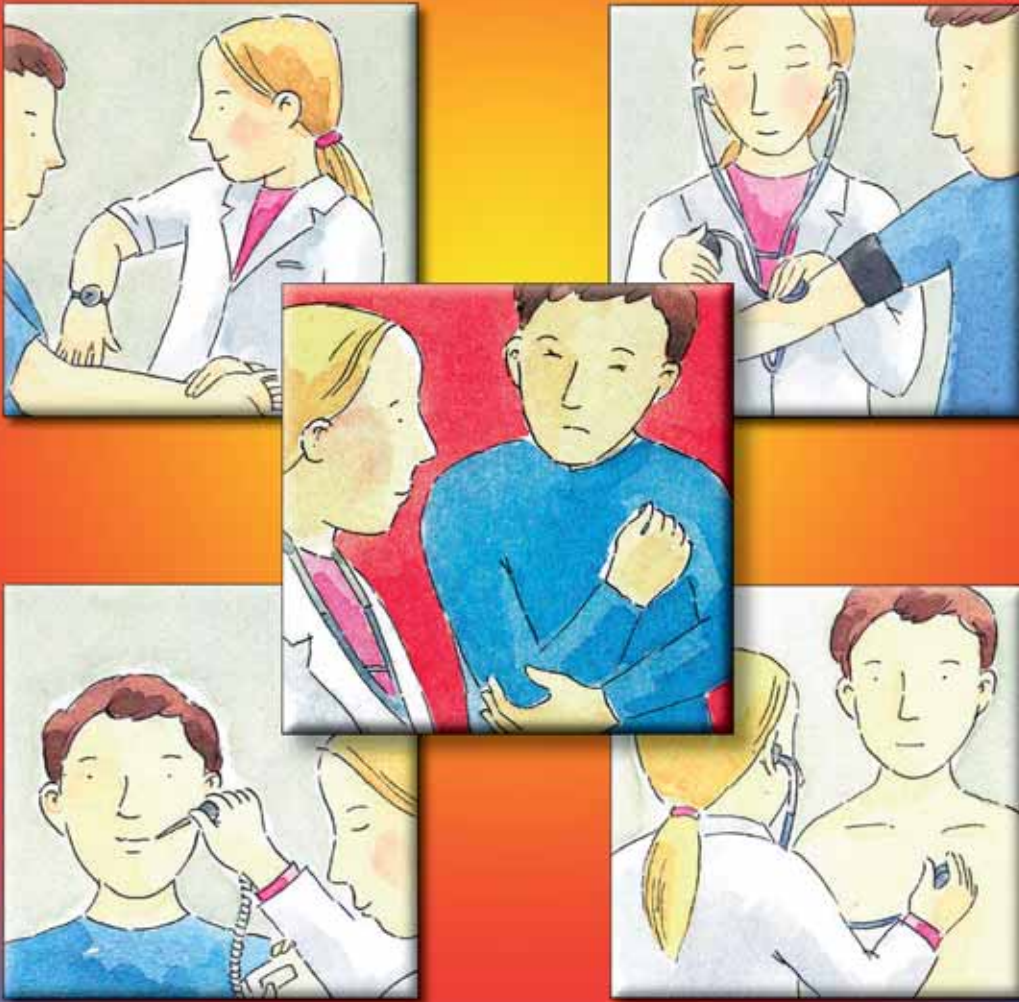


PAIN

The Fifth Vital Sign

A Resource on Managing Pain
for People with Bleeding Disorders



Canadian Hemophilia Society
Help Stop the Bleeding



Bleeding Disorders Initiative



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 mention of any product, service, or therapy in this booklet is not an endorsement by the CHS and we encourage you to discuss any decisions about your medical treatment or care with your primary health care provider.

The CHS would like to acknowledge those people who contributed to the development of *PAIN – The Fifth Vital Sign*.

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

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PAIN

The Fifth Vital Sign



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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.”

This eloquent statement was expressed by a patient interviewed during an informal survey on the impact of pain experienced by people with hemophilia.

Members of the bleeding disorder community have been aware for some time that their pain, both acute and chronic, hasn't always been appropriately managed. The topic was discussed at a panel presentation held during the Canadian Hemophilia Society (CHS) Medical Symposium at Mont-Tremblant, Quebec, in May 1999. Three adults shared their experiences with pain, its impact on their lives and their difficulty finding effective care. A pain specialist spoke about the range of options available to deal with severe pain, the barriers to getting effective pain treatment as well as two very important issues—the education of health care professionals about the various aspects of pain assessment and treatment, and the need for pain assessment being a part of the Hemophilia Treatment Centre's routine process.



INTRODUCTION

In the early fall of 2001, to determine whether the experiences described by members of the Mont-Tremblant panel were representative of other people with bleeding disorders, the CHS developed a survey which was sent to all the Hemophilia Treatment Centres (HTCs) in Canada. It was administered through an interview with an adult, teen, or parent of a younger child. The interviewers asked about the person's experience with acute and chronic pain, his personal support systems, his opinion of his quality of life, and, if pain was an issue, what strategies he used to deal with it. Eighteen interviews were conducted in all. Although the numbers were small, the opinions expressed were consistent across all clinics.

In summary, the results reinforced the message that pain experienced by people with hemophilia 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. The most common reasons given for not taking medication are that the pain isn't considered bad enough, the side-effects are a problem or that access to a pain specialist is difficult.

When asked what the CHS could do to help, one person said, *"Encourage open discussion of pain and any and all subjects related to it. Suffering along in silence is certainly not the way to cope."*

To this end, *Hemophilia Today*, the newsmagazine of the CHS, has published a series of feature articles related to pain management written by knowledgeable people.

At the CHS 50th Anniversary Weekend in Montreal, May 8-11, 2003, a consumer workshop provided an opportunity for people with bleeding disorders and their families to share experiences and ideas, hear a presentation on treatment options, experience advocacy training and discuss options with health care providers.

With the knowledge gained from these initiatives, the CHS is now proud to publish this resource entitled *Pain – the Fifth Vital Sign*.

"Encourage open discussion of pain and any and all subjects related to it. Suffering along in silence is certainly not the way to cope."

PAIN – The Fifth Vital Sign

CHAPTER

1

Peter Leung, M.D.

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

The most common reason for seeking medical care is pain.

Many adults and children in the bleeding disorder community, 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 questions which will be addressed in this chapter are:

- What is the origin of the term “pain - the fifth vital sign”?
- What is pain?
- How do we measure pain?
- Why is recognition of the “fifth vital sign” so important?



CHAPTER

1

PAIN
THE FIFTH
VITAL SIGN

Most health care providers and consumers are used to having the four routine vital signs recorded. Blood pressure, pulse rate, temperature and respiratory rate are documented every time a patient presents for a medical assessment. Yet the most common reason for seeking medical care is pain.

What is the origin of the term “pain - the fifth vital sign”?

Most health care providers and consumers are used to having the four routine vital signs recorded. Blood pressure, pulse rate, temperature and respiratory rate are documented every time a patient presents for a medical assessment. Yet the most common reason for seeking medical care is pain. In 1995, the President of the American Pain Society, Dr. James Campbell, coined the term “fifth vital sign”, suggesting that “quality care means that pain is measured and treated”. When we add the measurement of pain as one of the essential records for all patients, we are finally focusing on the main cause for seeking medical care.

Health Regulatory Boards in many American states have legislated guidelines to mandate pain assessment with all patient contacts. Pain is now officially considered the fifth vital sign by the Joint Commission on Accreditation of Healthcare Organizations; in other words, all health facilities have to include pain as the fifth vital sign for that facility to be accredited. The California Governor recently signed into law the Health and Safety Code (HSC). As part of this bill, HSC 1254.7 reads:

- (a) It is the intent of the Legislature that pain be assessed and treated promptly, effectively, and for as long as pain persists.*
- (b) Every health facility licensed pursuant to this chapter shall, as a condition of licensure, include pain as an item to be assessed at the same time as vital signs are taken. The health facility shall insure that pain assessment is performed in a consistent manner that is appropriate to the patient. The pain assessment shall be noted in the patient’s chart in a manner consistent with other vital signs.*

Surveys report 14% of the population have sick days due to pain, 75% use over-the-counter pain medications and 35% use prescription pain medications. Chronic pain accounts for more total annual costs than other chronic conditions such as heart disease, high blood pressure and diabetes.

What is pain?

In the hemophilia community, a new bleeding episode is recognized primarily because it causes pain. Hemarthrosis – bleeding into the joint – is most common. The pain from the inflammatory reaction of blood in the joint can become severe; the joint swelling then further aggravates the pain. Bleeding into the muscle also gives rise to pain and swelling and, if unabated, can damage nerves, tendons or other structures. Other sites may or may not be as painful and each person with hemophilia will have different common sites.

What then is pain? Pain is very difficult to define in words but the International Association for the Study of Pain did try.

“An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.”

Pain is always subjective. The person with pain is the one who decides if there is pain or not. It is always unpleasant and since we learn of pain from injury in early childhood, it is described in “damage” terms. Lastly, it is an emotional experience. We should note that there does not have to be actual damage to specific areas of the body to cause pain. In other words, when pain becomes chronic, we may not see the actual injury or the physical response such as changes in heart rate, blood pressure, or even grimacing and crying out.

Some books or pamphlets on hemophilia might talk about individual differences of pain perception but the pain level is yours and yours alone. Do not feel that your pain is less significant than that of others, and certainly you must not feel guilty or embarrassed because you need medication or treatment for both acute and chronic pain. Actually, inadequate initial pain management may be a cause for future abnormal pain behaviour.

The aim of pain control within the first few hours of a bleeding episode is relief of suffering. With chronic pain control there is the added aim of maintaining daily function. A balance among the efficacy of pain relief, the side effects if any, and the ability to be as functional as possible is the final goal of management. Any and all modalities of pain management—physical, pharmacological and psychological—should be incorporated into the scheme if beneficial.

How do we measure pain?

Unlike its vital sign counterparts, however, there is no gadget to measure pain; it must be evaluated by asking questions and observing behaviour. And, unlike temperature or blood pressure, getting accurate data about pain depends on two-way communication between the health care provider and the patient. These are some helpful tools:

Numeric Rating Scale:

Instructions: Choose a number from 0 to 10 which indicates how strong your pain is right now.

No pain at all = 0 1 2 3 4 5 6 7 8 9 10

Visual Analog Scale:

Instructions: Mark on the line below how strong your pain is right now.

No pain at all _____ The worst pain imaginable

Category Scale:

Instructions: Choose the word below which best describes how your pain feels right now.

