

# *Basic Concepts of Hemophilia*

A Self-Study  
and Planning  
Workbook for  
Families with a  
New Diagnosis  
of Hemophilia



**CDC**  
CENTERS FOR DISEASE CONTROL  
AND PREVENTION

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## Intent of the Provider Guide

This Guide is written for Hemophilia Treatment Center (HTC) providers who have primary responsibility for educating families about hemophilia. It accompanies the ***Basic Concepts of Hemophilia: A Self-study and Planning Workbook for Families with a New Diagnosis of Hemophilia***, and it offers advice and guidance for incorporating this workbook into ongoing educational programs provided by HTC staff.

## This Provider Guide will:

- Provide an overview of the companion workbook's content and format.
- Present options for using the workbook as an effective teaching tool.
- Facilitate the design of specific educational plans.
- Offer tips and suggestions for encouraging active learning.

# Overview of the Self-Study and Planning Workbook - A Unique Teaching Tool



## Why was the workbook written?

The workbook's intent is, as its name suggests, to help families new to hemophilia learn the basic concepts about the disease. It provides fundamental information, introduces relevant terms and concepts, and offers a language for asking questions or discussing hemophilia with others. Throughout, it encourages communication with the treatment provider. A basic assumption underlying the workbook is that the better parents and families understand hemophilia, the better they may actively participate in the care of their child and work effectively with their hemophilia treatment provider.

The workbook is designed to be used as a self-study document that allows users to take responsibility for their own learning. However, it can be even more effective if used as part of an educational effort by their hemophilia providers. That is why this guide was developed for you, the educator. Using the workbook is likely to assist family members in communication with you, the provider, and increase the family's ability to understand the importance of asking questions and documenting bleeding episodes and treatment. There are suggestions in the workbook for the families to ask their HTC provider about specific issues. It is helpful for providers to understand the context of questions that families may pose.

The workbook is appropriate for the parents or immediate caregivers of a child with a new diagnosis of hemophilia, a child making the transition to self-care, extended family members and babysitters who need to learn more about hemophilia.

## How is the workbook unique?

There are some excellent educational materials available for hemophilia. However, one area that has been lacking is something that families could do on their own. This workbook, through its self-instructional format, allows families the flexibility to work through the material at a pace that suits their individual learning styles, their readiness to learn, and their work and home schedules. Families are encouraged throughout the workbook to direct hemophilia-related questions to professional staff at their hemophilia treatment center (HTC). The interactive portions are particularly amenable to families and HTC staff working together. For instance, after a family completes a module, you could review their interactive exercises with them at their next clinic visit or over the phone.

This workbook is intended to enhance other educational opportunities and may provide a wide range of topics about which to offer additional education. The self-paced design also provides a structure for learning for those families who cannot, for geographic or other reasons, attend formal educational sessions.

# A Few Tips and Suggestions

How can you best support the workbook?

A few simple principles to keep in mind:

**Basic needs must be met first.**

Basic needs must be addressed first before any new learning can occur. Consider asking family members if they have any questions or problems that they would like to discuss at the beginning of the session. If there is a major concern, you may be able to resolve it before proceeding. If there are psychosocial or medical concerns, it may be necessary to ask other HTC team members to assist in addressing these.

**What is said first is what is remembered.**

Studies show that, if given a lot of information in one session, people will remember the first thing that they were told — not the last. Adopt an approach in which you first tell the patient or family what needs to be done, and then explain the rationale.

**People can only learn limited amounts of information at one time.**

Some educators say that the maximum number of new items a person can remember is seven (e.g., the 7-digit telephone number). Limit the amount of new information given to a patient or family member at one time. Break up the information into segments, if possible. Reinforce earlier learning items at each session.

**Most of us learn better through experiences and interactive discussion.**

Whenever possible, incorporate the family's past experiences to illustrate a point or facilitate a discussion. Ask if a similar episode ever occurred to them in the past, what happened, and how it felt. Use the responses to these questions to reinforce the intended information.



## How do you encourage active learning?

The key to effective learning is to get patients and families involved in their own learning. Encourage them to:

- Read the text carefully and thoughtfully — and at their own pace.
- Take time to fully understand the concepts, and make notes in the margins.
- Use a highlighter to help remember critical points. Work through the Personal Projects, Review Questions, and Case Studies to the best of their ability.
- Use a pencil so that they can change their answers if they need to.
- Circle any concepts that they find confusing or may want to pursue further. Jot down any lingering questions or concerns.
- Discuss confusing concepts, questions, and concerns with you or other treatment center staff.
- Share and discuss their new knowledge with others — family members, others parents of children with hemophilia, and friends.
- Keep the workbook handy as a resource for themselves and other family members.
- Bring the workbook with them to clinic appointments to discuss specific questions or concerns.

