GOAL OF WORKSHOP

The workshop, *Roadmap for managing pain*, will provide a forum for open discussion of pain related to bleeding disorders with the goal of increasing awareness of the problem, sharing successful strategies and identifying potential resources for improved pain management.

TARGET AUDIENCE

- People with hemophilia or another bleeding disorder
- Parents or caregivers of a person with a bleeding disorder

WORKSHOP FORMAT

An interactive educational session which could include one or more of the following elements:

- introductory PowerPoint presentation;
- panel discussion to allow people with bleeding disorders, parents and health care providers to share experiences and strategies regarding pain management;
- expert information session on options for managing pain (e.g. physiotherapy, alternative therapy).

The workshop could be offered at:

- chapter family weekends or annual general meetings;
- parent support group meetings;
- HTC information sessions;
- chapter/regional educational sessions.

SUGGESTED SPEAKERS AND/OR FACILITATORS

- CHS provincial or regional staff member
- Local HTC social worker (see HTC listing on CHS Web site: [www.hemophilia.ca](http://www.hemophilia.ca))
- Local HTC physiotherapist (see HTC listing on CHS Web site: [www.hemophilia.ca](http://www.hemophilia.ca))
- Physician specializing in pain
- Consumers representing various perspectives (parent, child/adolescent with a bleeding disorder, person with an inhibitor, etc.).
**SAMPLE AGENDA**

1. Opening remarks (see sample introductory remarks below)
   - *Chapter president or provincial/regional staff*

2. Introductory icebreaker

3. PowerPoint presentation
   - *HTC nurse coordinator, social worker or provincial/regional staff*

4. Interactive session
   - **Option # 1**
     - Panel discussion – Issues in managing pain (see suggestions below)
   - **OR**
   - **Option # 2**
     - Panel discussion – Options for pain management (see suggestions below)

5. Evaluation of workshop (see sample evaluation below)

6. Closing remarks (see sample closing remarks below)
   - *Chapter president or provincial/regional staff*

**Sample introductory remarks**

“Welcome to the workshop *Roadmap for managing pain*. The presentation is one of the modules from the Canadian Hemophilia Society program: *Passport to well-being* designed to empower people with bleeding disorders to maximize their quality of life.

The goal of this workshop is not to provide all the answers on pain management. Rather, it is intended as a guide, showing some of the different routes to take, some of the signposts along the way and, hopefully, destinations which provide some comfort and relief. Just as importantly, it aims to encourage open discussion of pain and to help people realize that suffering in silence is not the only way to cope.”

**Begin PowerPoint presentation** (distribute hand-out of slides for note-taking)
Option # 1: Suggestions for panel discussion - Issues in pain management

FORMAT
Three individuals would be invited to present a five-minute case study to share their personal experiences of dealing with pain. It is suggested that the speakers be sent guidelines for their presentation (see guidelines below) and that they be asked to provide their case studies in advance so that the expert panel may review them prior to the workshop. Following each presentation, a panel of experts will have 15 minutes to respond and discuss options and strategies that might be of help. Approximately 10 minutes should be allocated at the end of the presentation for the audience to ask questions of speakers or panelists.

MODERATOR
• HTC social worker

SPEAKERS
• A child or an adolescent with inhibitors
• An adult hemophiliac infected with HIV or HCV or co-infected
• An adult hemophiliac who has had one or more joint replacements
• A parent of a child on prophylaxis for a pediatric perspective

EXPERT PANEL MEMBERS
• HTC nurse coordinator
• HTC social worker
• HTC medical director
• HTC physiotherapist
• Physician specializing in pain

GUIDELINES FOR CASE STUDY PRESENTATIONS (to be sent to speakers in advance)
• State your type of bleeding disorder and your age (if you don't mind).
• Outline your situation: the event or series of events surrounding your pain experiences. Discuss why pain is an important issue for you.
• Discuss what your pain is like, how it impacts your daily life (or how your current pain control has changed your daily activities). What makes your pain worse, what makes it better? How does your pain affect your family/significant others?
• What has been pivotal for you in your pain management? What challenges have you experienced in obtaining good pain control (barriers to accessing treatment or the positive influences that have helped you get what you need).
• Who have some of the key players been in your pain management?
• What have you learned from your experiences that may help others with their own struggles?
Option # 2: Suggestions for panel discussion - Options for pain management

FORMAT
Three or more experts will be invited to give 20-minute presentations on a specific option for managing pain. Approximately 10 minutes should be allocated at the end of the presentation for the audience to ask questions of speakers or panelists.

MODERATOR
• HTC social worker

SPEAKERS
• HTC physiotherapist
• Orthopedic surgeon familiar with operating on hemophiliacs for joint replacements or other surgical procedures
• Physician specializing in pain management who has treated hemophiliacs
• Expert on alternative therapies to manage pain

INTERACTIVE DEMONSTRATION
One or more knowledgeable and interested instructors would be invited to give a 20-minute interactive demonstration (Yoga, Tai Chi, aquacise, introduction to weight training, etc.). HTC physio to help assess suitability of speakers/instructors. Participants can select one or rotate to several different activities.

Sample closing remarks
• Thank speakers and participants for attending
• Collect evaluations
• Hand out – Roadmap for managing pain booklet
Your feedback helps us to improve the quality of our programs. Please take a few minutes to reply and give your comments.

1. The format of this workshop involved a PowerPoint presentation followed by a panel discussion regarding options and strategies for managing pain. How would you rate the effectiveness of this format?

   1 2 3 4 5  
   Poor Fair Average Good Excellent

2. How well do you feel this workshop addressed relevant issues relating to pain management?

   1 2 3 4 5  
   Poor Fair Average Good Excellent

3. What part(s) of this workshop were helpful to you?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

4. Comments or suggestions for future workshops on this topic.

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

5. Please indicate your role within the bleeding disorder community:

   a) person with hemophilia: FVIII deficiency ____  FIX deficiency ____
   b) person with von Willebrand disease ____  Type ____
   c) parent/caregiver of a person with hemophilia or VWD ____
   d) HTC health care provider: nurse ____  clinic director ____
      physiotherapist ____  social worker ____  other ____
   e) CHS staff: national ____  provincial ____  regional ____