



PASSPORT to well-being

empowering people with bleeding disorders
to maximize their quality of life

ROADMAP FOR MANAGING PAIN





Canadian Hemophilia Society
Help Stop the Bleeding

The Canadian Hemophilia Society (CHS) exists to improve the quality of life of persons with hemophilia and other inherited bleeding disorders and to find a cure.

The CHS consults qualified medical professionals before distributing any medical information. However, the CHS does not practice medicine and under no circumstances recommends particular treatments for specific individuals. In all cases, it is recommended that individuals consult a physician before pursuing any course of treatment.

The CHS would like to acknowledge those people who contributed to the development of *Roadmap for Managing Pain*.

Jenny Aikenhead

Physiotherapist, *Alberta Children's Hospital, Calgary, AB*

Maureen Brownlow, RSW

IWK Health Centre, Halifax, NS

Nancy Dower, M.D.

Walter Mackenzie Health Sciences Centre, Edmonton, AB

Sophia Gocan, R.N.

Member, CHS National Programme Committee, Ottawa, ON

Ann Harrington, R.N.

St. Michael's Hospital, Toronto, ON

Heather Jarman

Pharmacist, St. Joseph's Health Care, London, ON

D. William C. Johnston, BMedSC, M.D., FRCS(C)

Orthopedic Surgeon and Site Medical Director of the University of Alberta Hospital, Edmonton, AB

Peter Leung, M.D.

Pain Management Service, St. Michael's Hospital, Toronto, ON

Pam Wilton, R.N.

Vice-President, Canadian Hemophilia Society

Clare Cecchini

Program Coordinator, Canadian Hemophilia Society

David Page

Blood Safety Coordinator, Canadian Hemophilia Society

Supported by Baxter BioScience

Baxter

For further information please contact:

Canadian Hemophilia Society
625 President Kennedy Avenue, Suite 505
Montreal, Quebec, H3A 1K2
Tel: (514) 848-0503
Toll Free: 1-800-668-2686
E-mail: chs@hemophilia.ca
Website: www.hemophilia.ca

**Note: Bleeding disorders affect both men and women.
The use of the masculine in this text refers to both.**

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INTRODUCTION

“It is difficult to convey how chronic pain totally invades and affects all aspects of your life. It is a constant inescapable entity. And it is difficult to make others understand. Everyone has endured pain, but not the kind of pain that you must live with 24 hours a day, 7 days a week, day and night.”

- a 50-year-old man with hemophilia

This eloquent statement was made by a person with hemophilia interviewed during an informal survey on the impact of pain.

It reinforces the message that pain experienced by people with bleeding disorders is not well understood, assessed or treated. Forty percent of the people interviewed reported having pain all the time. Children also have pain and often have difficulty describing the level of their pain. Many adults, especially those with chronic joint damage, say that pain is the major element affecting their quality of life. Yet it is only recently that attention is starting to be paid to this serious problem.

The most common reasons given for not taking medication are that...

- pain isn't considered bad enough
- side-effects are a problem
- access to a pain specialist is difficult.

The goal of this booklet, *Roadmap for Managing Pain*, 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 best way to cope.

THE IMPACT OF PAIN ON THE FAMILY

People who live with hemophilia and other bleeding disorders are veterans in the acute care of bleeds. They are, however, strangers in the uncharted waters of effective pain management. For many years, pain has been seen as an unavoidable part of the condition—something to be suffered, often alone and in silence.

Often, people are reluctant to complain. They have built an arsenal of weapons to deal with pain, including doing their best to ignore it. There are signs, however well a person hides it, that a person is dealing with pain, for example...



- mood changes
- a reluctance to communicate and interact with others
- increased irritability
- inability to concentrate
- difficulty sleeping
- a decreased interest in favourite activities
- a lack of appetite.

“My pain has progressed significantly in the last few years. It has an impact on most aspects of my life. My ability to climb stairs, walk distances (especially on uneven ground), type at the computer, hammer a nail and open a jar, to mention only some examples, have all been affected. On days when the pain is extreme, it can have a negative impact on my mood and it affects those around me.”

