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Transitions Toward Independence

This chapter provides answers to these questions:

PART 1 – Transitions from birth through the teenage years

- What is transition?
- Why is transition called an ongoing journey?
- What important transitions occur in the teenage years?

PART 2 – Transition to adulthood and adult care

- How does care change with the transition to an adult hemophilia program?
- When does the transition to adulthood and adult care begin?
- What is the parent's role in the transition to adulthood and adult care?
- How does the care team facilitate the transition to adult care?
- What other resources are available to assist the transition to adult care?

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PART 1 – Transitions from birth through the teenage years

■ What is transition?

The word “transition” generally means a process of change and evolution from one stage to another. It is often used to describe the process of learning and adapting to different stages of life, referred to as life transitions. In this broad sense, transition is a journey that all people go through, individually and together with their families and other important people in their lives over the course of the years.

In the context of hemophilia, transition also refers to the continual process of learning about hemophilia and how to manage the many aspects of care. Transition is more complex for families living with hemophilia. Each stage of development involves extra learning for the parents and the child, and the comprehensive care team as well. Transition is an ongoing team effort, with the overall goal being to help the child with hemophilia develop the knowledge and range of skills that he will need to manage on his own as an independent adult. This is often referred to as the *transition to adulthood* or the *transition to adult independence*.

Transition also has another meaning in the context of healthcare services including comprehensive care for hemophilia — the coordinated transfer of a patient from child health services to adult health services. This is often referred to as the *transition to adult care*.

“Transition is an ongoing team effort, with the overall goal being to help the child with hemophilia develop the knowledge and range of skills that he will need to manage on his own as an independent adult.”

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■ Why is transition called an ongoing journey?

Transition is an ongoing journey that evolves over many years. For families living with hemophilia, many parts of the journey are shared with the comprehensive care team. The comprehensive care team will guide your family through each stage of development and transition toward adult independence.

The main stages of development throughout the childhood and teenage years can be grouped in three general categories:

- Learning about hemophilia and how it is treated and managed (birth to age 8)
- Adapting to rapid growth and developing key skills (ages 9 to 13)
- Learning new roles and responsibilities for adult independence (ages 14 to 19)



Throughout these years, the care team will closely follow your child's growth and development. The team will frequently review his progress and treatment plan with you, usually when he visits the clinic for his regular check-ups. Together, you will decide whether adjustments are needed as his physical, emotional and psychological needs and his personal goals evolve over time.

The developmental stages are described in detail throughout the other chapters of *All About Hemophilia: A Guide for Families* and summarized in this chapter in **Table 1: Childhood transitions: from birth through the teenage years**. As always, it is important to keep in mind that every child develops and learns at his own pace.

“My hematologist is awesome at explaining things more clearly now that I can understand.

My nurse is also a key resource to me as I learn to self infuse.”

“When our son started high school, it became important to him to fit in and to not stand out because of hemophilia. It took a few poor decisions on his part before we worked together to iron out what information needed to be shared and with whom.”

■ What important transitions occur in the teenage years?

While transition is an ongoing and continual process that begins in early childhood, many of the big steps occur in the teenage years. Throughout these years, the care team will regularly discuss issues of transition when your child goes to the hemophilia treatment centre (HTC) for his check-ups. The teenage transitions will naturally progress differently for each individual and family.

It is important to remember that this period of major physical growth is also accompanied by new emotional and social challenges, and your child will need a lot of support and guidance. As his social circle and independence grows, so will the influence of his peers and other people who are important in his life. He will begin to look to other people for support and advice on many aspects of his life such as school, relationships, sports and recreational activities, as well as managing his medical condition.

Your vital role during the teenage years is to maintain an open dialogue with your child, guide him in making well-informed and responsible decisions, and create opportunities to help him develop all the necessary skills for adult independence. Over time, the responsibilities related to treatment and care will gradually begin shifting from you to your child. He will start to take over many of the tasks related to his health care such as self-infusion, ordering treatment products and supplies, and explaining his medical condition to his care team, teachers, employers, etc. Keep in mind that teenagers often need to be actively encouraged to take initiative and assume new responsibilities — and remember that every child develops at his own pace.

