

THE PAIN MANAGEMENT BOOK FOR PEOPLE WITH HEMOPHILIA AND RELATED BLEEDING DISORDERS

Haemophilia Foundation Australia

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Treatment of Hemophilia Monographs
Series Editor
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The Pain Management Book

for People with Hemophilia and Related Bleeding Disorders

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Introduction

Pain for people with haemophilia can come from two main areas:

- bleeds into muscles and joints;
- arthritis and related disorders, due to internal bleeding.

The pain which people with haemophilia need to manage can be both physical and psychological.

This booklet looks at the management of chronic physical pain, the sensation which many people with haemophilia have to live with constantly. When it comes to coping with pain, information and practice can make it a great deal easier.

Two types of pain:

Usually pain is classified into two main types: acute and chronic.

Acute is short term pain. It is the main way your body has of telling you that something is wrong. While the pain can be really severe, the acute variety can usually be controlled through treatment products and rest.

Chronic pain is different. Usually it is something that people have to endure a long time, if not their whole lives. Chronic pain usually evolves around parts of your body which cannot be made right - the damage is usually permanent.

Experiencing Pain¹

People experience pain differently. A joint bleed in the ankle may be "excruciatingly painful" for one person and "very sore" for another.

These different reactions are due to many reasons:

Physical: The sensitivity of your nervous system and severity of the damage caused to your body can determine how your body reacts chemically to pain. These factors also determine whether your nerves will send or block a pain signal.

Emotional and social: Your fears about pain, previous experience with pain and your attitude about your condition can affect how you react to pain and how much pain you feel. Your cultural and religious background, and the way people around you react to pain, may also affect how you react to pain.

How you deal with your pain will affect your pain. There are many ways to control pain. Everyone can learn how to manage their pain better. Some pain control methods focus on emotional and social factors. Other methods focus on physical factors. Using a combination of methods is often the most successful way to control pain.

Pain Signals

Medical scientists in the field think pain control methods help reduce pain by blocking pain signals. The signals are sent through a complex system of nerves in the brain and spinal cord. There are many things that can block these signals and so prevent the pain message from reaching your brain.

What makes your pain feel worse?

- stress;
- constantly thinking about pain;
- fatigue.

What blocks signals?

Pain signals are blocked by natural chemicals in the brain called endorphins. There are several things that can cause the brain to produce endorphins including:

- exercise;
- heat or cold treatments;
- massage;
- physiotherapy;
- positive attitude;
- relaxation;
- some medicines.

Different people need different methods. This means some techniques will work for you, but others may not. Some methods are things you can do for yourself. Others require help from health professionals or other experts in the field.

Medical Treatmentⁱⁱ

Many patients and doctors feel the best 'cure' is powerful medication, however it is important to realise that in many cases of chronic pain, medication alone may cause more problems than it solves. Taking any kind of medicine, particularly on a regular basis, must be considered carefully.



Certain medications may be effective for some people in easing pain. If your doctor has prescribed medication for your condition, consider the following tips:

Take your medicine as prescribed. Follow your doctor's advice about how much and when to take your medicine. If you're having problems with the medication, call your doctor. He or she may be able to change your dosage schedule or the type of medication to better suit your needs. Some medication labels warn: "Do not take on an empty stomach," or "Do not take with food." Take these warnings seriously. It is necessary to take some medications with food to reduce stomach upset. However, spicy and acidic foods may cause additional stomach upset, and food in the stomach

and intestines can make some medicines less effective. Food can also slow down or speed up the medicine's effect on the body. Ask your doctor or chemist whether or not to take your medicine with food.

Be careful of drinking alcohol, which can increase or decrease a medication's effects. If the medication causes stomach upset, adding alcohol can increase the discomfort. It may be better to reduce your alcohol intake or to stop altogether.

Monitor yourself. Know what benefits to expect and when they are likely to occur. Find out the side effects of your medications and what to do if they occur. Be aware of how your body is reacting to the medication.

Never give your medications to others, and never take medicine prescribed for someone else. Although you both may have the same type of arthritis, for example, a medication that works for another person may not help you. It's possible that the medication you take may be harmful to someone else. Each person should see a doctor for their specific treatment.

Follow your doctor's advice when you consider using over-the-counter medications. These medications may seem harmless because they can be bought easily. However, if they are abused, they can cause serious side effects. Additionally, prescription medications and over-the-counter medications can interact with each other inside your body. The interaction between medications can cause serious side effects.