Mild Discomforting Distressing Horrible Excruciating

CHAPTER

1

PAIN THE FIFTH VITAL SIGN

Unlike its vital sign counterparts, however, there is no gadget to measure pain; it must be evaluated by asking questions and observing behaviour.

CHAPTER

1

PAIN
THE FIFTH
VITAL SIGN

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”.



Once we measure the level of pain, we can go ahead with the treatment plan. The clinician may quantify it on a single dimension using, for example, a single VAS, but this approach risks being too simplistic. Pain has sensory, emotional, motivational, cognitive, and behavioural dimensions. We must be aware that clinical pain intensity does not necessarily vary directly with the extent or severity of clinical pathology. Hence the individual’s subjective response overrides the clinician’s bias of labeling the patient. Every patient deserves the most effective treatment, not what the provider feels he/she should have.

Why is recognition of the “fifth vital sign” so important?

Many barriers impede humane and competent assessment and management. Patients and health care professionals often differ culturally and socially. Treatment for chronic pain and chronic illness may be unavailable, unaffordable, or not covered by health insurers. The variability and unpredictability of pain in hemophilia make effective coping difficult, and can contribute to an adversarial relationship between patients and health care professionals.

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. Unrelieved pain can actually interfere with healing and turn acute pain into a chronic problem.

Recognizing pain as the fifth vital sign puts assessment at the forefront and sets the tone for cooperation. Asking “What level is your/your child’s pain?” brings the family and the provider into an alliance against the suffering. Once we have all parties on the same side, a therapeutic plan can be developed for future episodes and daily chronic pain. Then, there is no fear of the agony of the next episode because the patient can assume “control” and knows there is a path to follow with back-up plans in place. This all stems from a simple assessment tool, what we refer to as the “fifth vital sign”.

The Impact of Pain on the Family

Maureen Brownlow, RSW

IWK Health Centre, Halifax, Nova Scotia

For many years, pain has been seen as an unavoidable part of the condition—something to be suffered, often alone and in silence. In fact, this acute and chronic pain has never been suffered alone. Family members have always been aware of the suffering, although limited in their resources to deal with it.



The questions which will be addressed in this chapter are:

- How do we define family?
- How are families affected by the pain of a family member?
- What are some ways families deal with the challenges of pain?



CHAPTER

2

THE IMPACT
OF PAIN ON
THE FAMILY

Families are affected by the pain of a family member in a number of ways...

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. In fact, this acute and chronic pain has never been suffered alone. Family members have always been aware of the suffering, although limited in their resources to deal with it.

Within the range of issues faced by people with a bleeding disorder, pain has been an invisible presence. Yet it casts a net beyond the person who is directly affected. It is an added burden on top of the many already faced by the people themselves and their families.

How do we define family?

Who is “family”? Each family creates its own definition. Mother, father, step-parents, brothers, sisters, step-siblings, half-siblings, grandparents, aunts, uncles, cousins, in-laws... For many people, “family” includes close friends who share common interests and concerns. In families, support and care for each other is a lifelong commitment, stretching over miles and time zones, and nurtured by direct contact, phone, e-mail or “snail mail”.

How are families affected by the pain of a family member?

Families are affected by the pain of a family member in a number of ways, depending on the family situation, the age and role within the family of the person with the bleeding disorder: a child, a teenager or an adult with family and career responsibilities. Their pain is experienced on both the physical and emotional levels, as they struggle with feelings of futility and hopelessness. Young people miss school, with the resultant impact on their learning, as well as on their social lives. The young person may be seen as “different” because of a limp, crutches or a wheelchair. One grade 7 student with mild hemophilia and a painful knee bleed that required 6 months of treatment spoke of having his peers accuse him of “faking to get attention” because he used crutches in school. Building an arsenal of effective weapons to deal with pain begins with the person who has the pain. He gives out signals, either directly or indirectly, that the usual pain relief measures aren’t working. Often, boys and men are reluctant to complain. Family members may notice a mood change or a decrease in interest in favourite activities. This may result in more bleeding disorder clinic visits and/or visits to a variety of medical and other health care specialists and major testing, such as CAT scans or MRIs. For many Canadians, these specialized services are a distance from home. Following the visit, there may be recommendations for treatments at home, referrals to other services and follow-up visits.

CHAPTER

2

THE IMPACT
OF PAIN ON
THE FAMILY

Here are some examples of the thoughts of different people in a family when dealing with the impact pain has on them.

JOEY is a teenage child with a bleeding disorder.

Joey: “Is any of this going to make me feel better? I’m going to miss the dance tonight. Not that anyone wants to dance with me the way I move. I wish Mom and Dad wouldn’t fuss so much, although it helps to have someone here. I hate talking to new doctors. They just don’t get it.”

Mother: “I hope this will help. He’s missing too much school and he seems so down. How will I make up the time I’ve taken off for these visits and when I had to stay home? These splints and drugs are expensive. I wish we had a health plan. I have to try and remember what the doctor said so I can tell Joey’s father. I hope I get home before the daycare closes. How will Joey manage if this doesn’t work?”

Little sister: “What’s the matter with Joey’s knee? His treatment used to fix him. I wish I could miss school sometimes. I bet they’re going to the gift shop before they leave the hospital. I wonder why Mom and Dad are so grouchy lately.”

Grandparents, aunts, uncles, cousins: “Is Joey getting good care from that clinic? You’d think these doctors would be able to do more than they did when his Uncle Fred had sore joints 25 years ago. How can we help him and his parents?”

SAM is 60 years old with a wife, adult children and grandchildren.

Wife: “I wish he’d let me go to his clinic visit with him. I don’t think that the doctor is getting the whole story. He’s missing a lot of work, doesn’t want to do anything, and sleeps in the spare room most nights.”

Sam: “What’s the point of going to the clinic? They didn’t help anyone else I know. How will I make it another year until I retire? I feel sorry for my wife. We had big plans for after the kids left.”

Children: “I read on the Internet that people with hemophilia can have joint replacements now. I hope he asks about it at the clinic.”

*I wish
Mom and Dad
wouldn’t fuss
so much,
although it
helps to have
someone here.*



CHAPTER

2

THE IMPACT
OF PAIN ON
THE FAMILY

What are some ways families deal with the challenges of pain?

Pain affects people and their families emotionally, socially, academically, financially and spiritually. All families have established ways of dealing with life's challenges. Families in the bleeding disorder community have adapted to the physical demands of their condition by educating themselves about their particular situations, learning to do home treatments and by learning about safe activities. On the emotional and spiritual level, families develop internal strengths: positive coping abilities, openness in working with the members of the bleeding disorder comprehensive care team, creativity in dealing with problems and a sense of hope for the person's future.

Effective pain management is a new frontier for comprehensive care teams, the CHS and its members. It is hoped that this initiative will result in an increase in knowledge about people's options and help them rediscover a sense of hope. One of the main benefits of the Pain Management Program is to bring pain and the scope of its impact out into the open. This includes talking about it in and among families, joining together to share information and identifying areas where work needs to be done—essentially what people with hemophilia and other bleeding disorders have done for years at the individual, family, chapter and national levels.

One of the main benefits of the project is bringing pain and the scope of its impact out into the open.



My Cat Helps Me to Manage My Pain

PROFILE

Francis Roy gave this testimonial at the CHS workshop on pain management held in Montreal on May 10, 2003.

My name is Francis Roy. I am 13 years old and I live in Mont-Laurier with my parents and my younger sister, Cassey. Mont-Laurier is a small town, a three-hour drive north of Montreal.

I am a severe hemophiliac with factor IX deficiency. I developed a factor IX inhibitor when I was still a baby. People tell me that when I was a kid I was a little rascal who wanted to try everything. This probably partly explains why I had to be hospitalized so many times to treat bleeding. Dr. Rivard tried numerous times to get rid of my inhibitor but without success.

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). Since I bleed quite often, I am often in pain, which I don't like; this is why I think managing the pain is very important.

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.

I can inject my treatment myself but when I'm in a lot of pain I prefer my mother does it for me.

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. (continued on next page)



I am often in pain, which I don't like; this is why I think managing the pain is very important.

CHAPTER

2

THE IMPACT
OF PAIN ON
THE FAMILY

Last summer I rode my bike and had to use my leg to keep my balance. I didn't think I had hurt myself but I started to bleed in a large muscle in my abdomen – the psoas. I was doubled up in my wheelchair when I got to Ste-Justine. I was in great pain and the morphine my mother gave me every 3 or 4 hours didn't control my pain. 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 Nichan, my physiotherapist. I manage my pain and can do my exercises better. When I'm not bleeding, I don't need anything for pain.

One last thing. When I'm at home, I find that my cat helps me a lot to manage my pain. I see a huge difference since he became part of our lives.

The Role of the Comprehensive Care Team in Pain Management

CHAPTER**3**

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Walter Mackenzie Health Sciences Centre, Edmonton, Alberta

Pain is a complicated phenomenon. It has an impact on many areas of a person's life and is influenced by many factors.



The questions which will be addressed in this chapter are:

- Why is pain assessment important?
- How is pain assessed?
- Who are the comprehensive care team members involved in pain assessment?
- How does the comprehensive care team treat pain?
- Who needs education about the pain experienced by persons with bleeding disorders?



CHAPTER

3

THE ROLE OF THE
COMPREHENSIVE
CARE TEAM
IN PAIN
MANAGEMENT

An individual's experience of pain is affected by his age, physical condition, gender, culture, attitude toward life and personal and family supports.

Why is pain assessment important?

The first step in the treatment of pain is a thorough assessment. If the pain is acute, new bleeding must be suspected. If the pain is chronic, persistent tissue damage is likely. The management of these scenarios differs. An individual's experience of pain is affected by his age, physical condition, gender, culture, attitude toward life and personal and family supports. The result of the pain assessment influences the choice of treatment. Intractable pain may need narcotics, while low-level discomfort may be managed by non-medical interventions.

How is pain assessed?

The person experiencing the pain is the best judge of the character of the pain. The most useful tool that a hemophilia clinic team member will use to assess pain is a good set of listening skills.

- How is the pain described?
- What words are used? Throbbing? Burning? Grinding?
- What were the events surrounding the start of the pain?
- What do parents, partners or other accompanying family members have to say about the pain?

This is followed by a careful clinical examination.

Many different pain assessment tools have been developed to help health care providers assess and treat pain. (See *Pain – The Fifth Vital Sign* on page 7.)