When your child reaches his mid-teens, the care team will likely be spending part of the visits with him one-on-one. This time alone with members of the care team will help him develop self-confidence as he learns how to discuss his health with medical

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professionals, including any issues related to his treatment plan. It also gives him the opportunity to talk with the members of the care team independently and confidentially about physical, emotional or psychological challenges he may be experiencing as he approaches adulthood.

Canadian Hemophilia Society – Activities and support for youth

The Canadian Hemophilia Society and local chapters across the country organize a wide range of workshops, summer camps and social events for teenagers and young adults. These activities are great opportunities for young people with hemophilia to meet, share experiences and coping strategies, and simply to have a fun time. The interactions generally help improve self-confidence and self-esteem, and often result in strong bonds and lifelong friendships.



There are many ways your child can get involved with the Canadian Hemophilia Society and the local CHS chapter. The HTC nurse coordinator and social worker can recommend programs and mentors that may be of interest — and he himself could become a role model for younger boys with hemophilia. The CHS National Youth Committee is a great way he can get involved.

*For more information, contact the Canadian Hemophilia Society at **1-800-668-2686** or visit the CHS Youth Web site at www.hemophilia.ca/en/youth-web.*

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Table 1: Childhood transitions: from birth through the teenage years

The care team will guide your family through every stage of development and transition. It is important to keep in mind that your child will develop at his own pace.

CHILDHOOD – LEARNING ABOUT HEMOPHILIA




DEVELOPMENTAL STAGE	TRANSITION GOALS
<p>BABY’S FIRST YEAR (Birth to 18 months)</p> <p>CHAPTERS:</p> <p>An Introduction to Hemophilia Comprehensive Care for Hemophilia Management of Bleeds Growing with Hemophilia Staying Healthy Family Perspectives</p>	<p>As parents you learn how to:</p> <ul style="list-style-type: none"> • Work with your baby’s care team and pediatrician to manage his health needs (including vaccinations and medical check-ups). • Provide a safe and nurturing environment without being overprotective. • Watch for signs of bleeds and give first aid and/or factor concentrate. • Teach close family members and friends about hemophilia. • Be prepared for emergency situations – carry your child’s Medicare card and Factor First card, and keep an emergency travel bag ready. <p>Your baby begins to learn how to:</p> <ul style="list-style-type: none"> • Trust and rely on care from his parents and his care team.
<p>EARLY CHILDHOOD (Ages 1 to 8)</p> <p>CHAPTERS:</p> <p>Management of Bleeds Clotting Factor Therapy The Role of Prophylaxis Home Infusion Growing with Hemophilia Staying Healthy Family Perspectives</p> 	<p>As parents you learn how to:</p> <ul style="list-style-type: none"> • Teach your child about hemophilia, how it affects his body, and how to stay healthy and prevent bleeds. • Involve your child in more and more aspects of his care over time. • Take your child for regular check-ups at the HTC. • Keep the care team updated on your child’s progress and ask about the appropriate sports, activities and protective gear for his age. • Childproof your home and make sure other environments are safe (playground, daycare, school, friend’s house, etc.). • Teach your child about safe activities for his age, and risky ones to avoid. • Meet other families living with hemophilia, to share experiences and tips. <p>Your child learns how to:</p> <ul style="list-style-type: none"> • Start taking charge of his health and develop good habits related to self-care such as brushing his teeth, exercising and healthy eating. • Recognize when he is having a bleed and tell a parent, caregiver, teacher, etc. • Help with his treatment (get an ice pack, band-aid, factor concentrate, etc.). • Be more aware of his body, bleeding patterns, limitations and abilities. • Choose appropriate activities and know when he needs to wear a helmet, kneepads or other protective gear. • Explain basic information about hemophilia to friends and teachers. • Wear Medic-Alert identification and carry his <i>FactorFirst</i> card.