Lastly, be sure to discuss specific guidelines and treatment protocols unique to your HTC so that they can become more familiar with your individual clinical preferences.



# Options for Use

## How might the provider use the workbook?

The workbook's self-instructional format allows you flexibility in deciding how you may facilitate – either with the family members of a child recently diagnosed with hemophilia, or with that child when he or she is old enough to read and comprehend the workbook's contents. A few options are outlined below.

### Individualized Approach

The first option is to introduce the workbook to one or more family members during a clinic session. This may be done soon after the child's diagnosis in order to begin the educational process early and to provide the family some reference material that is readily available to them. You can negotiate with them a reasonable schedule for completing the modules that will enhance their understanding of hemophilia and supplement other education you may provide. The family might prefer to work on only one module at a time, discussing any questions or issues with you at a scheduled appointment before proceeding to the next module. Depending on distance from the HTC, some of these sessions may be by phone.

Alternatively, they might be more comfortable agreeing to devote a certain period of time to the workbook (for instance, 2 or 3 hours) before their next appointment. They would then discuss with you whatever material they were able to complete in that amount of time, working at their own pace.

This individualized approach emphasizes personal interaction between you and the family and affords time to discuss their specific issues and concerns. It also enables you to help the family apply the concepts covered in the workbook to their own unique situation.

### Group Approach

A second approach is to use the workbook in a group setting. Families could be asked to work through the modules independently, but they would then meet at an appointed time with their peer group to discuss the content and its implications. The sessions should be scheduled at regular intervals (e.g., once a week or once a month), with specific modules assigned for completion before each session. The group size should remain small (6-10 individuals) to promote discussion and allow members ample opportunity to share individual concerns, questions, and experiences.





The primary benefit of the group approach is the opportunity for families to exchange information on similar issues. This will hopefully help establish rapport and camaraderie among individuals facing the same types of problems, and offer support and encouragement at a peer-to-peer level.

For those families who live far from the center and have computer or telephone access, you might want to set up a chat line or schedule telephone conference calls. This may also be a good approach when extended family members would like to participate in the educational program.

A variation of this approach is to have families actually work through the modules during the group session. Although this would require longer sessions, it would assure that family members complete the work in a reasonable amount of time and would allow you to answer questions as they go along (rather than only after they complete an entire module).

# Planning to Use the Workbook

## Who does it?

Planning is one of the most important parts of the educational process. Nurses are usually the primary educators, but other staff may assist in the process. The physician or social worker, for instance, may be helpful during the planning and evaluation phases. Use of family members who have already been trained is often beneficial.

To make this decision, consider the following questions:

- 1 Has a POSITIVE relationship been established between this patient and family and you? If so, why has this relationship been positive? Build on these aspects of your relationship in creating a situation conducive for learning.
- 1 Has a NEGATIVE interaction occurred between this patient and family and you? If so, try to determine what factors contributed to this situation. If the patient and family have a positive relationship with another HTC team member, consider asking that staff member to assist in the educational process to make the learning experience as positive as possible.

Also, remember that you may bring some personal issues to your interactions that may affect communication. While you may not be able to change any of these factors, being aware of their potential impact and acknowledging that impact during the session may improve the quality of that session. Also, encourage participants to ask questions and to let you know if they feel you don't understand their concerns. This will help foster good communication and build their trust.

Some factors that may affect your communication are:

- Your age
- Your gender
- Your culture and ethnicity
- Your race
- Your religion

Often, just mentioning your possible concerns will break the ice and allow the teaching session to move forward. You might try an approach such as: “I know there may be some differences between my family background and yours. I hope you can let me know how **your** family thinks about medical care.”





## How do you select an approach?

No single approach will work equally effectively with all family members. Consider the following factors carefully before deciding the best approach for a particular individual or family.

### Learning Styles

People vary in their learning styles. Some of us are visual learners, while others learn best by listening. Some prefer to read independently and to think about issues alone before discussing them with others. Some are comfortable sharing personal concerns only with their provider, and are reluctant to “open up” in peer groups. Others are more willing to express their thoughts and emotions in a group setting.