– a 35-year-old man with hemophilia

In the longer term, ineffective pain management may lead to...

- missing school or work
- missing out on social and family activities
- feelings of futility and hopelessness.

Pain is an almost invisible presence. Yet it casts a net beyond the person who is directly affected. In fact, pain has never been suffered alone. Family members have always been aware of the suffering, although limited in their resources to deal with it. They are affected by the pain of a family member in a number of ways—emotionally, socially, academically, financially and spiritually—depending on the family situation of the person with the bleeding disorder.

“When I’m in pain, I tend to express it by complaining verbally—to tell the truth, by screaming. My family doesn’t like to see me suffer and they do their best to comfort me and distract me. My mother gives me my Niastase and also morphine for the pain if necessary. My sister tries to watch TV with me. My father talks to me about hunting and fishing, which I’m crazy about, and we often look at magazines together.”

– a 13-year-old boy with a factor IX inhibitor

Families in the bleeding disorder community have developed ways of dealing with the condition by...

- educating themselves about their particular situations
- being open in working with the members of the comprehensive care teams
- learning to do home treatments
- developing internal strengths
- being creative in dealing with problems
- maintaining a sense of hope for the future.

These positive coping abilities now need to be applied to the new frontier of pain management.

PAIN – THE FIFTH VITAL SIGN

Most health care providers and patients are used to having the four routine vital signs— blood pressure, pulse rate, temperature and respiratory rate—recorded at every assessment. Yet the most common reason for seeking medical care is pain. In 1995, the term, “fifth vital sign”, was coined, suggesting that that pain must be measured and treated.

What then is pain? A medical definition is: “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.”

A person with hemophilia, however, describes pain in these words.

“I experience pain daily. It can be mild or severe. It can be relentless. It can sometimes be unpredictable. I associate my pain with an imaginary companion I like to call the dragon. This dragon travels with me all day, every day. He makes it his point to remind me when I am doing something destructive by breathing his heat and making me uncomfortable. As I like being active, I would hate to see the trouble I might get into if I could silence this dragon completely.”

- a 35-year-old man with hemophilia

Pain in hemophilia is usually of two types:

Acute pain is usually due to bleeding into joints and muscles and, more rarely, the after-effects of surgery.

Chronic pain is associated with joint degeneration or other long-term complications of hemophilia.

Pain is always subjective—it is the person with pain who decides if there is pain or not—and always unpleasant. And it is an emotional experience. When pain becomes chronic, the actual injury, and even the physiological responses, may not be visible.

Why assessing and managing pain is so important

There are many roadblocks to the humane and competent assessment and management of pain.

- Patients and health care providers often differ culturally and socially.
- Treatment for chronic pain may be unavailable, unaffordable or not covered by health insurance.
- The variability and unpredictability of pain in people with bleeding disorders may lead to an adversarial relationship between patients and health care providers.

Recognizing pain as the fifth vital sign puts assessment at the forefront, and allows the patient and family to create an alliance with the health care providers against suffering.

The aim of pain control within the first few hours of a bleeding episode is relief of suffering. Unrelieved pain can actually interfere with healing and turn acute pain into a chronic problem.

With chronic pain control there is the added aim of maintaining daily function. The final goal is a balance between the efficacy of pain relief, the side effects if any, and being as functional as possible.

All modalities of pain management—physical, pharmacological and psychological—should be incorporated into the therapeutic plan, if beneficial. Then, there is no fear of the agony of the next episode because the patient can assume “control”, and knows back-up plans are in place.

Fortunately, there is already a major shift in attitudes toward pain medications. Not so long ago, there was a reluctance to prescribe pain killers because they might cause addiction or interfere with recovery. Research has shown that the risk of clinical addiction is overestimated and, in fact, quite rare at the dosages used for pain management. What's more, recovery takes place faster when pain is properly managed.

