GETTING CONNECTED

Information on Transition from Children's Health Services to Adult Services

NSW Agency for Clinical Innovation

INFORMATION FOR PROFESSIONALS

The ACI Transition Care Network:

What is transition?

⇛ Transition refers to the 'purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from a child centred to adult oriented health care system' (Blum et al 1993).

⇛ The Transition Care Network for Young People with a Chronic Childhood Illnesses Group was convened in December 2002 by the Greater Metropolitan Clinical Taskforce (GMCT) which evolved into the Agency for Clinical Innovation (ACI) in 2010. The Transition Network is one of 22 ACI networks. In 2004 a Network Manager and three Transition Coordinators were appointed. The Coordinators are based at Royal Prince Alfred Hospital (RPAH), the Kaleidoscope team associated with John Hunter Children's Hospital (JHCH) and Westmead Hospital (WH). The Transition Care Network aims to provide a coordinated approach to improving systems and processes for young people with chronic illnesses/ disability as they move from paediatric health services to adult health services.

Why we need to concentrate on it

⇛ Research on transition indicates that the current health system does not generally manage the movement between child and adult care well. Evidence is increasing to show that lack of well planned, effectively coordinated transition processes lead to young people opting out of health services which may then result in poor health outcomes and crisis presentations.

⇛ Successful transition means that the young person maintains their health and quality of life and continues to use health care services appropriately.

When (should the transition process begin)

⇛ Literature suggests that initiating ongoing discussions about transition should begin when the young person is about 13 years old in order to allow enough time for planning this transition. This will vary for each young person according to their developmental level.

Help With Transition?

How is the ACI Transition Network helping to improve transition?

A range of generic tools to aid transition have been developed:

- ⇒ Fact sheets for young people, their families and clinicians
- ⇒ GP resource kits
- ⇒ Reference list, including websites
- ⇒ Transition checklists
- ⇒ Webpage **www.aci.health.nsw.gov.au**

The Network Manager and Coordinators have also;

- ⇒ met with key clinicians to identify service needs
- ⇒ encouraged young people and their families to have a say in what is needed to improve the current system through forums and surveys
- ⇒ collected data on existing transition programs and service gaps

For further information contact:

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Transition Coordinators

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TRANSITION PLANNING CHECKLISTS

These checklists are designed to stimulate thought and discussion about transition issues at various developmental stages for young people with chronic health conditions. They are intended to serve as a guide only.

It is impossible for any one health professional to have the time, or all the skills required, to address all the issues that might be relevant for a young person and their family. It is therefore important that they are given information on resources and that other professionals are involved to address specific issues relevant to the adolescent. Health professionals such as occupational therapists, social workers, youth health teams and psychologists can support young people in the areas of educational and vocational planning, social connectedness and sexual health.

These checklists can be used by professionals, parents and young people either on their own, or in conjunction with other more detailed tools such as the *Readiness for Assessment Checklist* available on the Transition website. A list of relevant adolescent services can be also be found on this transition website

NB: Customised checklists for a range of conditions as cystic fibrosis, diabetes and gastroenterological conditions are available on this website

EARLY STAGE TRANSITION
(12-14 years)

The young person and family are introduced to the transition process. The young person begins to participate in his/her own care. Skills are supported and practised at home.

Self-advocacy

- ❑ Educate the young person in describing their chronic health condition, including: medication taken, how to get help and the signs of deterioration. Review with family.
- ❑ Encourage the young person to ask questions during each appointment.

Independent health care behaviours

- ❑ Discuss the medications and treatments needed daily, including problems or barriers to compliance.
- ❑ Discuss purpose of Medical Alert ID bracelet and emergency treatments, if relevant, and advise how to seek help from others.
- ❑ Discuss transition and why it is undertaken.

Sexual Health

- ❑ Discuss puberty changes, differences from peers and the impact of puberty on their condition.
- ❑ Discuss where the young person and parents can obtain information about sexuality and puberty.

Psychosocial

- ❑ Talk to the young person about social activities, peer involvement and supportive relationships.
- ❑ Discuss external support options with the young person (peer support, internet, support organisations)

Educational and vocational planning

- ❑ Talk about responsibilities at home (e.g. chores).
- ❑ Discuss restrictions (real or imagined) on educational or recreational activities.
- ❑ Discuss strengths at school for later subject choices.

Health and lifestyle

- ❑ Ask about smoking, use of alcohol and street drugs.
- ❑ Discuss the impact of above behaviours on health and general well-being.