Pain diaries are also helpful: preceding events, intensity of pain, activity level, interventions and response to treatment can all be recorded. In addition to determining how much pain, we also need to know what makes the pain worse (for example, climbing stairs); what makes it better; and whether it interferes with activities of daily living (school, work, recreation, personal relationships and sleep).

In children, pain and distress coexist. Distress is often a manifestation of pain, but distress can also reflect fear, anxiety, separation from family and agitated behaviour. If distress can be managed, pain may become less of an issue.

Unfortunately, young children do not have the vocabulary to tell us when something is wrong. Severe pain results in crying and inconsolability, but lesser pain may cause withdrawal, decreased activity and irritability. Parents are key to the recognition of a child's pain.

CHAPTER

3

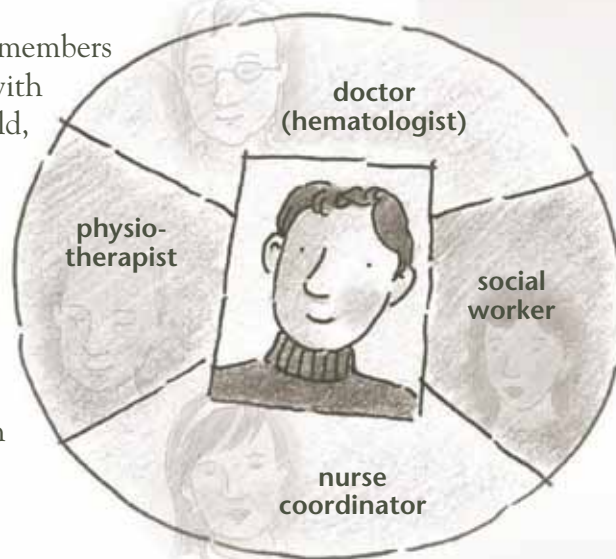
THE ROLE OF THE
COMPREHENSIVE
CARE TEAM
IN PAIN
MANAGEMENT

Part of pain assessment is assessing the person's/family's understanding of the pain.

- Do they see the connection between acute pain and the recommendation for R.I.C.E. (rest, ice, compression and elevation)?
- Do they recognize the need for an infusion?
- What are the barriers preventing the person or family getting appropriate pain control?

Who are the comprehensive care team members involved in pain assessment?

In various ways, all of the comprehensive care team members are involved in the assessment 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. The point at which the topic of pain, either acute or chronic, is presented to the team can vary. In a scheduled comprehensive care clinic visit, it may be mentioned first to the nurse who frequently is the person who does the initial assessment; to the physiotherapist or physician when joints are being examined; or to the social worker during a discussion of work, school or family dynamics.



How does the comprehensive care team treat pain?

The *nurse coordinator* can ensure that pain is assessed and treated by the appropriate team member. Good assessment and management of both acute and chronic pain can be helped by maintaining good bleed records and infusion diaries. Bleeding patterns can be quickly noted from accurate records. Factor doses may need to be adjusted to ensure good hemostasis. More than one treatment may be necessary. Short term prophylaxis may be recommended to manage a target joint.

The *hematologist* can develop a management plan for both acute and chronic pain, which could include medication. Only a physician may prescribe pain medication. If you do not live close to the Hemophilia Treatment Centre (HTC), your family physician will need to be involved in the management of your pain. In some parts of Canada, HTCs are located in large health centres, which include pain management teams made up of physicians, nurses, physiotherapists, psychologists, social workers and vocational counselors who have specialized knowledge in the management of all aspects of pain, using both traditional medical interventions as well as alternative therapies. You may benefit from a referral to one of these.

The person with the bleeding disorder and, in the case of a young child, his/her parents, are at the centre of the process.

CHAPTER

3

THE ROLE OF THE
COMPREHENSIVE
CARE TEAM
IN PAIN
MANAGEMENT

We need to educate ourselves about assessment and treatment resources that are available at the local and regional levels.

The *physiotherapist* will 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 which may be discussed with these teams.

Women with von Willebrand Disease or another bleeding disorder may be referred to an *obstetrician/gynecologist* familiar with managing excessive bleeding in women.

Additional challenges that some people with hemophilia live with are inhibitors, HIV and/or hepatitis C, adding another layer of issues to consider in the assessment and treatment of pain. With the introduction of Protease Inhibitors (PIs) for the treatment of HIV disease, a significant increase in bleeding was noticed only in patients with bleeding disorders, leading to pain. The bleeding was not typical of the usual joint or muscle bleeds but more soft tissue bleeding. With newer PIs being introduced, the hemophilia patient needs to remain vigilant and report immediately any unusual swelling or pain.

This underlies the importance of the coordinating role of the comprehensive care team as the person with the bleeding disorder and his/her family work toward an effective approach to pain.

Who needs education about the pain experienced by people with bleeding disorders?

We all do. People with pain, and their families, need to be aware that pain is a manageable condition. They need to be able to recognize the difference between pain from acute bleeds and from chronic conditions. They need to be aware of the first course of action for acute bleeds—R.I.C.E. and an infusion—and when to call the treatment team if a bleed isn't resolving appropriately.

Visits to the clinic, CHS local and national meetings, family weekends, youth camps and the CHS newsmagazine, *Hemophilia Today*, are some of the opportunities that the bleeding disorders community has to increase awareness of the issue. Team members need to be aware of the types of pain that bleeding disorders can cause and to consistently include pain as part of their assessment. We need to educate ourselves about assessment and treatment resources that are available at the local and regional levels.

Pain doesn't need to be suffered in silence. Discuss it with your clinic team and work out a plan that suits you. To paraphrase a theme from a CHS parent workshop, "You're worth it".

CHAPTER

3

THE ROLE OF THE COMPREHENSIVE CARE TEAM IN PAIN MANAGEMENT

*Pain doesn't
need to be
suffered
in silence.
Discuss it
with your clinic
team and work
out a plan that
suits you.*

Advocating for Better Pain Management

Pam Wilton, R.N.

Vice-President, Canadian Hemophilia Society, London, Ontario

“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 said she couldn’t believe how well her patients hid the pain.”

The questions which will be addressed in this chapter are:

- What is advocacy?
- Who can be an advocate?
- Why is advocacy important?
- What can you do if your pain is not well managed?
- What can you do if your physician refuses to refer you?
- What are some effective communication strategies?
- What can you do to ensure your pain is taken into account?



CHAPTER

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ADVOCATING FOR
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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.

What is advocacy?

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

Who can be an advocate?

You are your own best advocate. Depending on the situation, the role of advocate can be played by almost anyone. In the context of health care and, more specifically, pain management, there are individuals who naturally play the role of advocates. Nurses are the members of the health care team most often identified as advocates. Fortunately, most nurses accept this role as an important part of their practice and are very effective. The nurse in your Hemophilia Treatment Centre (HTC) is no exception. She already knows your history, your current health status, your support systems and your ability to follow through on treatment plans. Social workers and physiotherapists can also be advocates. Your HTC is part of a network of clinics across Canada and therefore the comprehensive care team has an established network of expertise that they can tap into for help in difficult situations.

A family member such as a spouse, parent or sibling is also a good choice, as is a close friend.

Why is advocacy important?

Pain should be viewed as a separate problem. It is most often defined as an unpleasant sensory and/or emotional experience primarily associated with tissue damage. Some experts, however, define it as a disorder of the nervous system. Therefore, you may need to seek help from experts in that field. It is sometimes difficult to get a referral to a pain management specialist because many people simply do not understand the extent of the pain. Pain is subjective and extremely difficult to measure. A bleeding disorder complicates management and expertise is often required to develop an effective management plan.

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.

What can you do if your pain is not well managed?

Pain management can be extremely complex. First, ask your physician why he will not consider stronger medications. Once you know why, you will be able to solve the problem.

The reality may be that your own physician wisely recognizes that your pain management requires knowledge and skill beyond his experience. If he acknowledges this, you can ask for a referral to a pain clinic or a pain specialist.

However, if he believes your pain is well controlled on the medications and treatments (e.g. physiotherapy) he has prescribed and you disagree, you will still need to ask for a referral to a specialist for a second opinion. You have a right to ask for another opinion but, unfortunately, your physician may not be willing to make this easy for you. Ask for his help. This will...

- convince him that you really do need help. He may revise his treatment plan.
- give him an easy way out. He will quickly refer you to someone else.

If your physician suggests that, in order to deal with severe pain, you have been using your pain relief medications excessively or inappropriately, remain calm. This is your opportunity to try again to impress upon him the extent to which your life is affected by pain. Ask him why he thinks this. It may be something as simple as miscommunication. If, in fact, the physician is right, this is also your opportunity to do something about it. Again be prepared to be open and honest. Work with your physician and the resources available to you to manage the problem. A family physician can also facilitate a referral.

What can you do if your physician refuses to refer you?

Ask the physician to explain why he is refusing to refer you to a specialist. The response will help you to understand why he is reluctant. It may make sense to you and you may be willing to accept the decision. If not, the answer will still help you decide what to do next.

Most specialty clinics require a physician referral. You could try and find a new physician to make the referral, but most people with bleeding disorders are treated at a HTC and, in most cities, there is only one—the number of physicians is limited. Given the shortage of family physicians in Canada, it may be difficult, and perhaps impossible, to find a new one. Besides, you need pain relief immediately. Frequent visits to the ER for pain management may eventually result in a referral, but for many reasons this should be reserved as a last resort.

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.

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ADVOCATING FOR BETTER PAIN MANAGEMENT

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.

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What are some effective communication strategies?

Take a buddy - Sometimes having a family member or a friend who knows your situation well accompany you to your clinic visit can help you to have confidence and to be more open about your situation. The person can even give you verbal reminders to raise your concerns.

Prepare ahead - Some people write their key points down before the visit. It can be easy to forget what you wanted to say in the heat of the moment. Also, some clinics prefer that patients let them know ahead of time if they wish to have “discussion time”. The receptionist will book a longer visit.



Be knowledgeable - Be ready to provide information about your pain—triggers, relievers, location, duration, severity and type—to the best of your ability. 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 help you to “grin and bear it”. Tell the staff what you need and why you need it. If you don't understand something or disagree with a treatment, say so!

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. Your physician will find it easier to understand you.

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 healthcare professionals are trying to do their jobs to the best of their abilities. Remember that your physician is not a pain expert and may have little experience treating chronic pain. What's more, the medical profession frowns on certain forms of pain management.

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” - It is more effective to focus on how you feel and what you need... (“Doctor, I am having trouble functioning. I really need to find an answer.”) ...than on any disputes with health care providers. (“You're not helping. You don't take this seriously.”)

It is more effective to focus on how you feel and what you need.

