

EXPERIENCES IN A TRANSITIONAL SPINA BIFIDA CLINIC IN REGIONAL NSW

Dr Jennifer Mann
Rehabilitation Physician
Port Kembla Hospital

INTRODUCTION

- A retrospective audit of clinical files 2006-2008
- Port Kembla Hospital 85 kms (90 minutes drive) south of Sydney.
- Paediatric spina bifida clinics located in Sydney

TRANSITION AND SPINA BIFIDA

- Losing young adults with chronic complex disability to follow up , poor adherence to treatments and thus poor health outcomes
- Spina bifida: Complex disabilities including cognitive issues, shunt issues, neurological and musculoskeletal issues, bladder and bowel issues

THE CLINIC

- 40 patients with spina bifida identified living locally in Illawarra
- Monthly clinic with doctor, spinal CNC and project manager
- Stand alone rehab hospital with outpatient allied health, seating clinic
- Identified local neurosurgeons and urologists

CLINIC MECHANICS AND REFERRALS

- 13 new patients
- 12/13 appointments made by mother
- No referrals from LMOs
- No referrals from paediatric spina bifida clinics
- No clinical information with patients (scans, past records)
- Mother's diaries most useful resource

PROBLEMS

- 4M/9F
- Age range 17-28 years
- None had been to spina bifida clinic in at least 7 years
- All had GPs but only for colds etc
- 8 had shunts, 2 had MRI in last 5 years
- 10 used manual wheelchairs, 5 used same one since early teens
- 11 used urinary catheterisation, 7 with recurrent UTIs, 3 had bladder/renal ultrasound in last 5 years

INTERVENTIONS

- Equipment referrals
- Bladder and bowel education
- Routine investigations
- Other specialist referrals

DISCUSSION

- Transitioning is important
- Need for education resources
- Seamless flow from paediatric to adult services???
- Role for adult rehabilitation services in management of young adults with complex disabilities