



Français en page 789

Transition to adult care for youth with special health care needs

The transition from childhood to adulthood is a life-phase that includes moving into the adult health care system. An increasing awareness of the need for transition services for youth with chronic health conditions has resulted from advances in medical technology and treatments that have increased the lifespan and quality of life of these youth. Developmentally appropriate care for adolescent patients with special health care needs should be integrated into paediatric and subspecialty practice structures. The transition is simpler for adolescents whose care is relatively uncomplicated, but even healthy teens may benefit from some transition preparation. Adolescents, their families and health care providers must work together to develop transition care that is effective in fostering health-promoting behaviours and in enhancing the long-term quality of the young adult's life (1,2).

The Canadian Paediatric Society supports the provision of developmentally appropriate care for youth with special health care needs as they move into the adult-oriented health care system. The present statement provides the background, framework and tools for paediatricians, family physicians, other health care professionals, parents and youth to ensure a successful transfer of care and transition to adult life.

CHILDREN AND ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS

As many as 15% of youth in North America have a chronic condition that impacts their health and causes some limitations in their lives (3). In British Columbia (BC), 9% of youth 10 to 14 years of age and 11% of youth 15 to 24 years of age have some disability due to a physical or mental health condition. In BC, most youth with chronic health conditions live at home; only 2% are institutionalized. Of those living at home, 89% are classified as mildly disabled, 8% are moderately disabled and 3% are severely disabled (4).

Two different cultures – paediatric- versus adult-oriented health care

Adult health care providers have identified a number of concerns about patients who have transferred from paediatric health care, specifically the lack of adherence to proposed treatment plans, deficiencies in knowledge about the condition and limited self-care skills (5,6). These differences may be partially explained by significant differences between the mandate and functioning of paediatric and adult services.

Paediatric care is family focused, relies on developmentally appropriate care with significant parental involvement in decision-making and prescribes care within a multidisciplinary team. Adult care is patient focused and investigational, requiring autonomous, independent consumer skills without many interdisciplinary resources (7). Adult health care differs significantly from paediatric care in the type and level of support, decision-making, consent processes and family involvement. These factors may play a role in the decrease in follow-up visits by youth after transfer to the adult care system. Some authors believe that this decline is, in part, attributed to the lack of transition planning and insufficient coordination with adult services (8).

Nonmedical issues addressed by transition care

Although researchers have found twice as many symptoms of depression, an increased incidence of social problems, and higher levels of stress in regard to death, body image, school and the future in these teens, many are emotionally and psychologically healthy, and may even report benefits – such as increased maturity and an ability to put things into perspective – from living with a condition (9,10). These youth need to be involved in activities consistent with their development, limitations and abilities. Self-esteem can be fostered by helping them acquire knowledge about themselves and their health condition, as well as by developing skills to express their needs and strengths (11,12).

Effects on the reproductive system, and consequences related to the underlying condition and its treatment, are important to adolescents, but the effects of their condition on sexuality are often unaddressed (13,14). As with all youth, sexually transmitted infections and contraceptive options need to be addressed (15). Young women need to know whether pregnancy will compromise their health and the effect that medical treatment may have on the fetus. Adolescents may be reluctant to ask whether their reproductive capacity is affected by their condition or its treatment (16-18).

Adolescence is a time when social conformity and acceptance by peers is important. Youth with chronic illness may experience social isolation, particularly if they have a visible disability or if they miss a lot of school. The transition to a normal adult social life can be inhibited by this isolation, by physical or cognitive limitations, and by health regimens that interrupt normal participation in daily

activities, school and social gatherings (19). An adolescent who has to spend time between classes and at lunch attending to treatments or medications misses invaluable social learning with peers (20).

Adults with a variety of chronic conditions have been shown to have higher unemployment rates (21). Without employment, young adults with disabilities are more dependent on parents and the health care system for medical coverage and cost of living. Adolescents and young adults with chronic health conditions may rely on extended health care benefits to cover or supplement the cost for medication, specialized equipment for mobility or communication, psychological support and counselling; marginal jobs often do not provide this coverage (22).

GENERAL PRINCIPLES FOR TRANSITION PLANNING

The Society for Adolescent Medicine states that, "all individuals, whether receiving primary preventative care or tertiary care, deserve services that are appropriate for their age and developmental stage" (23). Health care goals should include:

- adolescent involvement in management of the condition;
- adolescent and family understanding of the condition;
- understanding of personal potential for activity, education, recreation and vocation;
- completion of adolescent developmental tasks; and
- the attainment of self-esteem and self-confidence (23).

Transition – what does it all mean?

Transition has been defined as the "purposeful, planned movement of adolescents with chronic medical conditions from child-centred to adult-oriented health care" (1). The goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound before and throughout the transfer of youth into the adult system. The success of the transition is determined by both the process and the outcome of the person-environment interactions. By providing youth with developmentally appropriate knowledge and skills, we hope that they learn to advocate for themselves, maintain health promoting behaviours and use health care services into adulthood.

A successful process that prepares adolescents for adulthood and the adult system should be based on concepts central to positive youth development. Adolescents and their families should understand the condition and reasons for treatment, and have realistic expectations for the future (24). Knowledge and the opportunity to apply it may empower the adolescent to interact with family members and health care professionals, as well as participate in decisions that will affect their health (25). Knowledge alone does not ensure a successful transition, but without it, the teen enters the adult system at a significant disadvantage.