What can you do to ensure your pain is taken into account?

It is hoped that assessment of pain will become as routine as checking other vital signs. Say that you want to discuss pain management when you schedule an appointment at the HTC. Also, let the members of the comprehensive care team—nurse, physician, physiotherapist, social worker—know at the beginning of your appointment that you need to talk about pain management and you want to be sure that there will be enough time. Be ready to describe the pain: the type, location, duration, activities that cause or relieve pain, strategies that have/have not worked, the impact on school, work, your social life and your mood. Even if you are not experiencing any pain at the time, you can help to make it part of your routine check-up. Offer information about your pain just after your blood pressure is measured. Remember: pain is the fifth vital sign.

Care for bleeding disorders in Canada has advanced over the past decades so that many children and teens do not have chronic pain. Pain resulting from acute bleeds can usually be well managed. But sometimes people who experience pain on a regular basis tend to downplay the severity. This is especially true of older people with hemophilia who learned to hide pain so as not to worry family members and to avoid hospital visits. It is therefore not surprising that health care providers may not recognize its significance. While the ability to bear up under pain is an extremely useful coping strategy, it has its limits and can get in the way of finding the relief that is actually available.

CHAPTER

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ADVOCATING FOR BETTER PAIN MANAGEMENT

Say that you want to discuss pain management when you schedule an appointment at the HTC.

Effective Use of Opioid & Non-Opioid Analgesic

CHAPTER

5

Peter Leung, M.D.

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

There are many useful medications for controlling pain. The type and route of administration must be tailored to the patient. Most importantly, the underlying problem must be managed by knowledgeable health care workers.



The questions which will be addressed in this chapter are:

- What types of pain are experienced by hemophilia patients?
- What are the treatment options for acute pain due to bleeds and/or surgery?
- What are the treatment options for chronic pain?
- What are the different medications?
- What are the common side effects of all opioids?
- What are the other concerns related to opioids?
- Are opioids addictive?
- What are adjuvant medications? Why are they useful?
- What adjuvant medications can be used?
- Pain levels change. What adjustments can be made for good days and bad days?
- Does marijuana work for pain?
- Are there things to remember when traveling?
- Why are some doctors reluctant to give stronger pain medicine?



CHAPTER 5

EFFECTIVE USE OF OPIOID & NON-OPIOID ANALGESIC

What types of pain are experienced by hemophilia patients?

Pain is usually of two types:

- *Acute pain* - due to bleeding, surgery or trauma
- *Chronic pain* - due to damaged tissues and/or altered brain and spinal cord functions.

The pain of *acute* bleeds is due to the body's perception of unpleasant stimuli on nerve endings. Ongoing *chronic* pain can be associated with either joint degeneration or other hemophilia-related complications.

What are the treatment options for acute pain due to bleeds and/or surgery?

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 (NSAID). The addition of opioids (see following list) 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.

One option is the use of patient-controlled analgesia (PCA). This is a form of computer-assisted self-administration of IV opioid pain medication. It is commonly called a "pump". It can be used for acute bleeds or for post-operative pain control. The patient can press a button for delivery of doses, limited by the computer to a safe level.



The drug doses can be adjusted on an individual basis and the patient plays a role in determining the effectiveness of treatment. A PCA can be used with children as young as seven years.

Once pain is controlled, the IV opioids can be stopped and the patient switched to oral medication. Most hospitals provide PCA service and have information pamphlets and even videos to help the patient learn to use the PCA effectively.

There may be a tendency to minimize the severity of acute pain and the benefits to the patient of adequate acute pain relief. Some health care workers overestimate the risk of the stronger pain medications, even in the post-operative period.

What are the treatment options for chronic pain?

The ideal chronic pain medication would be predictable, easy to use, fast acting, effective with no side effects and no risk of tolerance.

Medications may be given by mouth or IV. The duration of the pain relief is variable. Physicians and patients must choose the individual drug wisely, as well as the route and the timing of administration.

What are the different medications?

The following is a brief summary of some of the available options in hemophilia use and is not exhaustive or to be treated as recommendations.

Non-opioids

- Celecoxib (Celebrex®) Given by mouth
- Acetaminophen (Tylenol®) Given by mouth

These are generally safe in normal doses for hemophilia patients.

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Opioids

The following is provided only as a rough guide in hemophilia use.

Codeine

- Available as a single dose or combined with acetaminophen and caffeine (Tylenol®#1,2,3)
- Can be prescribed in slow-release form (Codeine-contin®)
- Usually given by mouth
- Ceiling effect, that is, there is no increase in effect after the maximal dose is reached
- Inexpensive

Morphine

- Can be prescribed in short-acting or slow-release forms (MS-contin®)
- Can be given by mouth, subcutaneously (injected under the skin) or intravenously
- Special circumstances allow it to be given close to the spinal cord
- Inexpensive

Oxycodone

- Percocet® or Oxycocet® (Combination with acetaminophen)
- Can be prescribed in slow-release form (Oxy-contin)
- Inexpensive

Hydromorphone

- Dilaudid®
- Can be given by mouth, subcutaneously or intravenously
- Can be prescribed in slow-release form (Hydromorph-contin)

Fentanyl

- Very potent
- Very short acting
- 3-day Patch (Duragesic®) or lollipop form for children
- Expensive

Propoxyphene

- Darvon®
- Not frequently used

Pentazocine

- Talwin®
- Not frequently used
- Caution: may have an opposite effect if added to other opioids

What are the common side effects of all opioids?

- Nausea and vomiting
- Sleepiness
- Constipation
- Itchiness
- Tolerance
- Depression



What are the other concerns related to opioids?

- Addiction
- Abuse
- Diversion (used by others or sold)

Are opioids addictive?

There are no guarantees in medicine. Physicians take all possible precautions and still there will be patients who will use more than needed. On the other hand, who is to say how much is needed except the patient himself? As long as the amount used is for pain, then the chance of addiction is quite low. Short-term use for surgery or acute bleeds 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.

What are adjuvant medications?

Why are they useful?

Adjuvant analgesics are a diverse group of drugs used to enhance pain control in specific circumstances. They do sometimes reduce pain levels by themselves but often are best used in combination with pain killers.

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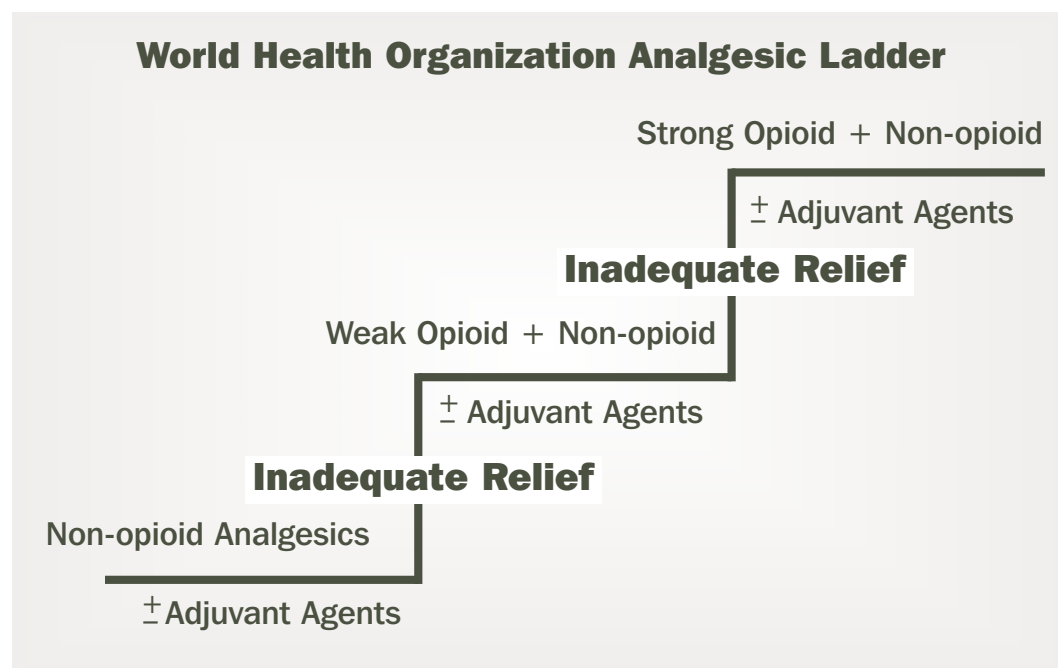
EFFECTIVE USE
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ANALGESICWhat adjuvant medications
can be used?**Anti-depressants**

- Amitriptylline (Elavil®)
- Nortrytilline (Aventyl®)
- Fluoxetine (Prozac®)

Anti-convulsants

- Carbamazepine (Tegretol®)
- Phenytoin (Dilantin®)
- Valproic Acid (Depakote®)
- Clonazepam (Rivotril®)
- Gabapentin (Neurontin®)
- Pregabalin

The rational use of pain medications can be based on the *World Health Organization Analgesic Ladder*.



Pain levels change. What adjustments can be made for good days and bad days?

While slow-release forms are ideal for managing day-to-day pain levels, most doctors will allow a certain amount of shorter-acting breakthrough medications for bad days and for acute bleeds. If the breakthrough medications are being used too frequently, the doctor will re-assess the situation, look for a cause and adjust the medication.

Does marijuana work for 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.

Are there things to remember when traveling?

When the patient is traveling, the doctor 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 doctor in another city manage the pain according to what the patient usually needs, and avoid too much or too little medication. It will also provide evidence at borders that a person is authorized to carry these medications.

Always keep the medication in the original bottle so that there is no doubt as to the kind of medication being carried. Do not mix different pills (blue, yellow, big, small, round, cylindrical) into one bottle. This can cause confusion and mistakes.



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Why are some doctors reluctant to give stronger pain medicine?

There are many different answers to this question. Some doctors do not have much experience treating pain. Others are concerned about the professional consequences. Unfortunately, one of the barriers to effective pain management is that the governing body of doctors still frowns on the prescription of strong pain medicine, especially opioids.

There is also a lot of discussion as to whether doctors can ethically refuse to prescribe effective opioid medication for pain. If this happens, ask the doctor for a referral to a pain clinic. Or try to find another doctor who works well with the patient to manage his pain. Good pain management does not always mean a lot of medicine.

In conclusion, it is important to remember that 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.

I Like to Call Pain the “Dragon”

PROFILE

Ian DeAbreu gave this testimonial at the CHS workshop on pain management held in Montreal on May 10, 2003.

My name is Ian DeAbreu I am 35 years old, co-infected, and have severe hemophilia A. With regards to pain and bleeding, I have two target joints: the right elbow and left knee. These joints are in poor condition and both have been candidates for replacement for some five years now.

