosis acceptance Diagnosis understanding and acceptance Trusted information sources Carer support Psychosocial support	Participation in neurologist-led clinics (face to face) Coordination of Nurse-led clinics (face to face) Triage of calls to Neurology Phone Home Visits Collecting, entering and accessing data from MS registries and patient's electronic health record (EHR), used to enhance patient safety, evaluate care quality, health outcomes, inform good treatment decisions and support	Improved understanding of patient diagnosis and disease course, including Clinically Isolated Syndrome (CIS) diagnosis and support  Availability to ask questions, when needed (especially via telephone) Improved self-advocacy and greater empowerment to make decisions related to their care Increased ability to cope with and manage their health in the context of their disease and its treatment Provision of information on research and clinical trial updates which meets their individual needs, is relevant to them and assists patients to meet their treatment goals Building patients' knowledge, understanding and preparedness for selfmanagement Development and improved coordination and management of individualised treatment plans
Treatment Options  Modifiable risk factors  Non-modifiable risk factors  Medical history, assessment and tests  Treatment options and decisions	Participation in neurologist-led clinics (face to face) Coordination of nurse-led clinics (face to face) Triage of calls to Neurology Phone Home Visits Referrals to other departments	Increase patient health literacy Developing a collaborative therapeutic relationship with the patient Providing information and suggesting strategies to manage disease effectively Emphasize the importance of a brain healthy lifestyle Benefits of early diagnosis and treatment to modify disease course Establishing and managing treatment expectations Better understanding of treatment options, side effects and toxicities

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sche asse Patie coad Colle acce	Pathology, MRI and scheduling of other assessments and tests	Distribution of evidence-based patient education materials (nurse-developed and distributed) that enhance patient adherence and self-care capacity
	Patient education, coaching and follow-up	Importance of monitoring, regular clinical evaluations and risks management protocols: to achieve goal of minimising disease activity whilst
	Collecting, entering and accessing data from MS registries and patient's	optimising safety Individualised treatment through shared decision-making Increased treatment efficacy, adherence and compliance
	electronic health record (EHR), used to enhance patient safety, evaluating care quality, health outcomes, inform good treatment decisions and	Access to psychosocial support: depression and other psychological disorders
		Treatment initiation, treatment administration, monitoring the development of treatment-related adverse events and support during treatment changes
	support	
Adapt and plan Pseudo relapse and relapse management	Liaise and negotiate specialist protocols with Emergency Department	Health assessment: Rapid identification of treatment failure and assistance with patient education and shared decision making around switching medications and treatments
Symptom management Comorbidities and	(ED) and Ambulatory Care Collecting, entering and	Monitoring treatment outcomes, relapses, identification of potential neurological progression and increase patient understanding of MRI activity
medication management	accessing data from MS	Identification, responding to and reporting of adverse events
Professional support network and referrals	registries and patient's electronic health record (EHR), used to enhance patient safety, evaluating care quality, health	Recognition of cognitive impairment, liaison of appropriate assessment and information provision support
Monitoring and risk management		Triage facility and support resulting in reduced psychological distress and stress
Referral	outcomes, inform good	Promotion of recovery and improved function during and following completion of treatment of relapse
DMT and Pregnancy preparation, DMT and breastfeeding	treatment decisions and support Adopt standardised data	ED avoidance, decrease in admissions, reduced readmissions and days in hospital
information & support GP liaison	management, track clinical and subclinical events	Coordinating appropriate treatment/response

