Multiple Sclerosis at End of Life

Information for the Care Team

SMRPCC

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Background

Many palliative care services may not have come across people with Multiple Sclerosis (MS) at the end of their lives. This document is designed to help palliative care staff understand the management of unique symptoms that people with MS can experience, and the benefits that can result in expert care from community palliative care programs.

Advanced MS is a broad term indicating a stage in the progression of MS characterised by increasingly complex support needs.

End-stage MS, on the other hand, refers to the advanced phase of the disease where people experience severe symptoms and impairments, leading to significant difficulties that may not respond effectively to usual treatments. This stage is often marked by life-shortening complications and requires compassionate palliative care.

The transition from advanced MS to end-stage MS occurs when treatments are no longer considered effective.

Multiple Sclerosis can, at the end of life, present differently for each person. It is important to remember that people with MS don't usually die from the disease. Rather, they usually die from complications of complex symptoms that can fluctuate from day to day. MS is not in itself a death sentence. The complications from the accumulation of disabling symptoms can contribute to the person's death.

This document includes:

- Contacts and resources for health professionals
- Information and education about Multiple Sclerosis and its management
- An example of a nursing care plan for someone with Multiple Sclerosis

Contacts for health professionals

For further information and assistance please contact:

- **MS Plus Connect**
  - 1800 042 1238
  - connect@msplus.org.au
- **Jane Turton | Progressive Neurological Conditions Program Manager, SMRPCC**
  - 0428 264 446
  - jane.turton@smrpcc.org.au

Resources for health professionals

A 22-minute podcast discussing the mental health and well-being of health professionals generally and nurses in particular. Please access here:

- https://smrpcc.podbean.com/e/health-wellbeing-for-health-professionals/

More podcasts, as well as webinars and articles from MS Plus at:

- https://www.msplus.org.au/resource-hub
- https://www.msplus.org.au/your-neuro-condition/what-is-ms/advanced-ms

What is Multiple Sclerosis?

Multiple Sclerosis (MS) is an incurable, chronic disease affecting the Central Nervous System (CNS) in which the body's own immune system mistakenly attacks and damages the fatty material – called myelin – around the nerves. Because this damage can occur anywhere in the CNS, people with MS can experience a wide range of symptoms unique to each person. Symptoms can also differ at various stages in the person's life.

Depending on the type of MS diagnosed, a person may be offered a Disease Modifying Therapy (DMT). This medication is not a cure, rather a medication that modifies and slows down the course of the disease progression. Not all people accept DMT treatments, and this can be due to personal preferences, or unacceptable side effects of the medication.

Disease-modifying medications or treatments and immunotherapies work by changing the activity of the immune system to slow frequency and severity of attacks to the CNS. This means the myelin sheaths are subjected to less damage. Immune suppressants are sometimes used, especially for people with progressive MS.

Historically, even twenty years ago, aged care facilities had many more residents – including younger people – with advanced Multiple Sclerosis. Now, with the availability of higher efficacy disease modifying therapies, NDIS, My Aged Care and access to supports at home, the level of disability experienced by people living with Multiple Sclerosis has improved and the number of younger people entering aged care facilities for ongoing care has reduced.

On average, the lifespan for people with MS is around 5-10 years shorter than the general population but this gap is decreasing as treatments continue to improve. Currently the average age at death of a person with MS is 70 years.

MS affects over 33,000 people in Australia, with 2.8 million diagnosed worldwide. Most people are diagnosed between the ages of 20 and 40 but it can affect younger and older people too. Roughly three times more women have MS than men.

There are generally considered to be three types or presentations of Multiple Sclerosis.

RRMS – Relapsing Remitting MS is the most common of presentations of MS. Approximately 85% of people will be diagnosed with RRMS first. Symptoms both new and existing, flare up and then subside. This is the 'relapsing' period, the relapse is followed by a time of complete or partial recovery takes place which is referred to as remission or remitting. During periods of remission, all symptoms might disappear, however some might continue or become permanent. There is, however, no apparent ongoing accumulation of disability.