I’m active. I hold an automobile mechanic license. I have designed and built our cottage, and still insist on being involved in all repairs and renovations around the house. I still enjoy wood work.

It’s interesting that I should be asked to describe the pain I live with and how I manage it. 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. While preparing for this talk, it became clear that, consciously or not, 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 Vioxx*, 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.

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.

My pain has progressed significantly in the last six 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 to 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 (continued on next page)

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.



*Editor's note: Vioxx® (Rofecoxib), in the class of Cox-2 inhibitors, was removed from the world-wide market by its manufacturer in September 2004 because of concerns over an increased risk of heart attack and stroke. As of publication, another Cox-2 inhibitor, Celebrex® (Celecoxib) remains available.

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in turn my mood can and sometimes does affect those around me.

I have experienced no challenges in obtaining good pain control because I have never focused on pain control. I have never asked for a referral to a pain control specialist. Until recently I was unaware that such a specialist even existed. It would be interesting to see how I could slot yet another specialist into my growing list of medical appointments.

Right or wrong, my perception is that visiting a pain control specialist will result in being advised to start consuming yet another drug.

Living with hemophilia and being co-infected requires me to make my daily activities revolve around the eight drugs I take. Any way you look at it these drugs, injected or ingested, have to be processed by my body. Drugs in combination make a “chemical soup” of sorts leaving one to wonder about the possibility of drug interactions. With co-infection in mind, now consider that some of the eight drugs I consume are amongst the most toxic, being processed by a liver struggling with HCV. I find myself thinking daily about what I take in and whether or not it may result in further liver injury.

Beyond issues of interactions and co-infections, I am also concerned that the severity of my pain would require a very strong pain killer. Something strong enough to negate my pain could result in a dulling of the senses and impairment or reduction in my overall ability to function. I live in a small community where there is no public transit and driving an automobile is a necessity, not an option. Besides that, I don't like living in a cloud.

It's not to say that managing pain by taking pain killers can't work for someone, but it's still a matter of choice. I believe you have to be comfortable with the idea, and it has to be a good fit with your personal situation.

Physiotherapy – Another Approach to Pain Management

Jenny Aikenhead

Physiotherapist, Alberta Children's Hospital, Calgary, Alberta

“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

The questions which will be addressed in this chapter are:

- What is acute and chronic pain?
- Why is an exercise or fitness program an essential part of your pain control regime?
- What should you do before starting on an exercise or fitness program?
- What else besides exercise has physiotherapy to offer you for pain relief?
- What activities can you participate in when you have arthritis?
- When physiotherapy, exercise or fitness programs no longer offer pain relief, what are your options?



CHAPTER

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PHYSIOTHERAPY –
ANOTHER APPROACH
TO PAIN
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What is acute and chronic pain?

Acute pain...

- is usually the result of an acute bleed or injury and then requires replacement factor.
- responds well to R.&R.I.C.E. (Replacement therapy & Rest, Ice, Compression, Elevation).
- can benefit from rest from activity, use of a splint, sling, walking aid or wheelchair.
- can benefit from ice to decrease swelling and muscle spasm.

Chronic pain...

- results from recurrent inflammation of a joint that causes destructive changes to the synovium (lining), cartilage and bone.
- affects different people to different degrees. This depends on many factors: the individual himself, his expectations, the situation, his cultural background, the intensity of the stimulus, stress, fatigue and the duration of the pain.

Why is an exercise or fitness program an essential part of your pain control regime?

It 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 will result in better alignment of the joint and decreased stress on its surrounding structures. Exercises will help reduce stiffness and by improving movement may alleviate pain.

Flexibility

Joint contractures and/or muscle shortening may result in pain and respond well to stretching exercises. Improved flexibility will also decrease 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. Improved ability to participate, and success, will improve confidence.

Feeling of well being and decreased anxiety

Mental stress and anxiety is known to influence sleep patterns, muscle spasm, the frequency of bleeds and increase the sensitivity to pain. Exercise can decrease feelings of stress.

Release of endorphins which decrease pain

Endorphins are natural chemicals produced by the body and act as a damper to the sensation of pain. The production of endorphins is thought to be influenced by exercise, heat, cold, positive attitude, some physiotherapy electrical modalities, relaxation and medications.

Endurance and possible weight loss

Cardio-vascular exercises will increase endurance and strength and therefore reduce stress on the joints. Weight loss may occur which also decreases pressure on the joint surface.

What should you do before starting on an exercise or fitness program?

Consult with a physiotherapist at the HTC who will...

Assess the pain

It is important to have a physiotherapist assess the history of the past and present pain, and the nature and intensity of the pain so as to find out its probable cause. Is it caused by an acute joint bleed? A soft tissue strain/bleed? Synovitis? Chronic synovitis? Arthritic pain?

Provide an exercise program

A specific exercise program can be developed to address the root of the pain; for example, weakness causing instability. The physiotherapist can give guidelines for the progression of exercises and recommend a suitable fitness program in the community. Often exercise programs are not continued because of changes in the intensity or type of pain and worsening of the arthritis. It is therefore important to keep your physiotherapist informed of the changes in or worsening of pain so that exercises can be adapted or modified to meet new criteria. It may be necessary to use replacement factor prior to exercise activity. This may be required each time or may only be necessary initially. Splints or supports may be required to protect the joint during exercise.

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PHYSIOTHERAPY –
ANOTHER APPROACH
TO PAIN
MANAGEMENT**Assist choosing an exercise or activity program**

It is essential to look at the chosen activity to see if it can benefit you individually. It may be necessary to provide an exercise program to develop the skills needed to participate, or adapt part of the program to suit you better. Weight training programs should be carefully reviewed to avoid injury. Progress should be gradual. These programs are not usually recommended for children under 14 years of age because lifting excess weight may affect the development of growth plates. Weight training can be done by children provided that maximum weights are not lifted. Weight machines are preferred to body building and free weights because there is less likelihood of injury.

What else besides exercise has physiotherapy to offer you for pain relief?

Non Electrical Treatments

- *Hot packs or heating pads* – Apply for 15 to 20 minutes for maximum effect.
- *Ice* – Apply for 5 to 10 minutes to decrease pain and muscle spasm by slowing down the rate that the nerves can conduct the pain signals.
- *Whirlpool, hydrotherapy, swimming and aquacize* – Exercise, especially in warm water, will decrease pain and muscle spasm as well as provide an excellent medium for strengthening exercises without causing stress on the joints.
- *Splinting or supports* – These may help to decrease the pain by resting the joint. They can also be used to support the joint while participating in an activity or exercise program.
- *Mobilizations or tractions* – These techniques may reduce pain by increasing movement. They should be performed by a physiotherapist who is familiar with hemophilia. High-velocity manipulations such as those performed by chiropractors, osteopaths or some physiotherapists are not recommended for anyone with a bleeding disorder.
- *Massage* – Massage can be used for stress relief. It induce relaxation and decreases muscle spasm. Deep tissue massage and soft tissue release is not recommended.
- *Shoe inserts or foot orthotics* – Shock absorber and supportive shoe insoles can reduce pain by cushioning the pressure on the foot and by accommodating foot deformities.
- *Crutches, cane or wheelchair* – These may reduce the stress and pain on the ankle, knee or hip.

- *Acupuncture* – Acupuncture is not contraindicated in hemophilia, although it is recommended that replacement therapy be used prior to the first treatment. Chronic pain and muscle spasm respond well to this type of treatment.

Electrical Modalities

These are used only as an adjunct to an exercise treatment.

- *Transcutaneous Electrical Nerve Stimulation (T.E.N.S.)* – This is a low frequency electrical current that is used to reduce acute and chronic pain. The electrical stimulus is thought to block the pain sensation caused by the nerve fibres. The electrical current is delivered by a small portable unit using two to four electrodes and can be used at home or work several times a day.
- *Codetrin* – This is another form of T.E.N.S. using several sets of electrodes. Each pair of electrodes is set to fire in random pattern to confuse the pain message.
- *Interferential therapy* – A low frequency electrical current used to reduce pain or swelling depending on the type of current used.
- *Muscle stimulation* – This technique involves an electrical stimulus that causes contraction of a muscle. It should be used as an adjunct to exercise to assist with retraining a weak muscle. The pain in the joint may be decreased by increasing the muscle strength and support of the joint.
- *Electrical biofeedback* – Biofeedback can be used in retraining a muscle to contract by using visual or auditory cueing or to teach a muscle to relax and result in a decrease in muscle spasm.
- *Ultra-sound* – This is a high frequency current used to decrease swelling and promote absorption of a hematoma and is usually used in acute pain.
- *Acustim* – This is a low frequency electrical stimulation used over acupressure points to try to reduce pain caused by muscle spasm.
- *Pulsed short wave diathermy* – Used more commonly in Europe, this is a form of electromagnetic energy which helps reduce swelling, pain and promote tissue healing.
- *Laser therapy* – This has been used in arthritis to reduce pain and increase healing but has limited use in hemophilia.

Some of the equipment needed for the therapies above is available in the hospital where the HTC is located. In addition, some patients rent certain pieces of equipment.

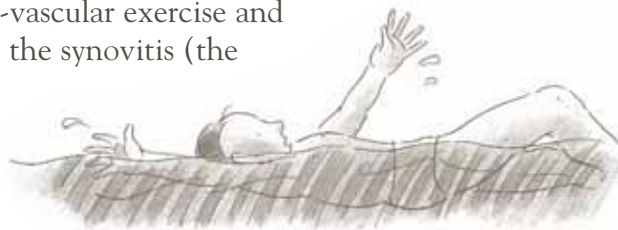
CHAPTER

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PHYSIOTHERAPY –
ANOTHER APPROACH
TO PAIN
MANAGEMENT

What activities can you participate in when you have arthritis?

Recommended activities are those that are low impact on the joint but allow mobility, strengthening and cardio-vascular exercise and that will not cause bleeding or aggravate the synovitis (the inflammation of the lining of the joint).



Swimming and aquacize

These are highly recommended because the buoyancy of the water allows exercising without stress on the joints. They can also allow you to take part in strengthening exercises by using weights or floats. Warm water will provide the extra benefit of relief of pain and stiffness.



T'ai Chi

This is an excellent exercise program that allows slow controlled movement and gentle stretching of the joints along with coordination and trunk (core stability) exercises.

Yoga

This is also a stretching and strengthening exercise but be careful that the classes are appropriate for someone with arthritis and not too advanced for your fitness level and ability.