Table 1: Childhood transitions: from birth through the teenage years (continued)

The care team will guide your family through every stage of development and transition. It is important to keep in mind that your child will develop at his own pace.

PRE & EARLY TEENS – DEVELOPING KEY SKILLS	
DEVELOPMENTAL STAGE	TRANSITION GOALS
<p>PRE-TEEN YEARS (Ages 9 to 11)</p> <p>Chapters: Home Infusion Growing with Hemophilia Physical Activity, Exercise and Sports Family Perspectives</p>	<p>As parents you learn how to:</p> <ul style="list-style-type: none"> • Begin giving your child more tasks and responsibilities related to his home treatment and care. • Foster his confidence and independence through activities such as the CHS hemophilia summer camp. <p>Your child learns how to:</p> <ul style="list-style-type: none"> • Self-infuse and record treatments in his home infusion diary. • Explain hemophilia and how his medical condition is managed to his teachers, camp counsellors, friends' parents, etc. • Start asking and answering questions by himself during check-ups with the care team.  
<p>EARLY TEEN YEARS (Ages 11 to 13)</p> <p>Chapters: Growing with Hemophilia Staying Healthy Physical Activity, Exercise and Sports Complications of Hemophilia Family Perspectives</p>	<p>As parents you learn how to:</p> <ul style="list-style-type: none"> • Help your child learn how to cope with the physical, emotional and social challenges that arise in the teenage years. • Involve him in decision-making and start to trust him to make smart choices. <p>Your child learns how to:</p> <ul style="list-style-type: none"> • Self-infuse and keep accurate treatment records. • Take responsibility for packing factor supplies for short/overnight trips. • Present his Factor First card and explain his medical condition to a hospital triage nurse should he ever need to access emergency care.

“Start preparing them early for what they will be expected to do by clearly outlining their future responsibilities.”

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Table 1: Childhood transitions: from birth through the teenage years (continued)

The care team will guide your family through every stage of development and transition. It is important to keep in mind that your child will develop at his own pace.

MID TO LATE TEENS – LEARNING NEW ROLES AND RESPONSIBILITIES

DEVELOPMENTAL STAGE	TRANSITION GOALS
<p>MID-TEEN YEARS (Ages 14 to 16)</p> <p>Chapters: Growing With Hemophilia Physical Activity, Exercise and Sports Transitions Toward Independence Family Perspectives</p>	<p>As parents you learn how to:</p> <ul style="list-style-type: none"> • Manage the rapid physical, psychological and social challenges that arise during the teenage years. • Begin to let go of some responsibilities related to your child's care and guide him to start taking control. • Continue to provide guidance as your child begins to develop other relationships that may influence his lifestyle, decisions and goals. <p>Your child learns how to:</p> <ul style="list-style-type: none"> • Take over most aspects of his routine care and treatment (self-infusion, booking check-ups, ordering factor products and infusion supplies from the HTC or blood bank), with some parental guidance and supervision. • Speak on his own behalf at HTC check-ups and begin to meet with the care team on his own. • Speak on his own behalf with teachers to catch up on homework if days at school have been missed.
<p>LATE TEEN YEARS (Ages 17 to 19)</p> <p>Chapters: Transitions Toward Independence The Future of Hemophilia Care Family Perspectives</p>	<p>As parents you learn how to:</p> <ul style="list-style-type: none"> • Provide support and advice related to relationships, university and career planning and other issues related to adulthood. • Adapt to a new role with the transition to adult care. <p>Your child learns how to:</p> <ul style="list-style-type: none"> • Take over the responsibility of managing his medical condition (schedule all his own appointments, discuss his healthcare issues with the care team on his own). • Treat/prevent all types of bleeds according to the treatment plan and guidelines set out by his care team, and use factor concentrates responsibly. • Navigate the healthcare system and access emergency care. • Prepare for transition to a different adult care team and clinic if such a change is involved. • Find accurate and reliable information related to hemophilia. • Be an expert on hemophilia and advocate for the best care possible.