Information Needs	Delivery Method/Activity	Benefit
Discharge planning support	Populate and use national and international MS registries and databases Participation in Neurologist-led clinics (face-to-face) Coordination of Nurse-led clinics (face-to-face) Triage of calls to Neurology Phone triage and support	Improved symptom management and overall chronic health disease management, increased confidence in self-management strategies Referral, planning and coordination support, addressing barriers and access issues and structured follow up Improved Quality of Life patient outcomes
Progressive Disease management  Medical evidence preparation and support for NDIS access Liaison and education with staff within residential disability and aged care providers Assistance with advance care planning	Collecting, entering and accessing data from MS registries and patient's electronic health record (EHR), used to enhance patient safety, evaluating care quality, health outcomes, inform good treatment decisions and support  Preparation of medical reports and assessment documentation  Participation in Neurologist-led clinics (face-to-face)  Coordination of Nurse-led clinics (face-to-face)  Triage of calls to Neurology Phone support	Providing evidence-based information, education and symptom management and rehabilitation support  Nurse health assessment  Improved clinical care and support whilst in other settings i.e. residential aged care or disability housing support.  Liaison with multidisciplinary team: better symptom control, pain management, improvement in continuity and coordination of care, daily living assistance, access to assistive technology, proactive medical care and disease management  Improved Quality of Life patient outcomes  Service and support coordination to avoid carer burden  Facilitating and promoting conversations about advanced-care planning that could lead to informed decision making on health care preferences, life prolonging treatments and proxy-decision makers and legal implications.  Creation of advanced-care directives

Information Needs	Delivery Method/Activity	Benefit
_	Visits to residential settings to ensure treatment plans are understood and adhered to; to establish protocols that avoid unnecessary ED admissions	
End of Life/Palliative Care Support	Face to face, phone support	Provision of patient centered end-of-life care during hospital admission  Liaison with multidisciplinary team: better symptom control, pain
Communicating and coordinating the goals of treatment and care options: checking their understanding, understanding preferences and implications Quality of Life maintenance and support around symptom management, pain, emotional, social and cultural needs Coordination of comprehensive interprofessional care, consistency and communication Caregiver support	Liaison with ED, ICU and other departments during periods of hospital admissions Liaison with multidisciplinary teams Referrals, coordination of support and care Triage of calls to Neurology Phone triage and support	management, improvement in continuity and coordination of care, daily living assistance, access to assistive technology, proactive medical care and disease management  Reduce the need for unnecessary hospital admissions  Ensuring access to palliative care whilst at home / hospice care / nursing home  Service and support coordination to avoid carer burden

## Information needs and Education: Capacity building within own hospital setting & external stakeholders

Audience	Delivery	Outcomes
Own hospital setting	Information and	Awareness and recognition of early signs and symptoms
Ambulatory care	education within	Understanding the negative impact of delaying diagnosis and
Emergency Department	various group settings such as in-	treatment
Incontinence services	house training,	Adoption of new diagnostic criteria
Other allied health	department or team	Importance of prompt referral to specialist MS neurologists or
Pain specialists and providers	meetings, peer support groups	specialist MS clinic to speed up diagnosis and treatment
Speech therapists	Telephone support	Establishment of MS specific protocols and pathways between departments
Spasticity specialists	and consultation	'
Psychology and Neuropsychology	MS-specific protocol and pathway development, negotiation,	Improved access to specialist MS care: making the diagnosis; monitoring procedures; support needs of newly diagnosed
<b>Stakeholders</b> GPs		Alignment of prescription guidelines to latest diagnostic criteria to give people the opportunity to start treatment and receive support once
Neurological and other community	implementation and review	diagnosis is confirmed
nursing support	Discharge coordination and support/Referral support	Consultation with other providers in order to increase understanding of treatment plans and goals, aiming to achieve the best outcomes for patients
Private neurologist and specialists		
Other in community allied health professionals		Provision of specialist documentation, assessment and support for eligibility assessments for Disability Benefits, Carer Benefits, Aged Care
National Disability Insurance Agency (NDIA)		and NDIA supports
Aged Care Providers		Provision of information and education to employers about how to increase flexible supports for employees with MS, where a referral to
Disability Providers		specialist MS employee supports is not available
Employment support		Liaison, information provision and support for other disability and aged
Other disability and aged care service providers		care service providers to ensure treatment plans are understood, implemented and supported