Bicycling

This can be started on a stationary bicycle and later progress to a road bike. The height of the bike seat can be adjusted to accommodate joint range. Risers can be put on pedals for leg length discrepancies. Remember your BIKE HELMET and PROTECTIVE PADS.



Walking, dancing, bowling and hiking

These are low impact activities on the joint.

For more information, see Passport to Well-being:
Destination: Fitness.

When physiotherapy, exercise or fitness programs no longer offer pain relief, what are your options?

See *Orthopedic and Surgical Management of Pain* on page 47.

Not All Kids My Age Are in the Same Boat

Sean Creighton wrote this article about his experiences in dealing with pain for the Spring 2004 issue of the CHS newsletter VOYAGE.

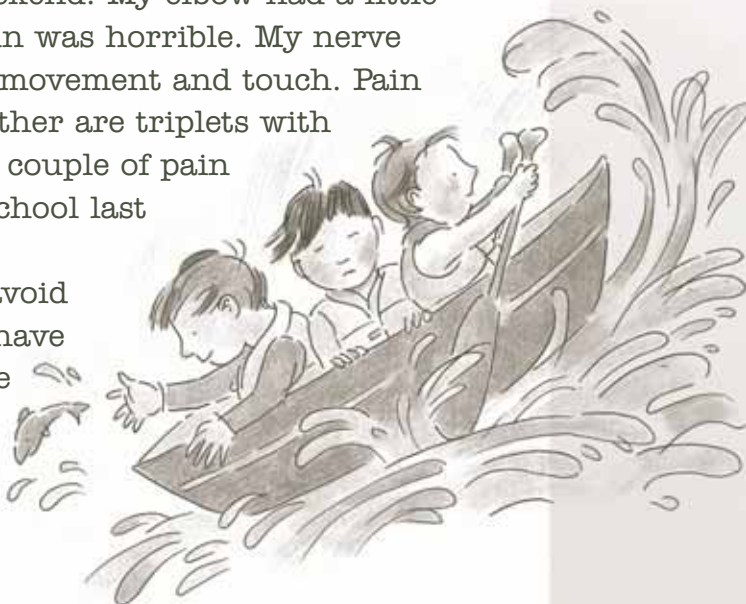
Hello, my name is Sean Creighton. Throughout my life, I have had to deal with pain. Not all kids my age are in the same boat. My pain ranges quite a bit, from arthritic pain to the pain of bleeds caused by hemophilia. Through it all, I have had the constant support of my fellow triplet brothers, who both have hemophilia, my older brother and younger sister and my mother and father.

My parents are undefinable! They even surpass the idea of unconditional love and they are in a league of their own. When I was only a couple of months old, I was diagnosed with hemophilia. This was a very large blow to my parents because there was no history of hemophilia in our family. My triplet brothers have it too, so it was a big adjustment for Mom and Dad.

When I was 7 years old I developed arthritis in my ankle from constant bleeds in that site. I hurt my ankle a few times and then it began to hurt a lot and very often. Then my life was normal for a while. Vioxx*, Tylenol, ice, compression, rest, and an ankle brace became my weapons to battle the pain. I learned new exercises and even learned when to take it a little easier. Then last year I underwent something called a pain cycle. What this is, is when I hurt my elbow it started to get worse and worse until I was hospitalized for the weekend. My elbow had a little swelling and fluid in it, but the pain was horrible. My nerve endings caused really bad pain, to movement and touch. Pain cycles aren't that common, but neither are triplets with hemophilia. I have gone through a couple of pain cycles since and I missed a lot of school last year, but there is good news!!!

I do a lot of physiotherapy to avoid the pain cycles from happening. I have had some serious bleeds and I have not gone through this pain, so I know the exercises are helping. I was very worried about how often

(continued on next page)



*Editor's note: Vioxx® (Rofecoxib), in the class of Cox-2 inhibitors, was removed from the world-wide market by its manufacturer in September 2004 because of concerns over an increased risk of heart attack and stroke. As of publication, another Cox-2 inhibitor, Celebrex® (Celecoxib) remains available.

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PHYSIOTHERAPY –
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this would keep happening to me. I learned to take little steps to get through the pain. I learned to go to school for 1 hour or half a day, to exercise and rest, to try different types of medications and to know when to use what and when to not use anything. I've also learned to fight the pain and to not let it wreck everything for me. Nobody ever likes pain that is for sure, but pain is a part of life and that is the way I deal with it. Next time you have a bleed or severe pain don't think to yourself, "Oh woe is me." Think, "This is one moment in my life. There will be more ups than downs so chalk one up for a down in life and move on."

I get mad sometimes, especially on the days when I wonder why my brothers don't have the same things happen to them? That's when I most need my Mom and Dad. My Mom has taken me to every doctor's appointment and stayed with me whenever I was admitted. Not to sound corny or anything but she is my rock. She has listened and she has a heart of gold as far as I am concerned. My father is also very important to me because he has also cared for me and can show true love in times of need. Not all kids know their parents this way. We are very close. Now, so that no one thinks my life is horrible, never judge a book by its cover. My life is quite active. I have been on volleyball teams and basketball teams at school and I am going to try to play with a soccer team this summer. My knee may not like this, but I need to try, because I didn't play last year. When I have pain, I just can't wait until it goes away and I can be me again. I know this will happen so I keep looking forward to getting better and doing the things I can to make that happen.

Orthopedic and Surgical Management of Pain

CHAPTER

7

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

Orthopedic Surgeon and Site Medical Director of the University of Alberta Hospital

Nancy Dower, M.D.

Hematologist, Walter Mackenzie Health Sciences Centre, Edmonton, Alberta

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.



The questions which will be addressed in this chapter are:

- How do acute bleeds lead to joint damage?
- Can recurrent bleeds be prevented?
- How is the synovium removed?
- When does a joint need to be replaced?
- What is involved with joint replacement surgery?
- What can I expect after joint replacement?
How long do the new joints last?
- What are the risks associated with joint replacement?
- What other surgeries are available to help manage pain?
- Are there less invasive options for managing pain from chronic joint damage?



CHAPTER

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ORTHOPEDIC
AND SURGICAL
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How do acute bleeds lead to joint damage?

Bleeding into a joint causes the lining of the joint (synovium) to be inflamed. Swollen strands of the synovium may extend into the joint between the bones where they can be pinched, resulting in further bleeding. Blood within the joint gradually destroys the smooth gliding cartilage surface of the bone resulting in pain and decreased range of motion.

Can recurrent bleeds be prevented?

Use of prophylactic factor replacement has been very effective at decreasing joint bleeds and delaying the onset of chronic joint damage.

Removal of the swollen synovium (synovectomy) can decrease recurrent bleeding into a target joint.

How is the synovium removed?

Three techniques can be used to remove swollen synovium:

Radioactive synovectomy: A radioactive isotope, such as ^{32}P or ^{90}Y trium is injected into a target joint, usually under fluoroscopic guidance in the radiology department. Within the joint, the radioactivity reduces the amount of swollen synovium. This technique has not been shown to increase the risk of developing cancer although this is a theoretical risk.

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 is usually done under general anesthetic and can be used for ankles, knees and elbows. Physiotherapy may be necessary post-arthroscopy for 2 to 4 weeks.

Open synovectomy: Under a general anesthetic, the joint is opened surgically and the synovium removed. Physiotherapy will be necessary for at least 4 weeks.

When does a joint need to be replaced?

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. Newer techniques and materials are expanding indications.

What is involved with joint replacement surgery?

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).

Factor replacement is extremely important, as this can be a bloody surgery even in non-hemophiliac patients. Clotting factor levels are kept at 100% usually by continuous intravenous infusion for 10 days or more. Specific management must be done by the hemophilia doctor.

“Despite having a high-titer inhibitor, my physicians recommended knee replacements. The operations went smoothly and my life has been transformed. I can walk again.”
– a 55-year-old person with hemophilia and an inhibitor

Pain control is critical during the recovery period so that early mobilization and physiotherapy can occur. Most patients are walking within 2 days (hip and knee) and are discharged within 10-14 days. Improvement continues for up to 6 months.

What can I expect after joint replacement? How long do the new joints last?

Most people are left with a pain-free joint. Range of motion usually is better with hip than with knee replacement.

Ninety percent of hip and knee replacements should last 10 years. Replacement of the artificial joint is sometimes necessary as the artificial joint can wear out or become loose. The success rate is usually not as good as for first time replacements.

What are the risks associated with joint replacement?

There are very low risks associated with general anesthetic. Your anesthetist can best assess these.

Intra-operative and post-operative bleeding should be limited by factor replacement. Transfusion with blood products may be necessary. Most hospitals performing joint replacements have autologous blood donation programs for patients to store their own blood preoperatively in case a transfusion is needed. Alternatively, blood products from anonymous donors can be used.

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Infection may complicate surgery. This may be superficial or in the deep tissue and bone. Infection may occur early or develop weeks or months after surgery. Infection requires antibiotic therapy usually by intravenous route and in-hospital. An infection may not clear up until the artificial joint is removed.

The new joint may dislocate. The components may become loose. If the joint fails, the surgeon may need to perform further surgery.

What other surgeries are available to help manage pain?

Other surgeries might be considered to manage pain from damaged joints. These 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 (Girdlestones Procedure).
- Removal of a wedge of bone from the femur or tibia to realign the leg and reduce pain (osteotomy).

Are there less invasive options for managing pain from chronic joint damage?

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

Five Joint Replacements/Fusions... And I Still Have a Slice

Michel Lalonde gave this testimonial at the CHS workshop on pain management held in Montreal on May 10, 2003.

I am a 49-year-old with severe hemophilia A (factor VIII deficiency).

I have had a total of five joint replacements/fusions since 1975:

- a total right knee replacement in 1975
- a right ankle fusion in 1986
- a left ankle fusion in 1988
- a total left knee replacement in 1990
- a right elbow replacement in 1999.