How pain is measured

Unlike its vital sign counterparts, there is no gadget to measure pain—it must be evaluated by asking questions and observing behaviour. These are some helpful tools:

For children aged 3 and older, a range of tools is available for self-reporting and behaviour observation; children from approximately age 5 are able to reliably complete a VAS (Visual Analog Scale) score. One useful tool might be the “Face Scales”.



Pain has sensory, emotional, motivational, cognitive, and behavioural dimensions. Hence the individual's subjective response must override the clinician's bias. Every patient deserves the most effective treatment, not what the provider feels he/she should have.

THE ROLE OF THE COMPREHENSIVE CARE TEAM IN PAIN MANAGEMENT

In various ways, all of the comprehensive care team members are involved in the assessment and management of pain.

The *person with the bleeding disorder* and, in the case of a young child, *his/her parents*, are at the centre of the process. They need to be able to recognize bleeds early and know the difference between pain from acute bleeds and from chronic conditions.

"I now know I have to get treatment as soon as possible when I think I am bleeding. Sometimes I think I can get away without treatment and I wait before telling my mother. This is often how the pain gets very bad... but not always."

- an 8-year-old boy with hemophilia

The *nurse coordinator* can ensure that pain is assessed and treated by the appropriate team member. In managing both acute and chronic pain, good bleed diaries are most helpful. So are pain diaries to record preceding events, intensity of pain, activity level, interventions and response to treatment.

The *hematologist* can develop a management plan for both acute and chronic pain which could include medication. If you do not live close to the Hemophilia Treatment Centre (HTC), your family physician will need to be involved. In some parts of Canada, HTCs are located in large health centres, which include pain management teams whose members have specialized knowledge in the management of all aspects of pain.

The *physiotherapist* can make various recommendations for treating acute or chronic pain. The overall goal is to prevent secondary complications due to pain, such as tight musculature or poor mobility.

The *social worker* can help the patient manage the life complications that occur due to pain.

Comprehensive care teams in pediatric and adult centres often have close working relationships with *rheumatology* and *orthopedic* teams whose expertise can be called upon to treat pain. Treatments such as joint injections, synovectomies or joint replacements are some of the options.

People with pain, and their families, need to be aware that pain is a manageable condition. It doesn't need to be suffered in silence.

Discuss it with your clinic team and work out a plan that suits you.



FOR BETTER PAIN MANAGEMENT

“My physician told me she never realized how much pain people with hemophilia had until she went to a CHS workshop on pain management. She couldn’t believe how well her patients hid the pain.”

- a 50-year-old man with hemophilia

Advocacy is a process of promoting a cause on behalf of oneself and/or others. An advocate is someone who works through that process.

You are your own best advocate but, depending on the situation, the role of advocate can be played by almost anyone.

- a family member—spouse, parent or sibling— or close friend
- a nurse, especially the nurse at the HTC
- a physiotherapist
- a social worker.

The HTC is part of a network of clinics across Canada and therefore the comprehensive care team has an established network of expertise it can tap into for help in difficult situations.

You may need to seek help from experts in the field of pain management. It is sometimes difficult to get a referral to a specialist because many people, including physicians, simply do not understand the extent of the pain. In addition to the hematologists at the HTC, a family physician can also facilitate a referral. It is always preferable to have your family physician and/or your hematologist working with you. So, in all likelihood, you will need to convince these people of your need for expert help.

Fatigue, immobility, frustration and anger are common in patients with chronic pain, making it difficult to communicate. When pain persists, confidence and respect for health care professionals can quickly erode.

Effective advocacy can help you communicate competently in a calm, yet assertive way, working with health care providers to develop an effective pain management plan.

Effective communication strategies

Take a buddy - A family member or a friend who knows your situation well can help you to have confidence and to be more open about your situation.

Prepare ahead - Write down key points before the visit.

Be knowledgeable - Be ready to provide information about your pain. Use resources such as this booklet to know your options.

Be proactive - Ask to discuss your pain management. Propose a solution if you think you have one.

Speak up! Be assertive! - State what the problem is and what concerns you have. It won’t always help to “grin and bear it”.