## Consider the following questions to help you select the appropriate approach.

- 1 To what extent does the patient or family have the discipline, commitment, and time to work on the modules independently?
- 1 Is a more structured class setting needed to help them set aside time to read the workbook and complete the exercises?
- 1 How willing and comfortable are they to share questions and concerns with you? With another provider?
- 1 Will they be equally comfortable discussing these same issues with peers, some of whom they may not know very well (at least initially)?
- 1 To what extent would they benefit from peer interaction and support?
- 1 What is their living situation?
- 1 How might their available time be affected by such factors as single parent status, geographic location, a language barrier or reading level?

If you do not know the specific learning style of a patient or family, discuss the questions above with them and agree on an approach that meets their needs. As you continue to work with a family, you will gain insight into how they learn best, and you can alter your techniques accordingly.

# Planning to Use the Workbook

## When does it occur?

If you choose individual sessions, planning the time for those sessions is also important.

- Set a predetermined time with patients and families that is convenient to both.
- Provide a sufficient block of time for the session to proceed without interruption.
- Avoid scheduling a full educational session during a comprehensive clinic.
- Use clinic time simply to review concerns and questions and to provide updates. If patients and families live far from the HTC, schedule an education session in conjunction with clinic, perhaps on the afternoon following morning clinic.
- Allow for geographic distances. Can this be completed over the phone, by mail, by email?

If a group session is planned, the same considerations as above are critical. In addition:

- Become familiar with the group members' learning styles so that you can structure and adapt the teaching sessions accordingly.
- Adjust the session to accommodate varying educational levels and reading ability.
- Be aware of differences in the members' knowledge base about hemophilia.
- Be sensitive to varying beliefs about blood and blood products.
- Help the group understand that people may have different opinions, and that is fine.

## Where does it occur?

The location and environment of any educational session, whether individual or group, affects its success. Consider the following:

### Noise level

Provide a calm environment where all participants can readily hear each other. Select a spot away from infants, young children, and other physical barriers to learning. If families cannot leave children at home, see if you can arrange child care.

### Interruptions and other responsibilities

Hold telephone calls, give pagers to other staff members, and ask participants to avoid interruptions during the session.

### Comfortable physical environment

Provide sufficient space, proper lighting, comfortable chairs, pens, paper, notebooks, and other teaching tools. Participants should be able to sit and relax while teaching occurs.





### How will learning be reinforced?

Repetition is an essential part of the learning process. Information must be presented over time and repeated in different formats to reinforce learning. The responsibility for reinforcement is shared by all HTC providers. However, it is up to the primary educator to keep them informed of modules covered and questions or concerns raised by individual families. Encourage them to reinforce pertinent information.

### How will progress be documented and evaluated?

After each session (whether individual or group), take the time to document progress in the patient's chart. You might consider recording the date, time, modules (or pages) completed, and questions or issues raised. In addition, record plans for follow-up, the next scheduled session, and modules or topics to be covered. This record will help “jog your memory” so you can pick up where you left off, or it will allow another staff member to assume your role should you be unable to continue. In this era of managed health care, documentation of teaching and evaluation sessions assumes increasing importance. Some payers may even require documentation of the amount of time spent on education and what written materials are given to the family.

# How is the workbook structured?

The workbook is not intended to stand alone; rather, it is a resource to be used in conjunction with education and reference materials that families may receive from you and others. It covers a variety of topics, including:

- The nature of hemophilia
- Principles of comprehensive care
- Complications of hemophilia
- Physical activity
- Family and social implications
- Research
- Other bleeding disorders
- Bleeding episodes
- Dental care
- Home therapy and infection control
- Advocating for the child with hemophilia

The workbook is divided into a series of modules. Each module focuses on a different aspect of **hemophilia**. They are called modules rather than chapters to emphasize that this is not a textbook. They are interactive, giving families the chance to apply the information they read to their own situation. The reader determines the direction and progresses through the materials in a way that makes sense to him or her.

The modules are sequenced to build on one another and ideally should be completed in order. Concepts explained in earlier modules are used again in later ones. A **glossary** of terms is provided at the end of the workbook and scattered throughout the workbook to help explain terms that may be unfamiliar. A list of additional resources is also included for those who want more information about any topic.

Each module begins with an outline of its overall purpose and specific learning objectives. It then presents narrative text on the module's topic. The text includes illustrations and figures whenever possible to help clarify the concepts. The workbook encourages the reader to learn language and concepts, but it is intended to be used by lay people and does not use the same precise medical language that would be used by providers.

During early trials with the guide, some providers found it useful to initiate the program with the first Personal Project, located on page 12. They felt this approach helps gauge the assistance families hope to get using the guide. Some providers also noted that the section on inheritance in the first module is particularly useful to parents who are already somewhat acclimated to hemophilia. Those parents with a brand new diagnosis may be better able to digest the details of this section after they have had time to get used to the diagnosis.