SPMS – Secondary Progressive MS can develop after many years of RRMS. It is a time where relapses are no longer defined, symptoms are not seen to subside, and recovery is not as complete. Increasing disability is seen in the person's physical condition. Prior to the disease modifying medications being available on the market, SPMS would develop after an average of 20 years of RRMS. Now, fewer people are likely to progress to SPMS or will take longer to accumulate disability.

PPMS – Primary Progressive MS makes up 10-15% of presentations. PPMS follows a progressive course from onset, with worsening neurological function and accumulation of disability despite absence of exacerbations. PPMS is more likely to be seen in males. Symptoms are less likely to improve, and the person will be experiencing increasing disability without the periods of remission or recovery as seen in RRMS.

By the time a person is residing in aged or disability care, they are generally considered to be in a Secondary Progressive stage of MS, without the expectation that symptoms will improve, rather that there will be a gradual deterioration in symptoms. By this stage any disease modifying therapy (DMT) may no longer provide a benefit and is likely to be stopped.

Symptoms of Multiple Sclerosis at end of life

MS is considered a chronic degenerative neurological disease. Towards end of life, severe symptoms and impairments do not respond effectively to the usual treatments. It is likely that a person's death will be caused by complications rather than the disease itself.

Some of the more complex symptoms include those listed below.

Mobility / paralysis

Multiple Sclerosis affects the ability to move freely and easily. Fluctuations in mobility can be caused by fatigue and heat sensitivity. An accumulation of disability occurs over the course of a person's disease.

The level of disability places the person at a higher risk of blood clots and falls. Falls with injury frequently precipitate the end of a person's life.

Progression of symptoms independent of relapse activity, is known as PIRA. PIRA is caused by chronic inflammation and neurodegeneration rather than lesion accumulation, and is the main cause of increasing disability in all types of MS.

Pressure injury and skin breakdown is common in people with MS at the end of their lives. Pressure breakdown occurs due to immobility and the loss of sensation to pressure areas. Diligence to pressure area care and the use of appropriate pressure relieving equipment as prescribed by an occupational therapist is vital at the end of life.

Immobility and inappropriate seating options often cause dependent oedema, which can be very painful. Care should be taken to ensure residents are not left with their legs in a dependent position. Elevation of legs and feet above the height of the heart will allow resolution of oedema.

Pain and spasticity

Pain in Multiple Sclerosis can be complex, involving many causes. As a result, we need to understand the reason for pain in our clients to understand how best to manage the pain.

Spasm: Sudden and painful involuntary tightening or contraction of a muscle. Muscle relaxants, stretching and massage are most effective in relieving muscle cramps and spasms. Heat and ice can also provide relief.

Spasticity: Abnormal muscle tightness and stiffness, causing limbs to feel heavy and difficult to move. Limbs may be locked in a bent position or feet and ankles crossed. Walking may no longer be possible due to spasticity in the legs.

Contracture: Shortening of muscles and tendons occur after periods of ongoing spasticity, making stretching the muscles no longer possible. The result is deformity, contracture and rigidity of joints. Often by the time a person enters the palliative stage the hip, knee and ankle joints show some degree of deformity.

Clonus / Myoclonus: Clonus is rhythmic, involuntary muscle contractions that occur when a muscle group is being stretched. We see this frequently as jerking movements of the legs. Myoclonus a brief muscle twitching.

Causes of complex pain include:

- **Neuropathic Pain** is caused by damage to the nerves in the spine and brain. Neuropathic pain feels like burning, aching, tingling, hypersensitivity or electrical shocks.
- **Lhermitte's Sign** is often a response triggered by movements of the head and neck and can feel like electric shocks running down the spine to the arms and legs. Some people describe it as a buzzing feeling. Fatigue, stress and heat can also be triggers. Often there is no treatment as it comes and goes so quickly. Neck and head movements that are known to result in Lhermitte's Sign should be avoided.
- **MS Hug** is a term given to muscle spasm pain that can feel like a tight band around the chest or stomach. MS Hug can be very painful, but like Lhermitte's Sign the pain can last a few seconds or several minutes. Massage, deep breathing and meditation can provide benefit as will drugs for neuropathy and antispasmodics.
- **Trigeminal neuralgia** affects the nerve running down the side of the face causing stabbing or burning pain. Trigeminal neuralgia can be caused by eating, talking or shaving. The pain can last seconds to minutes. Avoid triggers that bring on symptoms. Medication such as anticonvulsants are the drug of choice.
- **Uhthoff's Syndrome or phenomenon** is a temporary exacerbation of MS symptoms when the person's body is overheated: in warm weather, after strenuous exercise or when the person is unwell with a high temperature. Even a half degree rise in body temperature reduces nerve conduction speed in damaged nerves. Uhthoff's Syndrome may temporarily affect their vision, balance, fatigue, pain bladder issues, or cognition. Treatment is to manage the underlying cause, by getting out of the heat, drinking cool drinks and generally cooling the body down. Once the body temperature is returned to a normal level, symptoms will reduce.
- **Mental health pain** is common in people with MS. The rate of depression and anxiety, including the risk of suicide, is higher within the MS population than the general population.
- **Carer burden and relationship breakdown** are common concerns in people with MS and should be discussed regularly during the caring role. Provide information about available services and encourage engagement with those services.

Management of spasticity and spasm

- Benzodiazepines
- Antispasmodics
- Botox
- CBD Cannabidiol oil / Sativex® – Derived from cannabis, many people with MS claim benefits in pain relief, management of spasticity, relaxation and mood lifting. Sativex® can legally be prescribed in Australia.
- Occupational therapy and physiotherapy / massage
- Equipment, including pressure-relieving cushions and mattresses, and wheelchairs with leg elevation

- Heat packs, cooling packs and cooling garments
- Pressure area position changes

Management of general pain

- Change position, massage, heat and cold packs
- Occupational therapy and physiotherapy
- TENS (Transcutaneous Electrical Nerve Stimulation). Non-pharmacological treatment of pain and spasticity which stimulates nerve cells and blocks pain signals.
- Mental health support for both the patient and their carers
- General analgesics
- Opioids — not usually first line

Management of neuropathic pain

- Anticonvulsants
- Tricyclic antidepressants
- Anti-inflammatory medications
- Opioids — Tramadol
- CBD / Sativex®
- Steroids
- Topical creams such as Zostrix and Capsaicin

Sensory symptoms

- Sensory symptoms occur in approximately 40% of people with MS and are caused by the damage to nerves caused by the demyelination.
- A person may not be able to feel that their clothing is too tight, their drink is too hot, or even if the shower water is cold or hot or that they have been incontinent.
- A person may report sensory changes to their skin, including wetness, stabbing, prickling, numbness or electric shock sensations or hypersensitivity.

Respiratory changes

Respiratory function in a person with Multiple Sclerosis is affected by the weakening of the diaphragm and intercostal muscles and can result in chronic respiratory failure.

People with Multiple Sclerosis may also find they are not breathing deeply and have an ineffectual cough, leading to the increased risk of aspiration pneumonia, which is a leading cause of death in people with MS.

Breathing issues can also lead to poor sleep, altered levels of concentration and a weak soft voice.

Respiratory changes and respiratory failure at the end of life, can be managed by:

- Elevating the head of the bed slightly

- Using fans, and open windows
- Low dose Morphine

Fatigue

People with MS are encouraged early in the disease course to manage fatigue levels and avoid situations such as extremes of temperature, to aid in fatigue management.

80% of people with MS experience fatigue, at any stage of the disease progression. Fatigue can include physical and mental fatigue, and by end of life, people often report a constant exhaustion and weakness and often display mental confusion and disorientation.

Vision

Around 25% of all people with MS have reported that changes in their vision were a first symptom of MS. With Relapsing and Remitting MS (RRMS), symptoms often improve with time and steroid administration. As the disease progresses, half of people living with MS have accumulated changes to their vision that can include:

- Optic neuropathy
- Diplopia
- Impaired visual field
- Impaired colour discrimination

Poor vision is associated with lower quality of life, and increased frequency of falls.

Cognition

The accumulation of lesions and brain atrophy commonly causes changes in cognition in MS. Cognitive changes can occur at any stage of the disease process, however, will accumulate as disability progresses.

People with MS experience changes in memory, attention and concentration, and often describe a 'brain fog'. People living with MS experience symptoms including difficulty finding words, remembering things, and solving problems. General techniques aimed at helping people with cognitive deficits can assist. Managing all MS symptoms can also assist.