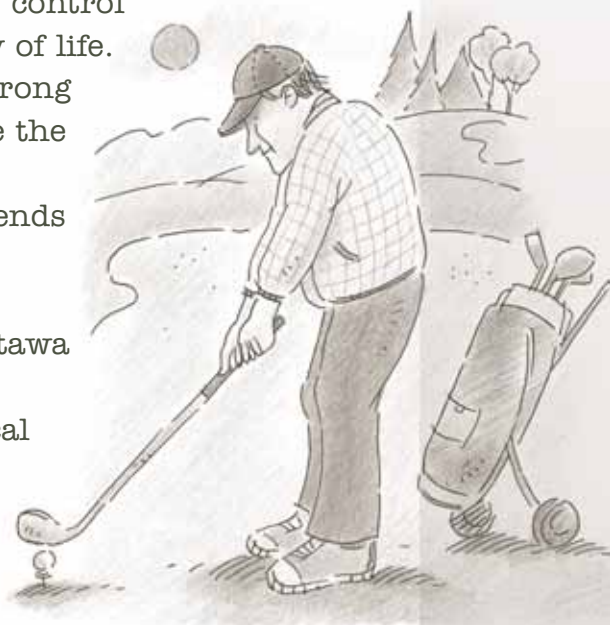
I had quite numerous bleeding episodes at a young age and throughout my teenage years which caused great stress on the joints and much pain. This affected my school and social life. For example, a bleeding episode in the knee could occur within a few hours without physical stress on the joint itself. 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.

To manage the pain caused by bleeding in the joints, the development of factor VIII concentrate has been comparable to the invention of the wheel or the microwave. It could control the bleeding, which would most of the time control the pain. In turn, this improved my quality of life. In the most serious cases, however, only strong medicines such as morphine could alleviate the pain and then, not always. Ultimately, the operations (replacement/fusion) were godsend and did relieve the pain.

Dr. Denis Desjardins, an orthopedic surgeon, and the medical team from the Ottawa Campus of the General Hospital have contributed greatly to improving my physical quality of life. Even when factor VIII was controlling the bleeding episodes, the pain

(continued on next page)

My wife and I play golf (I still have a slice) and I am able to enjoy some travel and visit family and friends.



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sometimes did not subside. Surgery was then the only alternative to eliminating the pain in my case.

On a personal note, I have a very supportive wife, a wonderful family and friends. I retired three years ago after 19 years as a nursing orderly in a rehabilitation institute in Ottawa. I really enjoyed my work.

I do not run or skate and I avoid stairs like the plague. My wife and I play golf (I still have a slice) and I am able to enjoy some travel and visit family and friends.

Overall, I believe my life is good!

Pain Management for Women with Bleeding Disorders

CHAPTER**8**

Christine Demers, M.D., *Hematologist, FRCPC, Quebec City, Quebec*

Christine Derzko, M.D., *Obstetrician-Gynecologist, FRCSC, Toronto, Ontario*

Joanne Douglas, M.D., *Anesthesiologist, FRCPC, Vancouver, British Columbia*

Rochelle Winikoff, M.D., *Hematologist, FRCPC, Montreal, Quebec*

The ideal management of pain in women with inherited bleeding disorders is through multidisciplinary clinics. Multidisciplinary clinics caring for women with bleeding disorders should include at least a nurse, a clinical hematologist, an obstetrician-gynecologist and an anesthesiologist.

**The questions which will be addressed in this chapter are:**

- What are the bleeding disorders that can affect women?
- What types of pain may be experienced by women with bleeding disorders?
- What are the treatment options for managing pain during menstruation and ovulation?
- What are the recommendations for managing pain during childbirth?
- What is the best way to manage pain in women with bleeding disorders?
- Who are the members of the multidisciplinary team involved in managing pain in women with bleeding disorders?



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FOR WOMEN
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...women are often more symptomatic than men due to excessive menstrual bleeding and peripartum hemorrhage.

What are the bleeding disorders that can affect women?

Of the inherited bleeding disorders, von Willebrand Disease is the most frequent disorder in women, followed by mild coagulation factor deficiencies such as factor XI deficiency and mild platelet disorders. Female carriers of hemophilia may also be symptomatic.

Symptoms related to inherited bleeding disorders are quite variable depending on the type and the severity of the condition. For the same degree of disease severity, women are often more symptomatic than men due to excessive menstrual bleeding and peripartum hemorrhage.

What types of pain may be experienced by women with bleeding disorders?

As in the general population, women with bleeding disorders can experience both obstetrical and gynecological pain, yet because of their underlying bleeding disorder, the pain may be both more severe than in other women and also may require particular approaches to management. During the menstrual cycle, women may experience pain both during menstruation and during ovulation. In women with bleeding disorders the pain at ovulation, known as midcycle pain syndrome, may be more severe than usual, as the release of the egg from the ovary may be accompanied by internal bleeding from the ovulation site itself.

The menorrhagia which is common in women with inherited bleeding disorders significantly diminishes the quality of life of these women. Between 40 and 50% of women who experience menorrhagia report that they are limited in their activities and that they find working more difficult during their menstrual periods. If these women also experience severe pain during their menstruation, it is likely that their quality of life will be even worse.

Specific obstetrical challenges also exist. Women with bleeding disorders experience pain both during and after delivery as do other women; however, the management of pain during labor and delivery is more challenging in these women than in women without bleeding disorders. There is a greater likelihood of excess bleeding not only associated with the delivery itself, but also as a result of the placement of the regional anesthesia used to provide pain relief.

What are the treatment options for managing pain during menstruation and ovulation?

Women with inherited bleeding disorders experiencing menorrhagia often require treatment in order to reduce and shorten the duration of their menstrual blood flow. Some of the treatments for menorrhagia are also effective in the management of menstrual pain or pain related to ovulation. Not only are combined oral contraceptives a very effective and safe therapy for menorrhagia and, therefore, the first line therapy for the management of menorrhagia in women with bleeding disorders, they are also very effective for the control of menstrual pain as well as for the suppression of ovulation for severe midcycle pain syndrome.

Non-steroidal anti-inflammatory drugs, while very effective in the management of menstrual pain in the general population, are seldom used in patients with inherited bleeding disorders because of their potential for aggravating menstrual bleeding. The exception to this may be the COX-2 inhibitors which are reported to not cause platelet dysfunction and thus may be useful to treat menorrhagia in women with inherited bleeding disorders. The safety of a number of these preparations, however, has recently been called into question.

What are the recommendations for managing pain during childbirth?

Pregnancy is not contraindicated in patients with coagulation disorders but it does require multidisciplinary management. Ideally, there should be a pre-pregnancy discussion regarding the optimal approach to delivery between the future parents and the medical team.

An inherited bleeding disorder is not an indication for induction or delivery by cesarean section; the decision to induce or to proceed with a cesarean section should be based on obstetrical indications.

The use of regional anesthesia (epidural and spinal) in the presence of a coagulation defect is of concern because, if a vessel in the spinal canal were punctured, a hematoma might occur, which in turn could cause severe and permanent neurological damage. Most experts accept that there is no contraindication to regional anesthesia if coagulation is normalized in a woman with a hereditary bleeding disorder. Factor levels performed late during the third trimester are useful to make a decision regarding the safety of regional anesthesia; however, there is no consensus on this issue and the decision should be individualized after discussion with the patient before delivery and clearly indicated in the chart.



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The risks and benefits of various forms of analgesia merit a multidisciplinary discussion and decisions should be made on an individual basis.

If an epidural is contraindicated, intravenous analgesics may be used although they will not completely eliminate pain. Another option for peripartum analgesia is the use of nitrous oxide mixed with oxygen, which is inhaled by the mother.

Regional anesthesia for cesarean section is absolutely contraindicated if there is evidence of a coagulopathy. If the coagulation status is borderline, the relative risks and benefits of general anesthesia and spinal anesthesia must be considered and discussed with the woman.

Non-steroidal anti-inflammatory drugs are used routinely in the general population to relieve pain and discomfort following delivery; however, as noted above, in general, in patients with inherited bleeding disorders, the use of non-steroidal anti-inflammatory drugs is avoided because of the possible additive effect on excess bleeding. Acetaminophen with or without codeine is the postpartum analgesic of choice for this group of women.

What is the best way to manage pain in women with bleeding disorders?

The ideal management of pain in women with inherited bleeding disorders is through multidisciplinary clinics. At the present time, there are only a few such clinics that exist in tertiary care centres.

Women with severe bleeding disorders (or with a fetus at risk of a severe bleeding disorder) should deliver in a hospital where there is access to appropriate blood products, consultants in obstetrics, anesthesiology, hematology and pediatrics. Recommendations for the delivery concerning the management of pain and bleeding should be discussed with the patient and written in the chart by the health care team. The risks and benefits of various forms of analgesia merit a multidisciplinary discussion and decisions should be made on an individual basis.

Who are the members of the multidisciplinary team involved in managing pain in women with bleeding disorders?

Multidisciplinary clinics caring for women with bleeding disorders should include at least a nurse, a clinical hematologist, an obstetrician-gynecologist and an anesthesiologist. They should ideally have a broader representation of expertise and include a family physician, a social worker, a pharmacist, a laboratory technician and a secretary.

One Woman's Experience

P R O F I L E

I am a 41-year-old woman with Type III (severe) von Willebrand Disease.

I've had bleeding into joints, but this is far less common for me than bleeding into muscles. When I was a child, my mom or I would wrap the affected area with an elastic bandage and elevate it. I don't recall having any pain medication. These days, I rely on ice and Tylenol, as well as treating with Humate P at times – but if the pain is minimal I try to go without an infusion. What I usually feel is a hard-to-describe mixture of pressure and pain ranging from intense aching to sharp jabs (when the limb is jarred, for example), and a frustrating sense of weakness.

Not surprisingly, giving birth ranks as one of my most severely painful experiences. One might not expect this to be a “bleeding disorders issue”, but it is. The most effective methods for controlling, minimizing or eliminating the pain of childbirth were not available to me because they could cause bleeds. My factor levels don't rise during pregnancy, and I had very limited options for pain relief. An epidural was out of the question. So was an injection into muscle. While I truly appreciate all the support I received at the time, I couldn't help but be anxious, knowing that I would be in pain and not knowing how my body would react in terms of bleeding.

As it turned out, the pain of labour became so extreme that I found myself panicking, trying to escape. I was allowed to inhale gas and was given morphine intravenously. These did help me to cope better, if only by enabling me to relax slightly between contractions, but they didn't take away the pain.

My other most extreme experience of pain was caused by an ovarian bleed. Every movement – even the slight jarring of sitting as a passenger in a car – was excruciating. By the time I got myself to a doctor's office, an enormous amount of blood had collected in my abdominal cavity. When the doctor pressed on my abdomen and let go, the pain was blinding. I almost shot through the ceiling. Stopping that bleed and reabsorbing the pooled blood took a long time. I was hurting, depressed and exhausted. I've had three similar bleeds. Now I take the Pill, avoiding ovulation to prevent another bleed. (continued on next page)

Sometimes having a sense of control provides a measure of pain relief in itself.



