IMPROVING TRANSITION FOR YOUNG PEOPLE WITH RHEUMATOLOGY CONDITIONS, A WORK IN PROGRESS

Lynne Brodie: Transition Care Network Manager, Agency of Clinical Innovation

Jane Ho: Paediatrician, Trapeze, SCHN

MSK Forum October 28th 2016
ACKNOWLEDGEMENTS OF CONTRIBUTORS

- Anne Senner, NSW Paediatric Rheumatology Project Officer, SCHN Paediatric Rheumatology Department
- Fiona Niddrie, Clinical Nurse Consultant Rheumatology, John Hunter Hospital
- Helene Rickard, Clinical Nurse Specialist I Rheumatology Department, Liverpool Hospital
- Fiona Tickle, Physiotherapist Liverpool Hospital
- Geraldine Hassett, Rheumatologist, Department Head, Liverpool Hospital
- Davinder Singh-Grewal, Paediatric Rheumatologist, Liverpool, JHCH/JHH and SCHN
- Gabor Major, Director of Rheumatology, The Royal Newcastle Centre
- Yvonne Matar and Caitlin Holder, consumers
Trapeze

a supported leap into adult health
Who is Trapeze?

Trapeze is the specialist adolescent chronic care service for The Sydney Children’s Hospitals Network supporting young people with chronic conditions aged 14-25 years as they move from paediatric to adult health services.
What does Trapeze do?

Trapeze staff facilitate, monitor and coordinate a young person’s care and strengthen links with their GP and community, so whenever possible, they are able to better manage their condition and stay out of hospital.
Overall aim of Trapeze

The aim of Trapeze is for young people to better manage their conditions as they move over to adult services so they can live their own lives and stay out of hospital.

“There’s this thing called ‘Trapeze’ and it’s really really helpful.” Bec, 18
How Trapeze Can Help

Find GP/strengthen links with GP/develop GP Management Plan

Teaching self-management skills

Preparation for referral to adult health services

Ensure key professionals have information to support young person

Coordinated Care

Centrelink and Medicare card applications

Acting as young person’s advocate

Assist with obtaining medication and equipment

Sending SMS appointment reminders and attending appointments

Offering support to parents/carers

Linking young person in with support groups
Working In Partnership with the Agency For Clinical Innovation

• Trapeze and ACI work in partnership to provide transition services to young people with chronic conditions.

• Regular joint meetings to discuss referrals.

• Attend transition clinics together
‘Transition for Young People in NSW:
Role of the ACI Transition Care Network

Lynne Brodie
ACI Transition Care Network Manager
Structure of the Network

A Network that has a state-wide role and reports to the ACI Chief Executive via the Executive Committee and Director of Primary and Chronic Care – established 2002

- Funded to provide a manager, 3 full time coordinators + 3 part time support workers to provide a state-wide service

- Executive Committee chaired by Sue Towns and Mae Rafraf

- Working groups - connective tissue disorders, chronic pain, paediatric rheumatology, CF, primary urinary incontinence

- Since January 2014 working closely with Trapeze
Different transition approaches

- State-wide specialist service - needed for rare genetics, connective tissue disorders, complex CP, congenital cardiac

- Joint paediatric /adult clinics eg CF, neuromuscular RNS

- Disease based models – SBART (hospital or community based)

- Transition clinics – eg diabetes Westmead, Nepean, Campbelltown, Hunter, Concord, intellectual disability clinics at Fairfield, Cremorne and Kogarah

- School based clinics for intellectual disability in the Illawarra and Shire

- Telemedicine for rural /regional patients
Main objectives: Transition Network

- Transition Network
- Adult services aim for long term retention
- Children’s services to prepare well
- Prevent rebound
- Prevent falling through the gaps

‘Starting at 18 is way too late. It feels like falling off a cliff when children’s services cease and the future is uncertain’
How the Co-ordinators help

They can help young people and their families by:
- helping to find adult services and providing support by attending first clinic
- ensuring a comprehensive handover, organising case conferences
- providing information about health services, finances, education, NGOs
- assisting the young person and parent / carer to adjust to a new adult service and team and the different ways things may be done in the adult service
- contacting the young person / carer to make sure they have successfully engaged with an adult health service and help sort out follow up appointments

They can help health professionals by:
- linking with appropriate adult services
- providing resources to help prepare young people
- following through and providing feedback
Transition issues for young people with rheumatology conditions – what does the literature say?