Preparation of legal documents may be impacted due to cognitive changes in people with MS.

Dysphagia and weight loss

The increase in weakness of the muscles required to chew and swallow food become weaker or stiffer, leading to choking risk and aspiration pneumonia.

Around 30% of people with Multiple Sclerosis will be offered PEG tube insertion, if their dysphagia is impacting hydration and nutrition. Managing prescribed food and fluid modifications is vital to avoid aspiration. At the end of life, dehydration and malnutrition should be managed conservatively.

Remaining engaged with speech therapists and dieticians is vital to ensure food and fluid consistencies are appropriate for the resident. Weight loss is frequently seen at end of life. Aspiration pneumonia is a common cause of death.

Sialorrhea

Damage to the nerves of the facial muscles including the tongue, lips, jaw and pharynx results in changes to swallow. MS doesn't result in increased production of saliva, rather a decrease in effective swallow. The result is pooled saliva which spills from the lips. Sialorrhea can be an embarrassing situation during the course of the disease and is often treated with Botox injections or radiation.

At the end of life, excessive secretions can be more problematic. Management of the excessive saliva can be effectively managed with the use of medications, both oral and subcutaneous.

Damage to the trigeminal nerve occurs in MS, creating severe pain in the lower jaw, teeth, and gums. Something as simple as brushing a patient's teeth can trigger symptoms of trigeminal neuralgia.

Many of the DMT's used to treat the disease can cause dental decay, gum disease and mouth ulcers. By end of life most people are no longer actively receiving DMT's but residual damage to the teeth and gums remains.

Managing sialorrhea and mouth pain should be aimed at treating the cause of pain or by managing excessive secretions balanced with dry mouth.

Speech and communication

At end of life, dysarthria is common for people with MS. Speech disorders can be mild or severe, leading to the inability to communicate. Remaining engaged with speech therapists will allow a person with MS to adopt assistive devices to aid communication.

Bowel and bladder

Bladder dysfunction in MS can be caused by spasticity in the detrusor muscle of the bladder causing an overactive bladder that empties at low volumes or incomplete emptying of the bladder. High urine residual amounts place the resident at higher risk of bladder and kidney infections. Many people by the end stages of their disease will have an indwelling catheter.

Antibiotics for urinary tract infections may be necessary. Consider the client's Advance Care Plan and Goals of Care.

Constipation caused by decreased fluid intake and immobility can be managed with aperients. A loss of sensation around the perianal area may result in the person being unaware they have been incontinent of urine or faeces.

Heat and cold sensitivity

People with MS can experience sensitivity to heat and cold. This sensitivity exacerbates the symptoms of blurred vision, fatigue and weakness. To manage heat and cold sensitivity people are encouraged to avoid the heat of hot weather, use air-conditioning and take measures to keep the body at cooler temperatures. Using cooling packs, cooling clothing items and layered clothing assists.

At the end of life, carers should take measures to ensure the resident's room is cool and they are not overheated due to bed clothes and clothing.

Emotional wellbeing and mental health

Studies show depression and anxiety are symptoms of MS, rather than being caused by having MS.

People living with MS have a higher prevalence of mental illness compared to the general population. Research indicates that 90% of people living with MS live with other chronic conditions, resulting in poor mental health. Including:

- Emotional distress
- Anxiety — people with MS are 2-3 times more likely than the general population to experience anxiety
- Insomnia/fatigue
- Depression — studies show that 30% of people with MS have depression
- Suicidal ideation or attempts

Management of mental Illness can include

- Use validated tools to assess for concerns of mental health such as the 'Psycho-existential Symptom Assessment Scale'
- Psychological therapy — Cognitive Behavioural Therapy CBT
- Medication
- Counselling
- Pastoral Care

Future considerations

Advance Care Planning / Goals of Care

Advance Care Planning allows the person to share their goals, values, beliefs and preferences for the time when they are no longer able to communicate their choices. MS often robs the person of their ability to communicate and can cause cognitive changes at the end of life.

To allow people with MS to discuss and document their wishes, it is imperative to ensure they have the often-difficult conversations prior to the loss of ability to communicate and prior to any significant cognitive impact.