Listen - Listen carefully to what the physician says. Don't be afraid to ask him to explain if you're not sure you understand.

Stay calm - You may feel frustration and impatience because of the pain. Staying calm can be difficult, but it is important.

Repeat yourself if necessary - If you find your concerns are not getting addressed, calmly repeat your problem and insist that you are serious about finding a solution.

Be polite and courteous, yet firm - The health care providers are trying to do their jobs to the best of their abilities, but may have little experience treating chronic pain.

Focus on the problem, not the people - You want relief from pain—that is the problem at hand. Focus on finding a solution, and not on any difficulties you are having getting help.

Use "I-statements," not "you-statements." - Focus on how you feel and what you need, not on any disputes with health care providers.

THE USE OF ANALGESIC



"I never considered myself one to take drugs to manage pain, at least not in the obvious sense like taking Tylenol, because I rarely do this. But I do have a strategy and do in fact take drugs to manage my pain. I infuse with clotting factor on a prophylactic basis to prevent bleeds and thereby prevent episodes of pain. I take Celebrex®, not everyday as I should, but when I start to feel constant nagging pain or know that I will be involved in activity the next day."

- a 35-year-old man with hemophilia

Most patients with acute pain can obtain relief with the careful use of common drugs such as acetaminophen (Tylenol®) or non-steroidal anti-inflammatory drugs (NSAIDs). The new COX-2 inhibitors (Celebrex®, Vioxx®) have less effect on platelet function than ibuprofen, which was often used for patients as the NSAID of choice. The addition of opioids, such as morphine, can increase the control of severe pain, depending on the individual patient.

If oral medication is ineffective, intravenous (IV) therapy is an option. Opioids can be given by IV bolus, or by continuous administration for even more control.

"At the hospital the pain management team put me on a pump so I could administer extra doses of morphine myself when I felt pain. I didn't have to ask for and wait to get my painkiller. It was also very useful when I started to move around again with the help of my physiotherapist. I manage my pain and can do my exercises better."

- a 13-year-old boy with a factor IX inhibitor

Many people worry that opioids are addictive or could lead to abuse. While there are no guarantees against this, physicians take all possible precautions. As long as the amount used is for pain, then the chance of addiction is quite low. Short-term use for acute bleeds or surgery is very unlikely to lead to addiction.

Addiction is not the same as tolerance. When people use opioid pain medication, their bodies become accustomed to the dose. One may need to increase the amount to get the desired effect. Changing to a different medication can sometimes avoid the increase.

Poorly treated pain is detrimental to patients. Poor pain management produces abnormal pain behaviour and may even cause patients to seek out street drugs because they are afraid of not being able to manage severe pain.

Marijuana is probably better to reduce nausea, improve appetite and promote sleeping. Its use must be individualized. For most patients it is not the magic drug. Legal access to marijuana is difficult.

When the patient is traveling, the physician can provide a specific letter detailing the medications and the amount needed. He/she may even set out a suggested plan of medication for mild and severe bleeds. This will help the physician in another city to manage the pain. It will also provide evidence at borders that a person is authorized to carry these medications.

There are many useful medications for controlling pain. In all cases, the type of analgesic and the route of administration must be tailored to the individual patient. What's more, the underlying health problem must be managed by knowledgeable health care workers.

PHYSIOTHERAPY – ANOTHER APPROACH TO PAIN MANAGEMENT

The Pain Service at the Hospital for Sick Children always recommends appropriate exercise to our patients. We know that exercise makes the body release chemicals, called endorphins, that not only make us feel less pain, but also make us feel good. It's something you can control and do for yourself.

*- Dr. Michael Jeavons, Psychiatrist,
Hospital for Sick Children's Pain Service*

An exercise or fitness program improves...

- *Muscle strength* - Stronger muscles tire less easily, which results in extra support and protection for the joint and reduces the stress and strain that can cause pain.
- *Joint range of motion* - Improved mobility of the joint results in better alignment of the joint and decreased stress on its surrounding structures. Exercises help reduce stiffness and, by improving movement, may alleviate pain.