PART 2 – Transition to adulthood and adult care

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

Adult hemophilia programs focus on adult health needs and medical issues, and the care team works directly with the person with hemophilia. This is different from pediatric hemophilia programs, which focus on the child and parents — the care team works with the family as a whole — and adapt treatment and care to each child’s development.

The members of the adult comprehensive care team have specific expertise on the health concerns and other issues experienced by adults with hemophilia. Some of the potential challenges in the adult years include musculoskeletal problems or broader issues related to academic or career planning, employment, relationships, and family planning, among others. The adult care team will provide medical care and guidance through these transitions.

The organization of pediatric and adult hemophilia care varies across the country. In some areas of Canada, the pediatric clinic is located separately from the adult clinic, sometimes at a different hospital. In these cases, there is a mandatory age (usually between ages 17 to 19) by which the patient’s care must be transferred to the adult hospital.

In other parts of the country, adult hemophilia care may be provided at the same hospital but in a different area, and some or all core members of the care team may change with the transition to adult care. In some cases, the HTC treats both children and adults with hemophilia at the same location, with the same team members throughout childhood and the adult years.

“Meeting new team members and developing trusting relationships takes time, as does developing confidence and assessment skills.”

“My HTC arranged for a group of us who were going to transition that year to have a tour of the adult HTC to help me become familiar with the new layout and to meet the new team.”

When it’s time, the pediatric care team will guide your family through the transition to an adult hemophilia program. The team will also coordinate the transfer of pertinent medical records if the young person will have a different care team and is moving to another clinic or hospital.

Table 2: Transition from pediatric to adult care

The pediatric care team will guide your family through the transition to adult care.

Programs are in the same hospital	Programs are in different hospitals
The patient is familiar with the HTC and hospital, including the specialized services such as emergency care.	The patient and family have to learn how to navigate through a new hospital and learn new HTC procedures.
The transition of care occurs around high school graduation or the 18th birthday – sometimes, the only change in the care team is that the pediatrician steps aside and a physician who specializes in adult care takes over.	The patient needs to get to know the members of his new care team, gain confidence in their expertise, and become comfortable talking to them about health issues or challenges related to having hemophilia – this can take time.
The bond of trust and open communication between the patient and the members of the care team continues, so the transition to adult care is less stressful.	The transfer to an adult clinic can involve some anxiety, learning and transition for the patient, his parents and the new care team – it can take time for everyone to learn their new roles.

■ When does the transition to adulthood and adult care begin?

While transition is a process that begins in early childhood, many of the critical steps occur in the early teenage years (ages 11 to 13) through the late teenage years (ages 17 to 19). These years involve considerable change and new challenges for everyone.

- The teenager gradually takes over responsibility for many aspects of his health care.
- The parents learn how to help foster his independence and gradually let go of their responsibilities as the primary caregivers.
- The members of the care team gradually shift the focus of their services and interactions more directly on the teenager.

The timing of the transition to adulthood will be influenced by several factors. These include the teenager's knowledge and skills related to all aspects of his health and care (nutrition and physical fitness, home treatment, communication with the care team, advocacy, decision-making, stress management, etc.). Another factor is the organization of healthcare services at the hospital where he receives treatment and whether he is required to transfer to another program and clinic or hospital.

When the actual transition to an adult hemophilia care program takes place, everyone's roles and responsibilities will change. It is important to keep in mind that it will take time for everyone to become familiar and comfortable with the new arrangements and responsibilities.

“During adolescence, it's important to help your child gradually gain independence as his experience and knowledge allow him to — but at times you still have to put your foot down and say, ‘No, this can't be, you cannot do that.’ Some decisions are tough but you learn to live with them and hope that he will understand when he is older.”

“It was harder to step back than I anticipated, but seeing my son easily assume responsibility for his own care confirmed we had all done a good job of preparing him.”

■ What is the parent’s role in the transition to adulthood and adult care?