Goals of Care (GOC) are usually formulated when people with MS present at the hospital. They can guide the treating team to understand what the individual goals are for the person with MS.

Appointing substitute decision-makers early ensures the person at end of life will have their goals and life choices recognised.

It is vital to encourage (where possible) continued engagement with Neurologists and Allied Health Teams to ensure clients or residents are receiving best practice care.

Referrals to community palliative care teams

Community palliative care teams can provide symptom management for people with MS. The complex pain that most people with MS experience at the end of their lives is not often managed effectively with simple analgesia, and advice on management strategies is appreciated.

Symptoms of the final stages of MS vary from person to person. Emphasis must be on recognising the signs of deterioration in any person with a chronic condition. This will allow people with MS to engage, in a timely manner, with community palliative care teams.

MS is considered end-stage when symptoms lead to life-threatening complications. Early referrals can allow the palliative care teams to develop a working relationship with the client with MS and their family and loved ones.

Support for health professionals working with people with Multiple Sclerosis

- MS Plus covers New South Wales, ACT, Victoria and Tasmania and has a variety of webinars and fact sheets on its website:
  - https://www.msplus.org.au
- MS Plus Connect offers a phone service:
  - **1800 042 138**

Conclusions

Most people do not die from Multiple Sclerosis alone. Deaths attributed to MS are commonly caused by infection (especially respiratory and urinary tract related); conditions associated with advanced disability and immobility, such as aspiration pneumonia; and chronic respiratory disease.

By increasing awareness of the complex issues people with MS may experience at the end of life, it is hoped more people will be referred to community palliative care teams to be provided with support to reach a 'good death'.

Care Plan for Multiple Sclerosis in Palliative Care

This care plan was developed with the assistance of Bridie Phillips, MS Nurse Advisor, MS Plus.

Care Need	Goal	Required Action	Outcome
Future planning • Advance Care Plan completion • Medical Treatment Decision Maker known prior to communication or cognitive change	• Advance Care Plan in place • Access to relevant medical, legal, financial and counselling services as required • Goals of Care (GOC) are known and stored in appropriate place	• Clients wishes known and documented and distributed • Medical treatment decision maker identified • Legal and financial issues addressed • Client and carer education and support	• ACP documented and communicated to all involved with client • All measures taken to ensure affairs are completed to client and carer satisfaction
Pain	• Client reports pain is managed • Client appears to have pain managed • Client appears to be comfortable	• Ongoing assessment of type of pain using validated tools • Correct administration of pain medication and appropriate route • Use position change for managing pain • Use warmth/cold to manage cramp and spasm if appropriate • Use diversionary techniques if appropriate and use allied health assessment	• Client's pain is adequately managed
Fatigue	• Fatigue is managed • Client can have quality time with family and be involved in discussions with health care providers by understanding fatigue levels and triggers to exacerbation	• Client assessment of triggers to fatigue and interventional measures to maximise energy levels, i.e. aircon, rest periods, sleep quality at night • Awareness that fatigue can impact pain levels, mental health state and cognitive function	• Client's fatigue is adequately assessed to ensure minimal negative impact and client can participate in and enjoy interactions with family, health professionals and caregivers without exacerbation of fatigue levels

Care Need	Goal	Required Action	Outcome
		• Client assessment of best timing for activities such as family visits, medical discussions, and decision making	
Heat and cold sensitivity	• Symptoms of MS are not exacerbated by fluctuations of heat and cold	• Cooling products are made available • Access to products for providing warmth such as heated socks • Airconditioning and fans are used • Bed cradles • Manage activities in the heat of the day • Be aware of bed clothing • Layered clothing for ease of cooling	• Client can treat the symptoms of heat or cold sensitivity with products provided and caregivers are aware these symptoms can change rapidly
Mobility	• Carer and client can transfer and operate safely and comfortably • Pressure area concerns are addressed	• Referral and continual reassessment with the physiotherapist / occupational therapist • Carer and client education and support re transfers and equipment • Equipment obtained for pressure area care	• Risk of injury, discomfort is reduced, and carer burden is lowered • Skin intact and free from pressure area injury • No carer injury from poor transfer technique
Sialorrhea	• Client not experiencing distress from sialorrhea	• Access to speech pathologist and medical services for information on how to manage secretions • Medication for excessive sialorrhea • Skin protection and clothing protection	• Secretions monitored and symptoms alleviated / managed
Dysphagia / Swallow	• Ensure resident's nutritional status is maintained • Identify intake issues / changes promptly and refer	• Current weight • Frequency of weight assessment • Weight loss is a risk • Oral Intake yes / no	• Weight loss refer to dietician • Increased episodes of difficulty swallowing, coughing or

