

TRANSITION AND CARE GUIDE

VERMONT REGIONAL HEMOPHILIA TREATMENT CENTER

PURPOSE

This comprehensive policy guides the transition of health care from care in our pediatric hemophilia treatment center (HTC) successfully to adult care in our HTC. This document is meant to provide a consistent care plan for transition and is available to all staff, patients, and parents/caregivers at the Vermont Regional Hemophilia Treatment Center

GOAL

To prioritize and effectively transition patients with bleeding disorders from pediatric to adult health care

TRANSITION PROCESS FOR HTC STAFF

Who is responsible?

While all staff in the HTC may play a role in transitioning, the primary responsibility will lie with the providers (physicians or APPs) and the HTC nurse coordinator.

At what age will the process start?

Transition readiness assessment will occur beginning between ages 9 and 10.

When will transition to adult clinic be expected to be completed?

Between ages 18 and 21.

How will this be accomplished?

We will encourage and assess disease knowledge and self-care skills to allow fluent medical transition to an adult hematology provider including changes in medical privacy that occur at the age of 18.

Transition readiness will be assessed either verbally or a written assessment annually for both patient and parent/caregiver.

At least 3 assessments should occur prior to transition.

Transition timelines will be provided to families.

Transition timelines and guidelines will be made available to patients and family on our website. A transfer of care package will be provided at the time of transition and include an emergency plan and medical summary specific to the patient's hematologic diagnosis.

How will cultural preferences be addressed?

Culturally responsive services including transitions of care are a priority of the Vermont HTC.

Throughout the transition period, staff of the HTC will acknowledge, respect and explore cultural preferences and diversity of experiences and modify the approach to transition appropriately to address cultural values, attitudes and activities.

Privacy and consent at the age of 18

Privacy and consent as relates to medical record access (electronic health record) will be governed by the policies of the University of Vermont Health Network and can be found in policy #UVMHN_MG4, "My Chart Proxy Access".

WHAT SUPPORT WILL BE GIVEN TO PARENTS/CAREGIVERS TO INCLUDE THEM AND HELP WITH THIS TRANSITION.

Parents/caregivers will have access to the transition of care policy. Parents will be verbally given the results of the transition assessments until the child turns 18 years of age. The following guidelines for helping their child transition will also be available to parents.

TRANSITION TIMELINE FOR CAREGIVERS

- 9-11 years
 - “ Help child learn about bleeding disorder, medications, allergies.
 - “ Have child gather own medications and supplies.
 - “ Explain benefits of medical ID
 - “ Encourage child to stay active and educate on sport safety

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| 12-13
years | <ul style="list-style-type: none">“ Explain to your child they will start to see their MD alone for part of their visit to help gain independence in managing own health and well-being.“ Encourage your child to ask HTC providers questions.“ Have your child infuse or administer own medication with your assistance“ Help your child track their med schedule |
| 14-15
years | <ul style="list-style-type: none">“ Begin to practice independently making appointments, calling to refill medication.“ Observe teen when they infuse or administer meds“ Explain to your teen what to do in a medical emergency. |
| 16-18
years | <ul style="list-style-type: none">“ Independently make appointments, refill meds, and report bleeds“ Encourage teen to discuss high risk behavior with HTC providers“ Discuss with who will make health care decisions. |