“OPPORTUNITIES ARE LIKE SUNRISES… IF YOU WAIT TOO LONG YOU’LL MISS THEM”  

William Arthur Ward

DEVELOPING AN INTEGRATED MODEL FOR MND CARE IN THE ILLAWARRA

Sue-Ellen Hogg – Speech Pathologist

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Current model of care - Overview

- Integrated multidisciplinary model of care
- Shared management by rehabilitation and palliative care from diagnosis
- Dedicated multidisciplinary allied health palliative care team across disease progression
- Staged transition specialist nursing/medical management from rehabilitation to domiciliary palliative care
- ‘Care coordinator’ model
- Utilisation of PCOC* assessment tools to facilitate patient directed care and enhance communication

*Palliative Care Outcomes Collaboration

Service Demographics

- Multi-disciplinary team based at Port Kembla Hospital provides support to MND clients and their families across the Illawarra

Illawarra Region extends from Helensburgh to Foxground (~90 km)
Population: 280,000
Average MND caseload: 18-20

Historical service…circa 2009

- Integrated multidisciplinary model of care
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Issues & gap analysis

Patient/staff perspective

- "Siloed" care – care compromised due to lack of:
  - Coordination
  - Continuity
  - Consistency

- No social work/Psychology

Evidence and best practice guidelines

- Multi-disciplinary clinics
  - "Coordinated multidisciplinary care is the cornerstone of management" (Leigh et al. 2003)
    - Improved prognosis
    - Improved QOL for patient and carer

- Palliative Care
  - "A palliative care approach is required from diagnosis to ensure that early discussions around end of life decisions are held and optimal symptom management for the person with MND and their family is achieved" (MND Australia, 2010)

- Respiratory Management
  - "Non-invasive ventilation using bi-level positive airway pressure prolongs survival and should be offered to PALS" (Bedlack, 2010)
    - Randomised controlled trial demonstrated median survival 7 months
    - Significant and sustained improvement in QOL

Seizing opportunities for change

- Utilising Dietetics Masters student to conduct formal gap analysis
- Developing business case for redesign – access to resources
- Investing in service development and coordination
- Utilising MND NSW support – local education day
- Formalised pathway of care...
Dedicated allied health palliative care team manage MND clients from diagnosis:
- Including social work!
- Referral to one – access to all ☑
- ‘Care coordinator’ allocated
- Multidisciplinary assessments/visits
- Access to palliative care specialist medical and nursing – including afterhours nursing care when needed
- Access to palliative care equipment loan pool
- Support group

Shared medical/nursing management
- Initially rehabilitation specialist and rehabilitation CNC
- Registered with and provided information about specialist palliative care service early – patient can opt in/out along the way
- Milestones in care mark transition
  - Unable to attend hospital
  - Complex symptoms affecting QOL
  - Afterhours support required

Sydney Clinic
MND NSW RA
PKH Rehab Specialist

Palliative Care Allied Health Team
OT, PT, SP, Dietitian, SW + Support Group + PC Equip.
Nursing
Rehab CNC
PC CNC & AH
Medical
Support Services

85% MND clients access to palliative care approach
Increased number of patients choosing to be managed locally
Reduction in acute hospital admissions
Increased number of patients supported to die in location of choice
Where to next…

- Extend model to Shoalhaven
- Integrated pathway for respiratory management
  - Assessment & monitoring
  - NIV access
  - Multidisciplinary management of dyspnoea
- Benchmarking and KPIs – holding ourselves accountable for 100% patients!

References