Core principles of transition planning

Preparation for transition starts early in childhood, with the health care team encouraging families to be informed participants in their child's care. The child should be given increasing levels of responsibility and information as they enter adolescence. As youth move closer to the age of transfer, professionals have the opportunity to provide developmentally appropriate information, and to teach skills of negotiation and communication required in the adult system.

Collaboration with family physicians and adult health care providers, including internal medicine specialists and agencies (to determine their expectations and available services in their area), is an ongoing process. Knowledge of community services is important. Community health clinics that provide screening and education on sexual health, drug and alcohol addictions, genetic counselling, and vocational and educational planning are important resources (26,27).

Although it may be tempting to leave teens with cognitive disabilities out of transition programs, their risks are perhaps even higher than other young people with special health care needs, and thus, they should be included in a way that is meaningful to them (28).

The On-Trac transition framework

Most existing transition programs worldwide are based on On-Trac, a comprehensive program based on goals that change for early, middle and late transition, and that can proceed at the teen's pace (25). This program has clinical pathways for these different stages, as well as many other resources. It promotes an environment that supports the family, while empowering the youth to become interdependent (with family and society) and responsible for their own health care (24). The formal process begins at around 10 years of age and proceeds until transfer from the paediatric setting.

Within On-Trac, objectives and interventions for the adolescent, family and health care provider are included for clinical pathways in these areas:

- evolving self-esteem and identity;
- fostering personal autonomy and independence;
- continued development in the sexual area;
- achieving psychosocial stability;
- continued educational, vocational and future financial planning; and
- health and healthy lifestyle-promoting practices, including healthy active living.

Additional strategies

- See teens without parents for part of the appointment to give an opportunity to learn how to present a history, ask and answer questions, and advocate for themselves.

- Provide books, newsletters and magazines that deal with youth issues and youth living with health conditions.
- Peer-support meetings in person, via newsletter or through the Internet can connect teens. Parent and sibling support groups are also important (29).
- Family or teen education days allow teens to meet each other, get information and talk about transition and the adult system;
- A formal acknowledgement of 'graduation', such as a certificate from the paediatric facility can mark transfer as a rite of passage.
- Give a transition letter explaining the location of the new facility, staff and what to expect.

RECOMMENDATIONS

General principles

- Paediatricians should be aware that transition is an ongoing process that may begin as early as the time of diagnosis and ends sometime after transfer.
- Appropriate resources and educational materials should be provided for youth throughout the process of transition.

Individual and family issues

- Transition planning must be youth-focused within the context of the family (evidence level II-3).
- Appropriate attention and supports should be provided for family members (evidence level I).
- Transition should occur at the youth's pace (evidence level II-3).

Multidisciplinary teams and community resources

- Transition planning and preparation should be integrated into existing specialty clinical settings.
- Teams must provide developmentally appropriate care, including a stepwise plan of increasing responsibility for self-care. The family physician should be an integral part of the treatment team. If the adolescent does not have a family physician, the team should facilitate a referral as soon as possible.
- Teens should be given information about their condition and available resources, including clinics providing sexual health screening for young adults.
- Skills training in communication and negotiation should be provided to enhance navigation in the adult care system.
- The provision of transition services may include individual counselling; psychoeducational groups; posters and checklists for staff, patients and parents; joint transition clinics and Web-based tools (evidence level I-1 to III) .

WEB SITES

Health care providers can download information for patients and families who do not have access to the Internet and can make the list of Web sites available to local libraries, schools and other community resource centres. Similar information is available in French at <www.jeunesensante.ca>.

- Transition Planning – Youth Health Program
BC Children's Hospital
– On-Trac materials: Resources
<<http://www.bcchildrens.ca/Services/SpecializedPediatrics/YouthHealth/Resources>>
- Good 2 Go – Good 2 Go Transition Program
The Hospital for Sick Children
– Transition menu, bibliography, printable graduation certificate and other resources
<www.sickkids.ca/good2go>
- MyHealthPassport – Good 2 Go Transition Program
The Hospital for Sick Children
– Create a customized, wallet-sized card with health information. <www.sickkids.on.ca/myhealthpassport>
- Health Care Transitions – Institute for Child Health Policy, USA. <<http://hctransitions.ichp.edu/>>
- Healthy & Ready to Work: A Transition Service for Youth – Maternal and Child Health, USA
<<http://www.hrtw.org>>
- SibKids and SibNet – Sibling Support Project
<<http://www.siblingsupport.org/>>
- Kids Can Cope – Adaptation to Childhood Chronic Illness, The Hospital for Sick Children
<<http://www.sickkids.ca/kidscancope>>
- Ability OnLine
– Internet community for kids with chronic conditions. <<http://www.ablelink.org>>
- Disability Resources on the Internet
<<http://www.disabilityresources.org>>

QUALITY OF EVIDENCE AND CLASSIFICATION OF RECOMMENDATIONS

The quality of evidence reported in the present document has been described using the evaluation of evidence criteria outlined by the Canadian Task Force on Preventive Health Care (30). The evidence demonstrating the need for developmentally appropriate services for youth, families and the health care system in general, in the context of youth with special health care needs transitioning to the adult-oriented health care system, is based on a heterogeneous sample of studies and recommendations, ranging from well-designed case-controlled studies (evidence level II-2) to opinions of respected authorities, based on clinical experience and reports of expert committees (evidence level III) (30). The

evidence in regard to the effectiveness of a recommendation relating to support for parents and siblings of children with chronic illness or disabilities came from a well-designed randomized trial and may be considered to be a recommendation.

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The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate. Internet addresses are current at time of publication.