MOTOR NEURONE DISEASE AND THE ALLIED HEALTH TEAM

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KEYWORDS
Motor Neurone disease
Allied health-led model
Multidisciplinary care

EXECUTIVE SUMMARY
Motor neurone disease (MND) has complex symptoms and often rapid deterioration. This case study provides an overview of a 67-year-old man with MND who had complex psychosocial and functional needs as well as nutritional, communication and nursing / medical requirements. The regional Palliative Care Service managing his care has an Allied Health MND service pathway. This supports people diagnosed with MND from diagnosis though to Palliative Care referral and death. The management of this gentleman shows how the different skillsets of every member of the multidisciplinary team helped maintain quality of life, manage complex symptoms and support a dignified death.

INTRODUCTION

MND is a complex disease process. The average life expectancy is 2 years with an expected rapid functional deterioration impacting every aspect of a person's life. To manage these clients a true multidisciplinary approach is required. Often the clinicians must scramble to keep up with the goals and functional needs of a client as they deteriorate quicker than the assessment and intervention process.

This case study explores the comprehensive care of a client with MND, a complex neurodegenerative disease. Interventions utilised the skills of a diverse multidisciplinary team. Best outcomes are noted when a service works collaboratively with effective communication and responsive care to support patient decision-making.

YEAR CASE STUDY WAS IMPLEMENTED

2023 to 2024

CASE STUDY DETAIL

Issue:

Mr M was a 66 year old male when he was diagnosed with MND. Prior to his diagnosis he was a very active and fit family man.

Due to his age Mr M did not qualify for the NDIS and when initially assessed by My Aged Care (MAC) did not meet the guidelines for a home care package due to high level function. Expected deterioration was not predicted by the assessor. Within six weeks there was rapid change and delayed reassessment. Final assessment was for a level 4 Home care package.

Mr M's pattern of deterioration was typical of the Amyotrophic Lateral Sclerosis (ALS) subtype, affecting both his upper and lower motor neurons. His mobility was first affected with weakened lower limbs, progressing to upper limb changes, which caused a cessation to his gardening hobby, and then interruption all activities of daily living. His swallow function became impaired and in the last 6 months of his life speech was affected. In the final 2 months he had no verbal communication. His cognition was not affected at any point although emotional lability was present.

During the 15 months from diagnosis to death, MND had profound impacts on Mr M's life. He had anxiety and depression, a facial pressure area, pruritus, lower limb oedema, deep vein thrombosis (DVT) as well as the changes associated with loss of all motor movement.

Approach:

Mr M was referred to the MND Outreach Allied Health service in January 2023. This multidisciplinary team provides assessment and management by multiple Allied Health clinicians with direct collaborative and operational pathways to the Specialist Palliative Care Service. The team works under the National Institute for Health and Care Excellence (NICE) guidance and provides evidence-based recommendations, monthly MND case conferences and timely and coordinated care. Mr M was supported to achieve his goals of spending time with his family, maintain dignity and communicate until the final day of his life. He also requested organ donation and Voluntary Assisted Dying (VAD). The team were able to recommended timely access to the Palliative Care service, and collaborate with other stakeholders including MND NSW, MAC, VAD, and organ donation to support his wishes.

***Summary of activities*:**

Mr M worked with the Allied Health team directly to manage needs:

Occupational Therapist: home modification, self-care, pressure care and wheelchair assessments; equipment prescription; and communication aid set up.

Physiotherapist: falls and mobility assessments and prescription for aids including for foot drop; and respiratory management including interventions for breathlessness, non-invasive ventilation (NIV), cough assist and secretion management.

Speech Pathologist: ongoing swallow assessment and information regarding percutaneous endoscopic gastrostomy (PEG) placement; oral hygiene education; assessment and education for augmentative and alternative communication (AAC) including eye gaze.

Dietitian: ongoing nutritional assessment and management including support and education for PEG feeding.

Social Worker: management of adjustment issues, anxiety and relationship building; support and coordination of the complex network of external stakeholders including centrelink, home care package, VAD and organ donation.

Clinical Psychologist: joint working with Social Work to assist with management of adjustment issues, anxiety and relationship building.

Palliative Care Medical and Nursing team: Complex symptoms management of pruritus, pain, breathlessness, pressure injury and bowel care in a home setting.

***Outcomes and Impacts**:*

- Palliative Care Outcomes Collaboration (PCOC) phase remained mostly stable due to good anticipatory and responsive care.
- Equipment and home modification supports aligned with RUG-ADL.
- Goals achieved such as being able to shower and toilet safely, sit out of bed and be with family.
- Mr M was able to communicate his end of life care wishes until the end.

Scalability:

This Allied Health MND outreach service utilises the staff from the Specialist Palliative care Service which is an already established, multidisciplinary team. The implementation of this is cost neutral, but requires consideration to workloads of staff. The pathway can be shared and set up in other services to ensure care for clients with MND is timely and based on the NICE guidelines.

Critical success factors:

- A specialised service is required to provide high level assessment and intervention to the complexities of MND.
- The Allied Health team lead and supported the client through their journey.