- Those with more severe disease remain under rheumatologists but those who don’t, aren’t necessarily well controlled (Hilderson et al 2010)

- There is evidence that the quality of medical care decreases once patients leave paediatrics in the UK with decreased adherence and poorer outcomes (Beresford 2004)

- Young people growing up with JIA report significant psychosocial sequelae that impact on friendships, family, relationships, intimacy (Eyckmans et al 2011)

- There is little evidence to support the best model of care for transition and no consensus on the benefits of joint clinics or transition clinics
Transition issues for young people with rheumatology conditions in NSW

Transition is being addressed as part of the Paediatric Rheumatology Project led by Anne Senner / Robyn Speerin

- Lack of clear pathways for transition
- Lack of information about transition
- Lack of one stop shop multidisciplinary clinics in adult hospitals
- Problems finding youth friendly services
- Few transition clinics
Plans to improve care at John Hunter Hospital

- Plans for Adolescent and Young Adult with Rheumatic Disease (AYARD) to be run in adult clinic area, incorporating transition

- Target group - patients 14 years or older

- A rheumatology specific formal transition process is being developed, including appropriate readiness assessments, documented transition plans and education.

- Clinics to be staffed by a paediatric rheumatologist, an adult rheumatologist, paediatric registrar, rheumatology advanced trainee, rheumatology CNC. Coordination with the existing ACI Transition Coordinator

- Plans to work together with other rheumatology transition clinics (eg. Liverpool) and other sites around NSW to set up a similar process and uniform resources.
Plans to improve care at Liverpool Hospital

- Young persons clinic being developed that will incorporate transition
- First clinic planned for April 2017 and then every 4 months
- Looking at incorporating similar systems to John Hunter Hospital so that data can be compared down the track.
- ACI Transition Coordinator will be involved in the planning
Experiences of young people: Yvonne

- Now 21 and in new grad year as registered nurse at SCHN
- Diagnosed age 5 with dermatomyositis
- Methotrexate weekly, Prednisolone daily, IV Methylprednisolone and Folic Acid. Hydrotherapy and physiotherapy weekly
- March 2016 – muscle aches +++ afraid of relapse
- Saw paediatric rheumatologist who reassured her that all was OK
- Has not thought about transition as has been in remission for 6 years
Experiences of young people: Caitlin

- 18 next March. Attends Georges River College in Oatley and is sitting her HSC

- Problems with her ankles and toes diagnosed as tendonitis as a child. Developed swelling in her hands and knees in 2011 - diagnosed with Juvenile Idiopathic Arthritis.

- Managed with methotrexate orally for 2 years before injections but these ceased as they made her very ill and didn’t work.

- Commenced on Humira - ceased due to an allergic reaction. Had a flare up +++ and diagnosed with systemic arthritis. She was prescribed steroids and Endone - symptoms gradually improved.
Experiences of young people: cont

- Moved to Sydney 2015 with her family - referred by her GP to a specialist at Randwick Children’s Hospital. Now stable. Takes Enbrel and Panadol PRN

- Some concessions for the HSC - able to use a laptop instead of writing and having scheduled breaks during each exam.

- Reports that several friends are moving to her school and she will be able to help them to adjust

- Has not transitioned although the topic has been mentioned by her specialist. Friends who have transitioned and reports they found it very difficult mainly due to lack of support and information about what is available
Websites

www.kidslikeus.info/company/links.html

www.healthtalk.org/young-peoples-experiences/arthritis/topics

www.chimat.org.uk/default.aspx?RID=126939

Trapeze: www.trapeze.org.au