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Another long trial was precipitated by the removal of a benign lump in my breast. The pain caused by the resulting bleed was not as intense, but the treatment included repeated mining for collected blood in my breast, using a big needle and syringe – which did hurt. However, I think you get somewhat inured to pain. After the incision in my breast reopened, I chose to have it restitched without the benefit of freezing, figuring the stitching needle would be less painful than the anaesthesia one. It was fine.

Sometimes having a sense of control provides a measure of pain relief in itself.

Complementary and Alternative Approaches to Pain Management

Sophia Gocan, R.N.

Member, CHS National Program Committee, Ottawa, Ontario

When people suffer from pain, they often consider the use of non-traditional medical approaches. This chapter provides an introduction to this topic.

The questions which will be addressed in this chapter are:

- What are complementary and alternative approaches to pain management?
- What are some commonly used complementary and alternative therapies?
- Are complementary and alternative health care helpful in reducing pain?
- Are complementary and alternative therapies safe?
- Can I use complementary therapies as well as conventional medicine techniques?
- Where can I learn more about complementary and alternative health care?



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COMPLEMENTARY
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What are complementary and alternative approaches to pain management?

Complementary and Alternative Medicine (CAM) are therapies that are considered outside of mainstream medical practices. The National Center for Complementary and Alternative Medicine (NCCAM) is a component of the United States National Institutes of Health. NCCAM describes CAM as: *a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine.* In Canada, CAM practices are referred to as Complementary and Alternative Health Care (CAHC).

Complementary therapies are used *together* with conventional medicine. An example of a complementary therapy is using aromatherapy to help lessen a person's discomfort following surgery. In contrast, alternative medicine is used *in place of* conventional medicine. An example of an alternative therapy is using a special diet to treat cancer instead of undergoing surgery that has been recommended by a conventional doctor.

While there is scientific evidence supporting some CAHC therapies, for most there are key questions yet to be answered through well-designed scientific studies—questions regarding the safety and effectiveness for the diseases or medical conditions for which various therapies are used.



The list of therapies considered to be CAHC changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge.

What are some commonly used complementary and alternative therapies?

NCCAM classifies CAM therapies into five categories, or domains:

Alternative medical systems

Alternative medical systems are built upon complete systems of theory and practice. Often, these systems have evolved apart from and earlier than the conventional medical approach used in North America. Examples of alternative medical systems that have developed in Western cultures include homeopathic medicine and naturopathic medicine. Examples of systems that have developed in non-Western cultures include traditional Chinese medicine and Ayurveda.

Mind-body interventions

Mind-body medicine uses a variety of techniques designed to enhance the mind's capacity to affect bodily function and symptoms. Some techniques that were considered CAM in the past have become mainstream (for example, patient support groups). Other mind-body techniques are still considered CAM, including meditation, prayer, biofeedback, humour therapy, and therapies that use creative outlets such as art, music, or dance.

Biologically based therapies

Biologically based therapies in CAM use substances found in nature, such as herbs, foods, and vitamins. Some examples include oxygen therapy, dietary supplements, herbal products, and the use of other so-called “natural” but as yet scientifically unproven therapies (for example, using shark cartilage to treat cancer).

Manipulative and body-based methods

Manipulative and body-based methods in CAM are based on manipulation and/or movement of one or more parts of the body. Some examples include chiropractic or osteopathic manipulation, reflexology, and massage.

Energy therapies

Energy therapies involve the use of energy fields. They are of two types: bio-field therapies are intended to affect energy fields that allegedly surround and penetrate the human body. The existence of such fields has not yet been scientifically proven. Some forms of energy therapy manipulate biofields by applying pressure and/or manipulating the body by placing the hands in, or through, these fields. Examples include qi gong, Reiki, and Therapeutic Touch. Bioelectromagnetic-based therapies involve the unconventional use of electromagnetic fields, such as pulsed fields, and magnetic fields.

Are complementary and alternative health care therapies helpful in reducing pain?

The growing popularity and increased demand for CAHC is evident. Many consumers report using CAHC in order to maintain current health and wellness, or to promote their health further and prevent future illness. Remember, however, that these are not scientifically proven treatments.

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.

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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.

A few of the benefits that different therapies may be able to exert include:

- Improved management of stress-related symptoms
- Easing your perception of pain
- Increased mobility
- Decreased anxiety
- Reduced tension
- Improved posture and flexibility
- Improved appetite or weight gain
- Restoring a sense of “balance” in your body
- Improved sleep
- Enhancing your sense of well-being
- Assisting you in experiencing inner calm and peacefulness
- Assisting you in obtaining better insight into your personal healing.

Or even more specifically:

- Improving blood circulation
- Decreasing swelling
- Increasing range of motion in joints.

The results that people experience, however, are highly individual, and not all CAHC therapies are equally suitable or credible. Before you try anything, learn as much as you can about the therapies you are interested in, then discuss them with your doctor.

Are complementary and alternative therapies safe?

Any information that you obtain regarding the safety and effectiveness of a CAHC therapy is not intended to substitute for the medical expertise and advice of your primary health care provider. Be sure to discuss all of your CAHC practices with your physician and other health care providers. Your health care team is an important part of helping you decide if a treatment may be appropriate and safe for you. Do not be afraid to ask their advice if you have a question. It is very important that you maintain open communication with your health care team. By working with your doctor and health care team, you can access reliable advice and your team can provide you with supervision of your progress.

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

Seek out only fully competent and licensed practitioners. Some providers are licensed by professional licensing bodies. Do not hesitate to ask individuals

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about their training and experience. Your provincial or territorial Ministry of Health can provide information on the training and supervision of CAHC therapy providers. There is a core group of professions (medicine, dentistry, registered nursing, optometry, and pharmacy) which are regulated in all of the Canadian jurisdictions, but for the balance of the professions there are significant differences across Canada as to whether a particular profession is formally regulated. Mainstream professional regulatory bodies or professional associations may have policies or regulations regarding the practice of alternative therapies by their members. The scope, depth, and duration of education and training for complementary and alternative practitioners vary according to the area of practice. Try to gather information from sources that look at both sides of a therapy—those who oppose and those who support the therapy. This will give you a balanced view of the therapy you are considering.

It is important that the choices you make are informed. Be cautious about any of the claims that you come across. Reliable information may be hard to find. Examine the scientific information that is available to back the effectiveness of a therapy before making health care decisions. 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.

Consult your physician and pharmacist to ensure the product will not cause you dangerous side effects.

Check with your primary care physician to ensure the therapy you are considering will be safe when taking into account your current health status. Some aspects of your health history could put you at higher risk for complications. Liver disease, for example, can be aggravated by certain herbal preparations. Find out about possible side effects and how a given therapy may interact with food, alcohol or other drugs.

The cost of some CAHC therapies may also be an important factor for you when deciding if you would like to explore a given therapy. Be sure to find out how much money a therapy will cost up-front. If you have private health insurance, inquire with your insurance carrier if it covers any of the costs you may incur. Most importantly, monitor your response to therapy.

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TO PAIN
MANAGEMENTCan I use complementary therapies
as well as conventional medicine
techniques?

Integrative medicine, as defined by NCCAM, combines mainstream medical therapies with complementary and alternative medicine therapies for which there is some high-quality scientific evidence of safety and effectiveness.

A truly integrated health care system is something we all strive for – obtaining the best and most effective treatments available to keep illness from occurring, and to heal our minds, bodies, hearts, and souls.

As these therapies become better understood and validated with sound scientific research, CAHC therapies will become integrated into traditional medicine.

This process of integration is assisted by current trends in conventional health care which are focusing more on the complete emotional, physical, psychological, social and intellectual needs of people. There is also increased attention to the evidence base of treatment and a greater regard for health promotion and disease prevention.

Where can I learn more about
complementary and
alternative health care?

While the Internet provides a wealth of information, there is no control over the information that is provided to the public. Personal stories and anecdotes may be misleading, and it is difficult to validate the information presented. It is best to use web sites that stem from the government, recognized medical organizations, well-known scientific sources, or academic institutions.



Health Canada offers information regarding CAHC therapies and has specific information regarding certain therapies. They also have valuable information available through the Health Protection Branch and the Office of Natural Health Products. www.hc-sc.gc.ca

The Canadian Health Network, funded by Health Canada, provides 89 items on alternative health. These include documents from and links to the Arthritis Society, the Canadian Chiropractic Association, the Canadian College of Naturopathic Medicine, the Canadian Medical Association, the Canadian Paediatric Society, the College of Massage Therapists of Ontario, the Community AIDS Treatment Information Exchange, and Health Canada, to name a few. www.canadian-health-network.ca

Your provincial or territorial Ministry of Health can provide you with information regarding the training and licensing of all health care providers. Links to each of the provincial and territorial government web sites is available from the Canadian Health Portal website. www.pcs-chp.gc.ca

NCCAM is the U.S. Federal Government's lead agency for scientific research on complementary and alternative medicine. www.nccam.nih.gov

www.camline.org is the address for CAMline, an evidence-based website on complementary and alternative medicine (CAM) for healthcare professionals and the public.

The National Library of Medicine www.ncbi.nlm.nih.gov/PubMed/ provides free, open search of Medline, a large biomedical database.

Books and magazines are also a good place to start obtaining information about a specific therapy. Be cautious, however, as there are no regulations requiring publishers to ensure the accuracy of the material they print in books or magazines.

Libraries also offer access to research publications. A few well-designed studies are now appearing in high-quality, peer-reviewed mainstream journals such as: the *Journal of the American Medical Association*, and the *New England Journal of Medicine*.

CHAPTER

9

COMPLEMENTARY AND ALTERNATIVE APPROACHES TO PAIN MANAGEMENT

Resources

1. Hemophilia Today, Canadian Hemophilia Society, www.hemophilia.ca/en/1.0.php
2. Handbook for Physical Activity Guide, Health Canada, www.phac-aspc.gc.ca/pau-uap/paguide/index.html
3. All About Hemophilia – A Guide for Families, Canadian Hemophilia Society, 2001, www.hemophilia.ca/en/13.1.php
4. The Pain Management Book for People with Haemophilia and Related Bleeding Disorders, Hemophilia Foundation Australia, World Federation of Hemophilia Treatment of Hemophilia Series, Number 22, April 2000, www.wfh.org/ShowDoc.asp?Rubrique=31&Document=259
5. Listing of Hemophilia Treatment Centres are available on the Canadian Hemophilia Society website at <http://www.hemophilia.ca/en/7.0.php>
6. Listing of Canadian Hemophilia Society Chapters and Provincial/Regional Offices are available on the CHS website at <http://www.hemophilia.ca/en/18.0.php>



1.800.668.2686
www.hemophilia.ca