Parents/family

- ❑ Provide parents with the opportunity to discuss their feelings about loss of control, concerns about the future.
- ❑ Discuss how parents may help to facilitate their adolescent's independence.
- ❑ Encourage parents to prepare and support their adolescent to start asking direct questions of the health care team.

MIDDLE STAGE TRANSITION
(15-16 years)

The adolescent and family gain understanding of the transition process and the expectations of the adult system. The young person practises skills, gathers information and sets goals for participating in his/her care.

Self-advocacy

- ❑ Discuss strategies to access support and information about their condition and treatments (e.g. support groups, internet, library, condition-specific health associations).
- ❑ Direct questions to the young person, with the expectation they will answer them.
- ❑ Provide and encourage the opportunity to meet with the young person alone to discuss concerns/questions (especially about topics such as sexual health).

Independent health care behaviours

- ❑ Greet the young person in waiting room first and then invite the family in.
- ❑ Encourage the young person to make the next appointment, talk with receptionist and discuss transport.
- ❑ Check that the young person understands the differences they may experience between the paediatric and adult services.
- ❑ Encourage them to learn about their medication and practise having a prescription filled.
- ❑ Discuss when, how and from whom to seek emergency/medical help.
- ❑ Discuss increasing independence at home (taking own medication, making appointments).

Sexual Health

- ❑ Make comments/ raise topics around sexuality and changes in shape due to puberty. Do not expect or require a response.
- ❑ Encourage the young person to ask questions to clarify the impact of their condition and/or medications on sexuality.

Psychosocial

- ❑ Prompt the young person and parents to express positive goals for self and health.
- ❑ Encourage leisure activities such as joining a club at school, a community or peer support group or attending camp.
- ❑ Identify support systems outside the family and how to access psychological support if required.

Educational and vocational planning

- ❑ Focus discussion on school; strengths, plans for future vocation/employment/study.
- ❑ Encourage visits to school counsellors to talk about career preparation courses, work experience or volunteering

Health and lifestyle

- ❑ Discuss plans for driving and identify any restrictions.
- ❑ Discuss issues of body image feelings, communication with peers and concerns re: dieting, exercise weight gain or loss, alcohol and other drugs, mental health and risk taking behaviour.

Parents/Family

- ❑ Allow time for parents to express their own issues or concerns about transition without the young person present.
- ❑ Explore ways parents can help educate and support young person to further increase their independence.
- ❑ Discuss the option of young person attending part of appointment on their own.

LATE STAGE TRANSITION
(17-18 years)

The young person and family prepare to leave the paediatric system with confidence. The young person uses independent behaviours (as able) to move into the adult system.

Self-advocacy

- ❑ Discuss choices for adult care (specialists/hospitals/community services).
- ❑ Assist in choosing adult care providers (family physicians/specialists)/
- ❑ Discuss with the young person how they are going to be introduced to the adult services

Independent health care behaviours

- ❑ Check that the young person knows who to contact for future health needs (names and telephone numbers).
- ❑ Ensure the young person has met with adult specialist / family physician before discontinuing paediatric care.
- ❑ Check that the young person has a plan of who to contact in the event that new care arrangements at the adult facility do not meet expectations (GP or paediatric health care providers) and is encouraged to feedback about their encounter with their new health care providers.

Sexual Health

- ❑ Discuss genetic risks, sexual capabilities, fertility, sexual vulnerability.

Psychosocial

- ❑ Initiate discussion about mental health issues with the young person.
- ❑ Have the young person identify person(s) he/she can contact for help or advice.

Health and lifestyle

- ❑ Identify any needs for personal assistance in care or issues of living away from family.
- ❑ Discuss the use of smoking, alcohol and drugs, the interaction with medication and impact on illness/condition.
- ❑ Discuss any risk-taking behaviour.

Educational and vocational planning

- ❑ Discuss employment or vocational options.
- ❑ Discuss medical coverage, transportation, living arrangements, impact on health condition, if the young person is to attend university.

Parents/family

- ❑ Discuss with parents their changing role as support person rather than main care giver to young person.
- ❑ Encourage parent to feedback issues around the transition process.

REFERRAL PROCESS

Anyone can refer to the Transition Coordinators including young people and their families. The referral form can be downloaded from the transition website completed and forwarded to the Coordinator by email or fax.

Once referred, young people and their parents /carers are supported through the transition process. They can be assisted to find new adult health services, to make and be supported at first appointments and provided with transition information.

Feedback about the progress of transition can be provided to referring health professionals.

Information for young people and their parents and carers can be downloaded for the transition website