- *Flexibility* - Joint contractures and/or muscle shortening may result in pain. These respond well to stretching exercises. Improved flexibility also decreases the chance of muscle bleeds.
- *Coordination and balance* - The development of these skills results in a quicker response to a sudden movement and a decreased chance of further injury to the joint.
- *Confidence and peer acceptance* - Exercising allows sharing with friends. Participation and success bring confidence.
- *Feelings of well-being and decreased anxiety* - Mental stress and anxiety are known to influence sleep patterns, muscle spasm, the frequency of bleeds and increase sensitivity to pain. Exercise can decrease feelings of stress.
- *Release of endorphins* - Endorphins are natural chemicals produced by the body and act as a damper to the sensation of pain. Their production is thought to be influenced by exercise, heat, cold, positive attitude, some physiotherapy electrical modalities, relaxation and medications.
- *Endurance and weight loss* - Cardio-vascular exercises increase endurance and strength and therefore reduce stress on the joints. Weight loss may occur, which also decreases pressure on the joint surface.



"Sometimes applying ice helps a bit. I have several orthotics I can use to immobilize the affected joint if the bleeding is in the joint. I also use crutches or my wheelchair when I have to. Because I had many hemorrhages, I didn't go to school for a few years. I have been back at school since September 2002 and I love it. I have a lot less bleeding because I am more active and my muscles are stronger."

- a 13-year-old boy with a factor IX inhibitor

A physiotherapist at the HTC can assess the pain and assist in choosing an exercise or activity program. Ask the physiotherapist about these other ways to reduce pain.

- Non-electrical treatments such as hot packs, ice, hydrotherapy, splinting, foot orthotics and acupuncture
- Electrical modalities such as Transcutaneous Electrical Nerve Stimulation (T.E.N.S.) and ultra-sound

Recommended activities for people who suffer from the pain of arthritis related to hemophilia are those that have low impact on the joint but allow mobility, strengthening and cardio-vascular exercise. They include:

- swimming and aquacise
- T'ai Chi
- yoga
- bicycling
- walking, dancing, bowling and hiking.

For more information, see the *Passport to Well-Being* module entitled: *Destination — Fitness*.



ORTHOPEDIC AND SURGICAL MANAGEMENT OF PAIN

Orthopedic interventions can be very effective in managing pain. Acute pain from recurrent bleeding into target joints can be helped by procedures such as synovectomy. Chronic pain from an irrevocably damaged joint can be relieved by procedures such as joint replacement. All invasive procedures must be performed under the protection of factor replacement. The hemophilia doctor must be involved to ensure that adequate levels of replacement are provided for the appropriate time post-operatively. Factor replacement may be recommended prior to post-operative physiotherapy sessions.

Synovectomy

Removal of the swollen synovium (synovectomy) can decrease recurrent bleeding into a target joint and reduce pain. Three techniques can be used:

Radioactive synovectomy - A radioactive isotope is injected into a target joint. Within the joint, the radioactivity reduces the amount of swollen synovium.

Arthroscopic synovectomy - Using small surgical incisions a tiny camera is inserted into a joint to guide the removal of the synovium through the other incisions. This can be used for ankles, knees and elbows.

Open synovectomy - The joint is opened surgically and the synovium removed.



Joint replacements

Chronic joint damage produces pain and decreased range of motion. When the pain is severe and interferes with the activities of daily living, joint replacement is an option. Knee and hip replacements are the most common. Elbow, shoulder and ankle replacements are done less commonly due to the complexity of the joints.

Before the elbow replacement in 1999, I was in tremendous pain continuously for a period of about 8 months to the point of having to stop working.

– a 49-year-old man with hemophilia

The damaged joint and adjacent bone are removed and replaced with plastic and metal components (knee) or with a metal ball and a plastic cup (hip). Pain control is critical during the recovery period so that early mobilization and physiotherapy can occur. Most people are left with a pain-free joint.

