

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

Competent Level	Proficient Level	Accomplished Level
<ul style="list-style-type: none"> • Under the direction of the RN, contributes to assessment, planning, delivery and evaluation of nursing care • Develops partnerships with clients that implement Te Tiriti o Waitangi in a manner which the client determines is culturally safe • Applies knowledge and skills to practice • Has developed experiential knowledge and incorporates evidence-based nursing • Is confident in familiar situations • Is able to manage and prioritise assigned client care/workload appropriately • Demonstrates increasing efficiency and effectiveness in practice • Responds appropriately in emergency situations 	<ul style="list-style-type: none"> • Utilises broad experiential and evidence-based knowledge to provide care • Develops partnerships with clients that implement Te Tiriti o Waitangi in a manner which the client determines is culturally safe • Has an in-depth understanding of enrolled nurse practice • Contributes to the education and / or preceptorship of enrolled nurse students, new graduate EN, care givers/healthcare assistants, competent and proficient EN • Acts as a role model to their peers • Demonstrates increased knowledge and skills in a specific clinical area • Is involved in service, professional or organisational activities • Participates in change 	<ul style="list-style-type: none"> • Demonstrates advancing knowledge and skills in a specific clinical area within the enrolled nurse scope • Develops partnerships with clients that implement Te Tiriti o Waitangi in a manner which the clients determine is culturally safe • Contributes to the management of changing workloads • Gains support and respect of the health care team through sharing of knowledge and making a demonstrated positive contribution • Undertakes an additional responsibility within a clinical/quality team, e.g. resource nurse, health and safety representative, etc • Actively promotes understanding of legal and ethical issues • Contributes to quality improvements and change in practice initiatives • Acts as a role model and contributes to leadership activities

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

Canterbury

District Health Board

Te Poari Hauora o Waitaha



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

Neurologist Review

- 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

- 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
- 4th 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