Roadmap for Managing Pain
Workshop Guidelines

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 persons with bleeding disorders and health care providers to share experiences and strategies regarding pain management
- expert information session on options for managing pain
  - (e.g. physiotherapy, alternative therapies)

The workshop could be offered at:

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

Suggested speakers and/or facilitators

- member of the CHS Working Group on Pain Management (see list below)
- CHS provincial or regional staff member
- local HTC social worker (see HTC listing on CHS website: [www.hemophilia.ca](http://www.hemophilia.ca))
- local HTC physiotherapist (see HTC listing on CHS website: [www.hemophilia.ca](http://www.hemophilia.ca))
- Physician specializing in pain
- consumers representing various perspectives
CHS Working Group on Pain Management

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Sample agenda

1. Opening remarks (see Sample introductory remarks below)
   *Chapter President or Provincial/Regional Staff*

2. PowerPoint presentation (use enclosed CD and copy of slides)
   *Member of Pain Management Working Group, HTC Social Worker or Physiotherapist or Provincial/Regional Staff*

3. Interactive Session

   **Option # 1**
   Panel Presentation – Issues in Managing Pain (see Suggestions below)

   Or

   **Option # 2**
   Panel Presentation - Options for Pain Management (See Suggestions below)

4. Evaluation of workshop (see Sample evaluation below)

5. 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 new Canadian Hemophilia Society program: *Passport to Well-Being* designed to empower people with bleeding disorders to maximize their quality of life. Over the next year you will have the opportunity to participate in the other modules: home care, fitness and charting your course. At each session you will receive a visa stamp on your passport; collecting all four stamps will make you eligible to enter a draw for exciting prizes.

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 presentation - Issues in Pain Management

Format

3 individuals would be invited to present a 5 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
- Member – CHS Pain Management Working Group

Speakers

- Child or adolescent with inhibitors
- Adult hemophiliac infected with HIV or HCV or co-infected
- Adult hemophiliac who has had one or more joint replacements
- Pediatric perspective - parent of a child on prophylaxis

Expert Panel Members

- HTC nurse coordinator
- HTC social worker
- HTC Clinic Director
- HTC physiotherapist
- Physician specializing in pain

Guidelines For Case Study Presentations (to be sent to speakers in advance)

1) State your type of bleeding disorder and your age (if you don't mind).

2) Outline your situation: the event or series of events surrounding your pain experiences. Discuss why pain is an important issue for you.

3) 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?
4) 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).

5) Who have some of the key players been in your pain management?

6) What have you learned from your experiences that may help others with their own struggles?

Option # 2: Suggestions for panel presentation - Options for Pain Management

Format

3 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
- Member – CHS Pain Management Working Group

Speakers

- HTC Physiotherapist
- Orthopedic Surgeon familiar with operating on hemophiliacs for joint replacements or other surgical procedures joint replacements
- Physician specializing in Pain Management who has treated hemophiliacs
- Expert on Alternative therapies to manage pain

Sample closing remarks

- thank speakers and participants for attending
- collect evaluations
- hand out - Roadmap for Managing Pain Booklet
- invite participants to pick up a passport and have it stamped with the Roadmap Visa at the Passport to Well-Being Booth (if not available, set up a table for this)
Roadmap for Managing Pain Workshop Evaluation

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 presentation 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 Pain Management issues?

   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 - f VIII deficiency _______ f IX deficiency _______
   b) person with von Willebrand Disease _______ Type _____
   c) parent/caregiver of a person with hemophilia or VWD _______
   d) HTC health care professional – nurse _______ clinic director _______ other _______
   e) CHS staff – national _______ provincial _______ regional _______