Other surgeries

Other surgeries that might be considered to manage pain from damaged joints are:

- Removal of small bony growths around the joint margins (cheilectomy)
- Fusion of the joint to leave a painless immobile joint (arthrodesis)
- Removal of the radial head to improve rotation of the forearm
- Removal of the ball part of the femur to allow a fibrous union to develop. This may be done if a hip replacement fails
- Removal of a wedge of bone from the femur or tibia to realign the leg and reduce pain (osteotomy).

Less invasive options

Injection of a corticosteroid into an affected joint can be used in the short to medium term to decrease inflammation and pain. This could be used while awaiting surgery.

“Ultimately, the operations—replacements and fusions—were godsend and did relieve the pain. I do not run or skate and I avoid stairs like the plague, but my wife and I play golf—I still have a slice—and I am able to enjoy travel and visit family and friends.”

- a 43-year-old man with hemophilia

COMPLEMENTARY AND ALTERNATIVE APPROACHES TO PAIN MANAGEMENT

“When I’m at home, I find that my dog helps me a lot to manage my pain. I see a huge difference since he became part of our lives.”

- an 8-year-old boy with hemophilia

Complementary and Alternative Health Care (CAHR) are therapies that are considered outside of mainstream medical practices.

A complementary therapy, such as aromatherapy to help lessen a person’s discomfort following surgery, is used *together* with conventional medicine. In contrast, alternative medicine, such as a special diet to treat cancer instead of undergoing surgery that has been recommended by a conventional doctor, is used *in place of* conventional medicine.

While there is scientific evidence supporting some CAHC therapies, for most there remain unanswered questions regarding safety and effectiveness. As these therapies become better understood and validated with sound scientific research, some CAHC therapies will become integrated into traditional medicine.



Types of complementary and alternative health care therapies

CAHR therapies can be divided into five categories, or domains:

- *Alternative medical systems* including homeopathy, naturopathy, traditional Chinese medicine and Ayurveda
- *Mind-body interventions* including patient support groups, meditation, prayer, biofeedback, humour therapy, and therapies that use creative outlets such as art, music or dance
- *Biologically-based therapies* using substances found in nature, such as herbs, foods, and vitamins
- *Manipulative and body-based methods* including chiropractic or osteopathic manipulation, reflexology and massage
- *Energy therapies* including qi gong, Reiki and Therapeutic Touch.



The value of complementary and alternative health care therapies in reducing pain

It is important to ask yourself what you expect from CAHC therapies. While you may not be able to find relief for your pain, some CAHC therapies may be able to provide you with indirect benefits.

Consider the potential benefits before starting a treatment. Monitor how you feel as a result of the treatment. Then make a decision about whether to continue it.

The safety of complementary and alternative health care therapies

To protect yourself from potential risks involved when using CAHC therapies, be sure to:

- Discuss all of your CAHC practices with your physician and other health care providers. Ensure the therapy you are considering will be safe when taking into account your current health status.
- Try to gather information from sources that look at both sides of a therapy—those who oppose and those who support the therapy. Consult publications and web sites that stem from governments, recognized medical organizations, well-known scientific sources or academic institutions.
- Be cautious about any of the claims that you come across.
- Seek out only fully competent and licensed practitioners. Ask individuals about their training and experience. Check with provincial or territorial Ministries of Health.

Some CAHC products contain powerful pharmacological substances which can be toxic on their own, or when used with other medications. Some can affect the ability of your blood to clot. This is especially dangerous for a person with a bleeding disorder. Some substances known to negatively affect clotting are...

- black cohosh
- cat's claw
- feverfew
- garlic
- ginkgo biloba
- pau d'arco.

CONCLUSION

For many, the pain of acute bleeding is the most vivid memory of living with a bleeding disorder. Thanks to better treatment, such episodes are much rarer today, but still a reality, especially for those with an inhibitor. The long-term consequences of bleeding, however, mean that many adults are living with damaged joints and the burden of chronic pain. For many years, this pain went largely unrecognized or was accepted as unavoidable. Today, we know a roadmap for pain management must be drawn so that people can find their way to some relief.



RESOURCES

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