

“OPPORTUNITIES ARE LIKE SUNRISES...
IF YOU WAIT TOO LONG YOU'LL MISS
THEM” *William Arthur Ward*

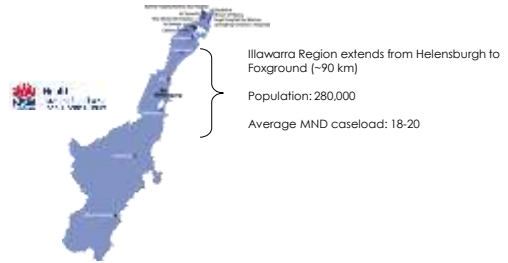


DEVELOPING AN
INTEGRATED
MODEL FOR MND
CARE IN THE
ILLAWARRA

Sue-Ellen Hogg – Speech Pathologist

Service Demographics

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

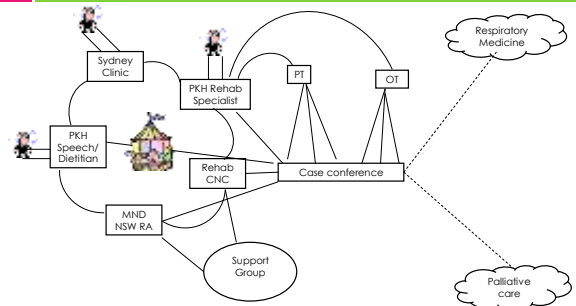


Current model of care - Overview

- 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

Historical service...circa 2009



Issues & gap analysis

Patient/staff perspective

- 'Siloed' care – care compromised due to lack of:

- × Coordination
- × Continuity
- × Consistency



- No social work/Psychology

Issues & gap analysis

Patient/staff perspective

- Lack of timely palliative care involvement
 - 30% accessed palliative care
 - 5% prior to terminal phase
- Associated with high levels of carer stress
 - Difficulty accessing appropriate care in the home
 - Distressing acute admissions
 - Poorer quality of life
- Patients, carers and clinicians all rated improving access to early PC as a high priority

Issues & gap analysis

Evidence and best practice guidelines

- Multi-disciplinary clinics ⁽¹⁻⁴⁾
 - "Coordinated multidisciplinary care is the cornerstone of management" (Leigh et al. 2003)
 - Improved prognosis
 - Improved QOL for patient and carer
- Palliative Care ^(5, 6, 9)
 - "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 ^(4, 7-9)
 - "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...



Current Model and Pathway

- 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

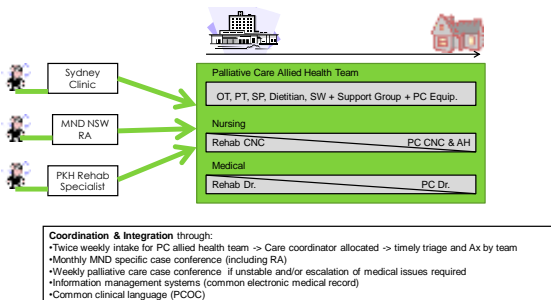


Current Model and Pathway

- 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



Current Model and Pathway



Outcomes

- 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

1. Leigh et al. (2003) The management of motor neurone disease. *Journal Neurology Neurosurgery & Psychiatry* 74:32-47
2. Traynor et al (2003) Effect of a multidisciplinary amyotrophic lateral sclerosis (ALS) clinic on ALS survival: a population based study, 1996-2000. *Journal Neurology Neurosurgery & Psychiatry* 74: 1258- 1261
3. Miller et al. (2009) Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: multidisciplinary care, symptom management and cognitive impairment (an evidence based review). *Neurology* 73: 1227-1233.
4. Bedlack (2010) Amyotrophic lateral sclerosis: current practice and future treatments. *Current Opinion in Neurology* 23: 524-529.
5. Oliver et al. (2010) *Palliative Care in Amyotrophic Lateral Sclerosis, (2nd edition)* Oxford University Press.
6. MND Australia (2010) *Palliative Care and People living with MND – Policy and Position statement*
7. Miller et al. (2009) Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional and respiratory therapies (an evidence based review). *Neurology* 73: 1218-1226.
8. Bourke et al. (2006) Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial. *Lancet Neurology* 5:140-147.
9. MNDA UK (2008) 'Year of care pathway'