## Hemophilia

an inherited disorder in which proteins that cause blood to clot are missing or reduced.

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The workbook is distinguished by three types of interactive exercises.

## *Personal Projects*

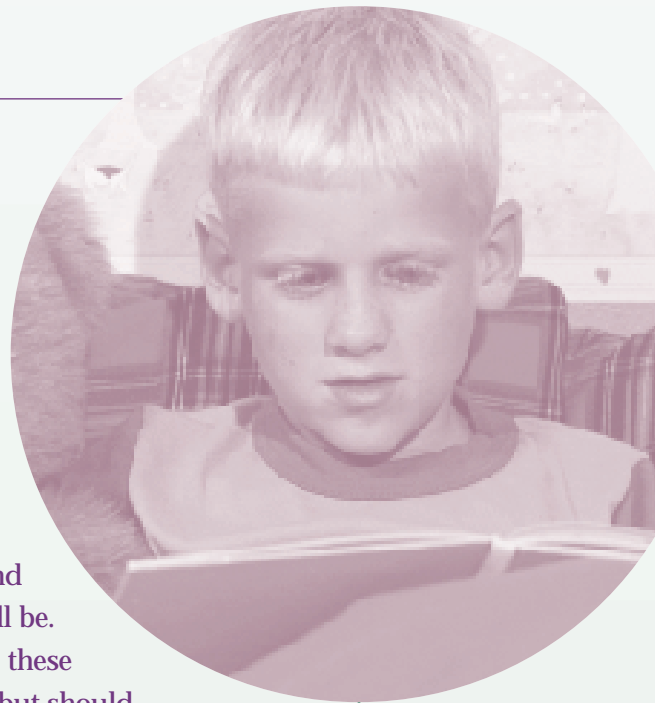
These exercises give family members the opportunity to think about the concepts presented and apply them to their own situation. A few questions are posed to help focus their thoughts. The more honestly and thoughtfully the families answer the questions, the more value they will be. Since each family's experience is different, there are no right answers to these questions. The family may not want to share these responses with you but should feel free to discuss any questions these projects engender.

## *Review Questions*

In addition to the Personal Projects, each module contains a series of Review Questions. The questions are designed to facilitate mastery of the material presented in that module. Although the Review Questions resemble a formal test or quiz, readers should be encouraged to turn back to the relevant pages to find the answers if they cannot remember them. The goal is to master the information provided in the workbook, but not necessarily to commit all of the facts and concepts to memory. Unlike the Personal Projects, the Review Questions have correct answers. An Answer Key is included with the workbook so that readers can compare their answers with those in the Answer Key and correct any mistakes.

## *Case Studies*

Each module also contains one or more Case Studies. These are descriptions of situations that illustrate issues presented in the module. Parents and other family members are asked to read a case and answer questions about how they would feel or behave if they actually experienced the situation presented. They can then compare their responses with suggested responses offered in the workbook.



# A Few Tips and Suggestions

## What additional resources exist?

**Remember:** The workbook is NOT meant to be comprehensive, nor is it a definitive medical reference on hemophilia. There are other wonderful resources available to supplement and expand knowledge. Continue to remind patients and families that they are often their own best resources. Encourage them to:

- Have a positive attitude
- Get support from you, other HTC providers, other health and psycho-social professionals, family, and friends
- Educate themselves about hemophilia using all available resources
- Get involved with other parents and families who also have hemophilia in their lives
- Be an advocate for themselves and their children

## Resources Section

### General Resources

The National Hemophilia Foundation  
116 West 32nd Street  
11th Floor  
New York, NY 10001  
(212) 328-3700  
[www.hemophilia.org](http://www.hemophilia.org)

World Federation of Hemophilia  
1425 Rene Levesque Blvd., West  
Suite 1010  
Montreal, Quebec, Canada H3G 1T7  
(514) 875-7944  
Email: [wfh@wfh.org](mailto:wfh@wfh.org)  
Website: [www.wfh.org](http://www.wfh.org)

CDC Hepatitis Hotline  
(888) 4 Hep CDC  
Website: [www.cdc.gov](http://www.cdc.gov)

The Liver Foundation  
1425 Pompton Avenue  
Cedar Grove, NJ 07009  
(888) 4 Hep CDC

HANDI (Hemophilia and AIDS/HIV Network for the Dissemination of Information) -- an information center based at the National Hemophilia Foundation; HANDI will share the location of the Hemophilia Treatment Center closest to where you live or will be traveling. They also have free brochures on bleeding disorders.  
1 (800) 42-HANDI



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