

An Introduction to Health Care Transition For Parents of Teens with Kidney Disease

TRANSPLANT MANITOBA
Pediatric Kidney Program



What is Health Care Transition?

The goal of Health Care Transition is to prepare young people to live with their health conditions as adults and to succeed in the adult health care system. We will reach this goal by working together as a team with you and your child!

By the age of 18 most young adults should be ready to leave the Children's Hospital and receive their health services from the adult health care system. Our overall approach is to encourage self-reliance and independence as appropriate to the child's age and stage. The transition process starts there and proceeds based on the child's needs and abilities

Support

Our team of healthcare providers works together to provide care and support to your child and family. These include: doctors, nurses, social workers, dietician and clinic clerks. This team will be helping your teen gain independence and learn about the adult program so they are prepared when the time comes to transfer care.

If your child is a patient in the transplant clinic, the transplant social worker will become involved 1 to 2 years before transfer and will continue to be available after care has been transferred.

Health Care Transition involves youth learning:

- What they need to do to stay healthy on their own terms.
- How to develop skills in advocating for their own health care needs.
- How to ask questions and make decisions about their own health care treatments.
- How to become independent and comfortable with health care routines such as using medicines on a schedule and booking their own appointments.
- How to develop the skills necessary to self-manage his or her health care.
- How to access the adult system.

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Transition Planning & the Family

Being a parent today is a challenging job. Being a parent of a child or teen with a chronic illness is even more so demanding. The kidney care team recognizes this and wants to support children and their families in coping with illness. We are also aware that when one person in the family has serious medical problems this has an impact on all members.

We encourage families to be active members in the process of transition planning. You are already supporting your teen to become more independent and we encourage parents to continue to provide emotional support while gradually easing themselves out of the role of direct care provider. While letting go may be difficult, especially for teens with a chronic illness, it is still important that your teen be encouraged to become as independent as possible given their age, abilities and limitations. We encourage parents to do the following:

- ✓ Talk with your teen about his or her condition so they can explain it to others.
- ✓ Encourage your teen to speak up for themselves with the doctors, nurses and other team members.
- ✓ Be patient and support your teens development of skills to care him or herself and special skills related to their particular health care needs
- ✓ Encourage self-reliance in areas of your teen's life such as banking, volunteering and time management.
- ✓ Remember: Taking good care of yourself, managing stress and learning to cope with new problems are important for all members of the family.

