

Transitioning to Adult Care

By Heather Bauman

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At one time or another we all find ourselves learning and adapting to a new stage in life. This is a process called transition, and for some of us it can be a journey that spans many years. For families living with hemophilia, many parts of the journey are shared with the comprehensive care team.

Three main stages of development – childhood to teenage years

Stage 1: Birth – age 8	Learning about hemophilia and how it is treated and managed
Stage 2: Ages 9 – 13	Adapting to rapid growth and developing key skills
Stage 3: Ages 14 – 19	Learning new roles and responsibilities for adult independence

But what happens next? When a child is on their way to becoming an adult, the Canadian Hemophilia Society refers to this time as the **transition to adult care**. It is the coordinated transfer of a patient from child health services to adult health services.

Whenever there is change, there can be a lot of questions. Let's have look at some of the most common ones to help you and your child on this journey.

How does care change with the transition to an adult hemophilia program?



Pediatric hemophilia programs

- Focus is on the child and parents
- Treatment and care is adapted to each child's development
- Care team works with the family as a whole



Adult hemophilia programs

- Focus is on adult health needs and medical issues
- Care team works directly with the person with hemophilia

At the appropriate time, the pediatric care team will guide the family through the transition to an adult hemophilia program.

When does the transition to adulthood and adult care begin?

Factors that influence the timing of the transition to adulthood include:



Knowledge and skills



Physical fitness



Home treatment



Communication with the care team



Ability to make decisions



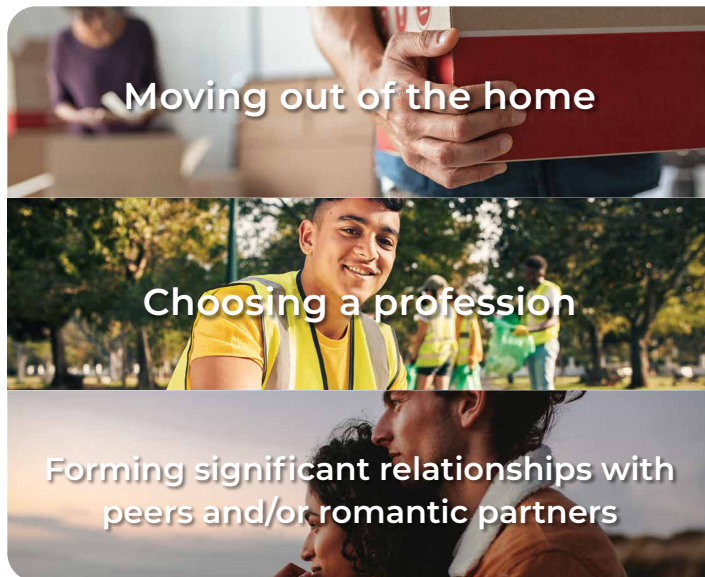
Stress management



Necessity to transfer to another program, clinic, or hospital

What are some transitional challenges?

During adolescence, a young person with hemophilia must deal with all the typical changes associated with this phase in life:



In addition, the person transitioning to adult care needs to accept increasing and ultimately full responsibility for managing their condition, including:



Self-injection



Managing treatment away from home



Ordering supplies



Maintaining adherence to treatment



Attending appointments



Possibly navigating the insurance system for the first time

Why is treatment adherence so important?

Adherence to treatment is critical in patients with hemophilia.

Lack of adherence can lead to:

- Recurrent joint bleeds
- Reduced quality of life
- Chronic pain

Unfortunately, adherence to treatment is generally low during the transition to adult care.[†]

[†] Based on the professional experience of the author.

Potential reasons for nonadherence during the transition from adolescence to adulthood

The WFH has identified the following barriers to treatment adherence commonly found in adolescents:

Social issues	<ul style="list-style-type: none">• Lack of family and peer support• Reduced parental supervision• Lack of trust with new medical team• Interference with lifestyle (e.g., travel, sport)• Lack of disclosure
Emotional and developmental issues	<ul style="list-style-type: none">• Rebellion against regimented treatment• Denial• Poor decision-making• Developmentally immature• Anxiety/fear• Developmental delay or disability resulting from intracranial hemorrhage
Practical issues	<ul style="list-style-type: none">• Inconvenience/scheduling barriers• Lack of time• Insurance issues• Poor organizational skills/remembering to take treatment• Reluctance to self-administer/poor venous access
Educational issues	<ul style="list-style-type: none">• Lack of knowledge about:<ul style="list-style-type: none">– The benefits of treatment– The consequences of nonadherence

Adapted from the Canadian Hemophilia Society. All About Hemophilia. A Guide for Families. Chapter 13: Transitions Towards Independence.

Keys to a successful transition

A successful transition program should be responsive to the needs of the patient, the parents, and the healthcare providers.

Communication, collaboration, and preparation are the key elements for a successful transition program:

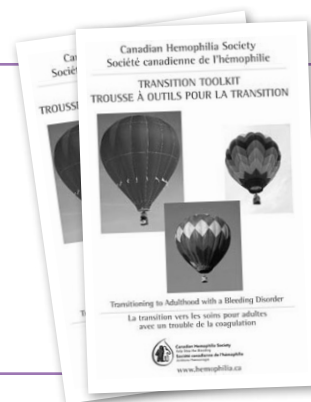
- Good communication and collaboration should be established between the team, the person who is transitioning to adult care, and their family
 - Members of the adult care team should be skilled in counselling adolescents
- Early planning, jointly with adolescent patients and parents, allows for a gradual shift in responsibilities
 - Ensures smooth navigation through the complexities and barriers to successful transition and treatment
 - Helps the transitioning person to be ready, able, and comfortable to take full responsibility for their condition and transition to adult care
- The planning process should involve the person transitioning, their parents (or caregivers), as well as the pediatric and adult care teams
- Patient education is an important aspect of the transition
 - Lack of knowledge about the benefits of treatment and the consequences of not taking treatment can lead to nonadherence

What can a parent do to help the transition?

- Stay involved in the various aspects of your child's health and medical care
- Continue to dialogue at home and show an interest in their appointments
- Encourage your child to take charge of their health and medical condition
- Guide your child through all the tasks and responsibilities related to managing their hemophilia
- Help them develop skills and confidence, and build independent relationships with the members of their care team
- Assess their knowledge, skills, and progress as they near the time for transition



Contact your local chapter of the Canadian Hemophilia Society for the transition toolkit and information on orientation activities in your region.



Learn more about managing hemophilia A at different stages of your life at www.personalizehema.ca/PK_and_you/Different_stages_of_your_life

About the Author



Heather Bauman graduated from the University of Alberta with a Bachelor of Science in Nursing in 2005. She has been working in the bleeding disorder clinic for over 4 years. Prior to this role, Heather worked in pediatric oncology and taught clinical courses for the Faculty of Nursing (University of Alberta)

for 9 years. She serves on the Stollery Oncology/Hematology Quality Council and is a Western Nursing Representative for the Canadian Association of Nurses in Hemophilia Care (CANHC). For the past 3 years (pre-Covid), she has attended Camp Kindle (summer camp) with bleeding disorder patients. Her interests include tennis, snowboarding, and traveling.



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