Care Need	Goal	Required Action	Outcome
	to allied health professional as needed • All staff trained in method of nutritional intake	• Fluid thickness (use IDDSI framework) • Food Grade Assistive devices used (2 handled mug, plate guard, assistive cutlery etc.) • Any supplements being provided (type, amount, and frequency) • Amount/ type of assistance required – e.g. sitting upright during meals and 30 minutes post feed, staff assist with feeding, teaspoon used for feeds, double swallow between	choking refer to speech pathologist • Episode of aspiration pneumonia refer to speech pathologist and consider Advance Care Plan
Continence	• Client free from discomfort of bowel incontinence • Client free from discomfort from constipation • Client free from discomfort of bladder incontinence • Client free from adverse events due urinary retention • Minimise risk of infection • Monitor Bladder function • Maintain dignity: loss of sensation perianal region	• Use of aids and equipment and appropriate transfers to ensure mobility and safety for toileting • Adequate hydration and nutrition • Monitor side effects of medications • Monitor for constipation • Treat constipation with aperients • Regular review by dietician • Monitor bladder changes • Regular assessment for bladder infection • Care of in-dwelling catheter or supra-pubic catheter if necessary	• Regular bowel habits • Optimal well-being maintained • Side effects managed • Bladder free from infection • Catheter care • Dignity maintained
Respiratory function	• Client will be free from distress of respiratory failure	• Respiratory failure managed • Elevate head of bed • Low dose Morphine / Rivotril for anxiety • Improve air flow in the room and room temperature	• Record and document concerns • Medication for EoL care in the home • Room ventilation • Elevated head of the bed

Care Need	Goal	Required Action	Outcome
			• Client comfort maintained
Communication / Dysarthria	• The client can communicate effectively with treating team without explaining it to new staff • Communication equipment is supplied in a timely manner and suits the needs of the client	• Ensure current forms of communication are known and documented • Ensure those in contact with the client know how to communicate with the MS person • Regular assessment and review with speech pathologist	• Fatigue is reduced • Communication is optimal • The client feels supported, listened to and is able express their personality, values and wishes
Mental health concerns • Grief and loss • Inability to communicate pain / discomfort • Cognitive dysfunction: inability to retain information or process information, amplified with high levels of pain, fatigue, poor sleep	• Acute mental health concerns are managed • Mental health of client and carer are addressed and managed	• Provide emotional support to client and carers • Refer to counsellor / spiritual leader / allied health for interventional aids for communication • Ensure decision-making and important discussions are in periods where client is alert • Family meetings to ensure client / carers and family are all on same page • Ensure symptoms are well managed so no interplay with mental health status	• Client's wellbeing and mental health is adequately nurtured, and mental health is well supported in an appropriate way
Quality of life	• Optimal symptom control • Participation in activities of choice	• Ongoing assessment of quality of life • Consider therapies that will assist relaxation and wellbeing, e.g. music therapy, counselling, pastoral care • Care and support for carers • Bereavement support	• Maximise quality of life with interventional therapies, medications and mental well being

Further resources from SMRPCC

We've also published the following guides about progressive neurological diseases, which you can find on the Resources page on our website - https://smrpcc.org.au.

MND

- MND – Information for the Palliative Care team
- MND – Information for the Aged Care Team

Parkinson's

- Deterioration in Parkinson's Disease
- Parkinson's Disease – Issues for the Aged Care Team
- Parkinson's Disease – Issues for the Palliative Care Team
- Parkinson's Disease – Palliative Care Conversations
- Parkinson's Disease – Palliative Care Conversations-Facilitators Guide