Encountering Transverse Myelitis: The Patient Journey and Health Practitioner Experience

Josh Caldwell
Family & Peer Network Coordinator, New Zealand Spinal Trust

Karen Marshall RN MN
Clinical Nurse Specialist, Burwood Spinal Unit
Introduction

- What is Transverse Myelitis
- Admission, Diagnosis, Treatment in ICU
- Transfer and Weaning Rehab in BSU
- Weaning Rehabilitation in BSU
- Discharge

- Josh’s World View
Levels of Practice Definitions: Enrolled Nurse

<table>
<thead>
<tr>
<th>Competent Level</th>
<th>Proficient Level</th>
<th>Accomplished Level</th>
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<tr>
<td>• Under the direction of the RN, contributes to assessment, planning, delivery and evaluation of nursing care</td>
<td>• Utilises broad experiential and evidence-based knowledge to provide care</td>
<td>• Demonstrates advancing knowledge and skills in a specific clinical area within the enrolled nurse scope</td>
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<td>• Develops partnerships with clients that implement Te Tiriti o Waitangi in a manner which the client determines is culturally safe</td>
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<td>• Applies knowledge and skills to practice</td>
<td>• Has an in-depth understanding of enrolled nurse practice</td>
<td>• Contributes to the management of changing workloads</td>
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<td>• Has developed experiential knowledge and incorporates evidence-based nursing</td>
<td>• Contributes to the education and/or preceptorship of enrolled nurse students, new graduate EN, care givers/healthcare assistants, competent and proficient EN</td>
<td>• Gains support and respect of the health care team through sharing of knowledge and making a demonstrated positive contribution</td>
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<td>• Is confident in familiar situations</td>
<td>• Acts as a role model to their peers</td>
<td>• Undertakes an additional responsibility within a clinical/quality team, e.g. resource nurse, health and safety representative, etc</td>
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<tr>
<td>• Is able to manage and prioritise assigned client care/workload appropriately</td>
<td>• Demonstrates increased knowledge and skills in a specific clinical area</td>
<td>• Actively promotes understanding of legal and ethical issues</td>
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<td>• Demonstrates increasing efficiency and effectiveness in practice</td>
<td>• Is involved in service, professional or organisational activities</td>
<td>• Contributes to quality improvements and change in practice initiatives</td>
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<td>• Responds appropriately in emergency situations</td>
<td>• Participates in change</td>
<td>• Acts as a role model and contributes to leadership activities</td>
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PDRP Competencies

1.1 Accepts responsibility for ensuring that his/her nursing practice and conduct meet the standards of the professional, ethical and relevant legislated requirements.

1.4 Promotes an environment that enables health consumer safety, independence, quality of life, and health.

1.5 Participates in ongoing professional and educational development.

1.6 Practises nursing in a manner that the health consumer determines as being culturally safe.

2.1 Provides planned nursing care to achieve identified outcomes.

2.6 Contributes to the health education of health consumers to maintain and promote health.

3.3 Uses a partnership approach to enhance health outcomes for health consumers.
Transverse Myelitis

• Neurological disorder
  – Inflammation across both sides of one level or segment of spinal cord
    • *Transverse* – position of inflammation
      – Across the width of spinal cord
    • *Myelitis* – Inflammation
      – Damage or destroy myelin
  – Nervous system scars interrupt the communication pathways between the nerves in the spinal cord and the rest of the body
Transverse Myelitis

• Cervical (Neck) Nerves
  – Neck, arms, hands, muscles of breathing
• Thoracic (Upper Back) Nerves
  – Torso, some parts of arms
• Lumbar (Mid Back) Nerves
  – Hips, legs
• Sacral Nerves
  – Groin, toes, some parts of legs
Epidemiology

- 1-8 per million per year
- Thoracic most common
- Ages 10-19 and 30-39 predominately
- No gender or familial association
- 75-90% monophasic, small percentage reoccurrence
- Some type of permanent disability
Causation

• Complication as a result of
  – Syphilis, measles, Lyme disease

• Viral infections
  – Varicella zoster, herpes simplex, cytomegalovirus, Epstein-barr (HPV-4), influenza, echovirus, HIV, hep A, rubella
Signs and Symptoms

• Presentation
  – Rapidly progressing muscle weakness or paralysis
    • Lower extremities first
    • Potentially moving to the arms with varying weakness
  – Sensation diminished below level of SCI
  – Pain and temperature sensation diminished
    • Parathesis – tingling, coldness, numbness, burning
  – Joint position – proprioception may be decreased
  – Bladder, bowel function, sexual function affected
  – Spasticity
  – Fatigue and Depression
Treatment

• No effective cure
• Corticosteroid therapy
• Plasma exchange
• Mechanical ventilation
• Interdisciplinary rehabilitation
  – Mobilisation, bladder, bowel, sexual, skin, spasticity, pain, depression, ADL’s
Prognosis

• Recovery begins
  – 2-12 weeks from onset
  – May continue up to 2 years

  – 1/3 little disability
  – 1/3 moderate disability
  – 1/3 no recovery
Josh
Admission

• 1148 hours 06 March 2016 Presented to ED with neck and upper back pain
  – Pain started yesterday numbness and tingling in hands
    • Hx of presenting complaint
      – Previous morning onset of neck stiffness and upper body stiffness
      – States fell out of the car as legs “wouldn’t work”

• Objective, General Appearance, Behaviour, Examination Findings
  – Restless, moving around in bed
  – Weaker in R) limbs – particularly arm ? behavioural
• Organic pathology not explained
• Maintaining normal sats and gases
• No UMN signs
• Guillain-Barré syndrome
  – MRI brain and C Spine, LP
  – Monitor Peak Flow, Bladder scan
  – ICU Outreach Team Informed
06 March 2016

- 1621 Transferred to EOA
- 1920
  - Peak flow 0.98 / Feels breathing is shallow
  - Lost sensation in L) leg
    - Hourly peak flows
    - NMB
    - IVF
- ICU Admission
  - ECG Sinus Bradycardia
  - IDUC inserted / O2 at 2 litres via nasal cannula
  - Elective intubation
Diagnosis

• MRI
  – Anterior spinal artery infarction
  – Transverse Myelitis
  – CTA - NAD
  – LP – NAD
  – Nerve Conduction Studies – NAD

• Transverse Myelitis
  – Corticosteroid treatment
  – Plasmapheresis (13 March – 5 doses)
ICU Interdisciplinary Treatment

- **SLT review**
  - Cough & swallowing assessments, cuff deflation

- **Physiotherapy**
  - Chest care - IPPB, passives, limb positioning, mobilisation

- **Medical**
  - Ventilation, percutaneous tracheotomy

- **Social Work**
  - Diary provided, supported the family

- **Nursing**
  - Collaboration with other disciplines
Transfer to BSU – 30 March 2016

- BSU nurse
- 1° Weaning from ventilation
  - Mandatory Mode of Ventilation - V A/C
  - Cuff deflation
  - Progressive ventilator free breathing (PVFB)
  - Off vent for turns
  - Cough assist machine, neublisers
SLT Input - interdisciplinary

• Cuff deflation as tolerated
• Eat with cuff down
• 4\textsuperscript{th} March Portex Speaking Valve
  – 10 mins initially as part of two hour wean
  – Rapid progression to full use during awake hours

• 14 April 2016 off vent 0715
• 18 April 2016 tracheostomy removed

• Rehabilitation for independence
NZ Transverse Myelitis Support Group
www.myelitis.org.nz

The Transverse Myelitis Association
www.myelitis.org