



**NATIONAL HEMOPHILIA FOUNDATION**  
*for all bleeding disorders*

MASAC Document #147

**TRANSITION GUIDELINES**  
For People with Bleeding Disorders

The following resolution was approved by the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation on November 8, 2003, and adopted by the NHF Board of Directors on November 9, 2003.

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The transition process should start at the time of diagnosis and continue throughout life. A multidisciplinary National Hemophilia Foundation task force was formed because it was recognized that certain aspects of transition may be difficult for individuals with bleeding disorders, as well as for Hemophilia Treatment Center (HTC) staff and the family. The goal of this committee was to develop transition guidelines that could be used by HTC staff with children who have bleeding disorders and with their parents. Nurses, psychosocial professionals and physical therapists worked together to develop guidelines for the transition of the pediatric patient with a bleeding disorder to adult care.

There are many types of transitions for the person with a bleeding disorder. These include acceptance of the bleeding disorder, self care, progressing through school, vocational/career planning, moving to an adult center, starting a family, middle age and retirement. Transitioning is a team effort and it includes the patient, parents and staff. The goal is to proceed through each phase, ensuring that recommendations for each developmental milestone are met.

According to Mary C. Paone, author of *Setting the Trac-A Resource for Health Care Providers*, "The goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound prior to and throughout transfer into the adult system." To develop transition guidelines for people with bleeding disorders we used Paone's framework. It was adapted to meet the needs of the bleeding disorders community. Six major components of her framework include: self-advocacy, independent health care behaviors, sexual health, social supports, educational/vocational/financial planning, and health and lifestyle behaviors. Communication and HTC team support are essential for the successful completion of the guidelines. We have attempted to make them user-friendly. Instructions for using the transition guidelines are included.

The Transition Task Force would like to acknowledge Mary C. Paone, RN, MSN, Youth Health/Transition Planning, Children's & Women's Health Centre of British Columbia, Vancouver, B.C. for her encouragement and inspiration in developing these guidelines for people with bleeding disorders. We would like to thank Mary Jane Petruzzi, MD, Hemophilia Center of Western New York for reviewing the guidelines.

The following Hemophilia Treatment Centers piloted the Transition Guidelines and we thank them for their suggestions:

Fairview University Medical Center, Minneapolis, Minnesota



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Puget Sound Blood Center Seattle, Washington

Louisiana Center for Bleeding and Clotting Disorders at Tulane University

Health Sciences Center, New Orleans, Louisiana

Vanderbilt Hemostasis & Thrombosis Clinic, Nashville, Tennessee

Cook Children's Medical Center, Fort Worth, Texas

Hemophilia Center of Western New York, Buffalo, New York

We are grateful to Cuansharee Palmer, and Stacie Lesinski secretaries, of the Hemophilia Center of Western New York Buffalo, New York for their technical support.

Linda Belling and Lynn Obstein  
Transition Task Force Co-Chairs

#### INSTRUCTIONS FOR USING THE TRANSITION GUIDELINES

1. The guidelines are designed to be adapted to the needs of each individual HTC.
2. The guidelines are for use with people who have bleeding disorders including rare coagulopathies, carriers, and symptomatic carriers.
3. The guidelines were developed for use by physicians, nurses, social workers, physical therapists, and genetic counselors working together as a team. However, some HTC's may not have all the disciplines available to see patients. In that instance, the guidelines can be covered by the available staff.
4. It is suggested that one staff member coordinate utilization of the guidelines to ensure that each specialty knows which areas they will discuss. Coordination of tasks should be decided before the patient is seen.
5. The guidelines are age-specific, with three to four ages grouped together.
6. Strategies should be discussed as appropriate for each age (i.e. not all strategies will be discussed at each visit). Some may need to be discussed more than once.
7. Phrases found in bold type within the strategies are intended to act as triggers (quick reminders).
8. Each strategy should be initialed and dated, on the lines at the right, after it has been discussed. This will allow the next person using the guidelines to know what has been discussed.



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9. It is anticipated that the staff will use only the age-specific set of guidelines during the patient visit. However, it is advisable to file the full set of guidelines in the chart in case they are required for reference.
10. The guidelines may be used during an office visit, comprehensive care visit, parent visit, and telephone contact or as needed.
11. There is space at the bottom of each age group to record literature provided and document comments.
12. A list of resources is included for any questions regarding use of the guidelines.

[Download Transition Guidelines \(PDF\) >>](#)

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