Your role will evolve considerably from the mid-teen years and onward but it is important to remember that your child will still need a lot of support. At times, you might find it hard to step back, particularly if you’re not sure he is ready to take over certain tasks or responsibilities. You will need to find a balance between letting him take control of the management of his medical condition, and ensuring that he can make the transition while also maintaining himself in optimal health. Open communication, dialogue and teamwork remain as important as ever.

Stay involved in the various aspects of his health and medical care.

Continue to dialogue at home and show an interest in his HTC appointments. Many parents continue to accompany their children to HTC appointments and stay abreast of the health issues, even if they are no longer invited to the actual appointment. Talk openly with your child about the process and discuss any concerns either of you may have. Work with his care team to help facilitate his transition to adulthood and an adult hemophilia program. Encourage your child to take charge of his health and medical condition.



Provide guidance and support as he takes on more responsibilities.

Guide him through all the tasks and responsibilities related to managing his medical condition. Talk about what he is expected to do and whether or not he feels ready for it. Encourage him to share his feelings and opinions about his treatment or any aspect of his care with you and his care team. Teach him the importance of being actively involved in his medical care. Ask how you can be of help, and be the available and supportive parent you have always been.

Foster independence to help him confidently take control of his health.

Help him develop skills and confidence, and build independent relationships with the members of his care team. Encourage him to attend educational and social events organized by the Canadian Hemophilia Society and his local CHS chapter — these are good opportunities to meet teenagers his age and meet a wide range of mentors of all ages. Let him take over the management of all aspects of his care when he is ready to take full responsibility for managing his health and medical needs.



“At a CHS national meeting, a group of young adults with hemophilia discussed their experiences transitioning to adult care.”

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“It took awhile before our son felt comfortable explaining hemophilia. Once he had a fall and couldn’t work at his part time job for 2 weeks because he was on crutches. He found it very difficult to deal with his same age peers at work because they didn’t know anything about his health challenges.”

Assess his knowledge, skills and progress as he nears the time for transition.

Review his treatment plan and main responsibilities related to self-care. Ensure that he understands that factor concentrates are expensive, and uses them responsibly. Check that he carries his Medicare card and Factor First card with him at all times. Make sure he knows how to get to the hospital and explain his condition to the triage nurse in the event that he needs emergency care.

Continue to provide support after the transition and through the young adult years.

The young adult years are full of change. Along with taking over the management of his medical condition and overall needs, there will be new challenges and transitions such as starting college or university, joining the workforce, moving away, living on his own, parenting and so on. While you won’t be driving the decisions anymore, these are all areas where he could really benefit from your guidance, advice and the wisdom you’ve gained going through these adult transitions.



■ How does the care team facilitate the transition to adult care?

In his early teenage years, the pediatric care team will begin working more directly with your child in preparation for the transition to an adult hemophilia program. Their services and interactions will shift in focus from the family as a whole to your child alone. However, as a parent you will still be very much a part of the learning process. The care team will continue to guide you in your evolving role and provide psychosocial support, and you will continue to be involved in discussions and decision-making.

This last stage of your child's transition to adulthood and adult care continues to be a gradual process and a team effort, carefully coordinated and supervised by the care team. As the transfer to an adult hemophilia program nears, apprehension about the transition is natural. It is important for you to discuss concerns about the transition together as a family and with the care team.

■ What other resources are available to assist the transition to adult care?

Many pediatric hospitals have transition to adult care programs designed to help teenagers approaching adulthood make the transition. This gives patients time to adjust to a new hospital, learn how the services are run, and become more familiar with the new care team. The pediatric care team will coordinate access if such a program is available at the hospital.

The Canadian Hemophilia Society has developed a toolkit for teenagers and young adults approaching the transition to adult independence and an adult hemophilia program. The CHS and its local chapters also organize orientation workshops and activities to help families prepare for the transition.

“My son is quite well prepared for the transition and the HTC team is outstanding. This is a good combination.”

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Canadian Hemophilia Society – Orientation on transition to adult care

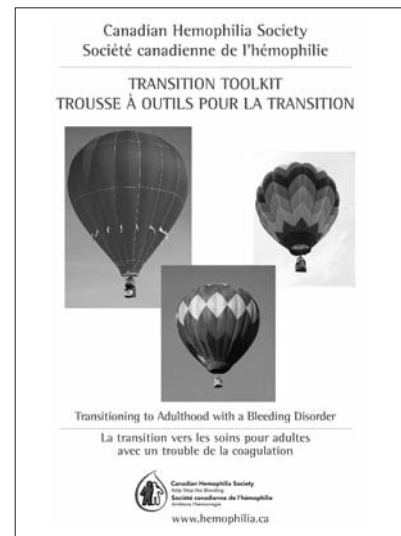
The transition to an adult hemophilia program is a major step for families. The Canadian Hemophilia Society offers orientation workshops to help families prepare for the transition.

- Introduce young adults to the changes in their roles and responsibilities as they make the transition to adult care.
- Give young adults an opportunity to meet others who are also making the transition to an adult clinic, and learn from older adults who have been through the process.
- Give parents an opportunity to learn about the changes in their roles and the new system that will be in place following the transition to adult care.
- Give families an opportunity to meet the members of the adult care team and familiarize themselves with the adult hemophilia treatment centre — this is especially useful if care is being transferred from a pediatric to adult program and/or a different hospital.

“I think we are helping to facilitate an easier experience by holding meetings where youth who are approaching transition have the chance to meet and learn from young adults who have already gone through the process.”

– HTC team member

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



Checklist: Is he ready for the transition to adulthood?

There are many responsibilities that come with adulthood. This checklist is a useful tool to help you and your child assess whether he is ready for the transition. All the tasks listed are considered essential for a young adult taking over the management of his health and medical condition. If you have concerns that your child may need additional support to achieve these goals, talk to his comprehensive care team.

- ✓ Takes charge of the main responsibilities related to care beyond the HTC setting.
- ✓ Books appointments and has regular check-ups with the family doctor and the care team, and other medical specialists as needed.
- ✓ Knows how to lead a healthy lifestyle and make smart choices and responsible decisions.
- ✓ Uses factor concentrates responsibly, documents treatment and outcomes in his home infusion diary, and follows the treatment plan and guidelines from his comprehensive care team.
- ✓ Keeps track of his inventory of factor concentrates at home, and orders and picks up more treatment products and supplies.
- ✓ Carries his Medicare card, Factor First card and other necessary medical information at all times.
- ✓ Is prepared for emergency situations and knows how to explain his medical condition to a hospital triage nurse should he need to access emergency care.
- ✓ Knows where to find accurate and reliable information related to hemophilia, including new developments and treatment options.

“More and more people, young and old alike, are turning to the Internet in search of medical information. It is very important to know where to find accurate and reliable information related to hemophilia. The Canadian Hemophilia Society Web site, www.hemophilia.ca is a good starting point.”

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- ✓ Discusses his health concerns and related challenges with the care team as they arise, and participates in figuring out strategies and/or solutions.
- ✓ Seeks advice from members of the care team about adult issues such as sexuality, family planning and genetic counselling.
- ✓ Knows what information about his medical condition to share with relatives, friends, employers, co-workers, and healthcare professionals.
- ✓ Understands his rights related to employment, medical treatment and care, and healthcare insurance (the HTC social worker can provide relevant information and advice).
- ✓ Knows how to develop new skills and coping strategies to handle challenges and transitions as they arise in the adult years.
- ✓ Knows how to rely on friends and family members for support and advice.

Conclusion

The transition to adulthood and adult health services involves major changes for everyone involved. However, it is important to remember that it is not the end of the journey together, but rather a new beginning focused on adult independence. With solid preparation, young adults living with hemophilia have every reason to look towards their futures with confidence and the excitement of youth as they embark upon their individual life journeys.