People with bleeding disorders should avoid taking aspirin in any form because it aggravates bleeding.

Dependenceⁱⁱⁱ

It is easy to slip into the habit of drinking alcohol or taking more medicine to escape your pain. If you answer 'yes' to any of the questions below, you may need to find new ways to handle your pain:

- Do you drink alcohol more than once a day?

- Do you use up pain medication faster than you used to?
- Do you spend all day in bed?
- Do you talk about pain a lot of the time?

Some people who have had to endure pain over a long period may find they have become dependent on their medication or other drug substance such as alcohol or marijuana.

Others may not realise they have become dependent or deny their dependency. If any of the following questions apply to you, you may be developing a dependency problem^{iv}:

- Have you ever increased your dosage of your medication without consulting your doctor?
- Have you ever substituted one drug for another, thinking that one particular drug was the problem?
- Have you ever used a drug without knowing what it was or what it would do for you?
- Have you ever lied about what or how much you use?
- Do you think a lot about drugs?
- Does the thought of running out of your drugs terrify you?
- Have you ever felt defensive, guilty or ashamed about your drug taking?

While pain relief is important, dependence on any drug can create a different set of problems. There are degrees of dependency from mild to severe. It is impossible to say how long or how often a person has to use a drug before dependency develops as there are many contributing factors. Dependence can be psychological, physical or both.

Psychological dependence. Psychological dependence on a drug has developed when drug use becomes far more important than other things in a person's life. They crave the drug and feel they can't cope without it. Psychological dependence is usually much stronger and more difficult to overcome than physical dependence. The body can often eliminate a drug within days or weeks. The mind and emotions can take a lot longer.

Physical dependence. This occurs when a person's body adapts to a drug and needs it to function 'normally'. High tolerance to the drug will have developed.

If you feel you, or someone close to you, is becoming or has become dependent to any drug, consider speaking to your Haemophilia Counsellor about this.

Exercise^v

Another key to coping with pain is to follow an exercise program designed by your doctor, or physiotherapist at your Haemophilia Centre. Your program should include special range-of-motion exercises to help keep your joints moveable. It should also include general fitness exercises, such as swimming or walking. These help keep your heart, lungs, bones, and muscles strong. Exercise also helps relieve stiffness and gives you an improved sense of well-being. It can help lift your spirits.



Here are some tips to help you exercise more effectively:

- Before beginning your exercises, do a few gentle warm up movements, such as a five-minute walk around the garden, or gentle stretches such as lifting your arms over your head;
- Start with just a few exercises and slowly add more. Your physiotherapist will guide you on how to do this. Sudden resumption of vigorous

exercise without proper supervision can lead to muscle bleeds;

- If you have a flare up (a period during which symptoms become worse), do only gentle range-of-motion exercises;
- Don't do too much: you will know you have done too much if you have joint or muscle pain that continues for two hours after exercising or if your pain or tiredness is worse the next day. Next time decrease the number of times you do each exercise or do them more gently. If this doesn't help, ask your doctor or physiotherapist about changing exercise. A good rule to remember is, to stop exercising if you start having sharp pain or more pain than usual. Pain is your warning signal;
- It is important to keep a positive attitude about your exercise program. Remembering that exercise can help reduce the pain and enable you to keep up with most of your daily activities will help. But also remember there will be days when you won't feel like doing as much. On these days, do a little less exercise;
- If you have a joint replacement, check with your physiotherapist about which movements to avoid.

The keys to keeping up with your program are:

- Make exercise a regular part of your day;
- Listen to your body's signals - know when to cut back or stop your exercise.

Using Your Joints Wisely and Saving Your Energy^{vi}

Using your joints wisely means doing everyday tasks in ways that reduce the stress on painful joints. Saving your energy means "listening" to your body for signals that it needs to rest. It also means learning to pace yourself so you don't become too tired.

Here are a few guidelines for using your joints wisely and saving your energy:

Be aware of your body positions. Avoid activities that involve tight grip or that put too much pressure on your fingers. Use self-help devices, such as jar openers, reach extenders, zipper pulls and buttoning aids. These aids put less stress on

your joints and make difficult tasks easier. For more information on self-help aids contact your nearest Independent Living Centre or Arthritis Foundation.

Use your largest and strongest joints and muscles. For example, use a shoulder bag to carry items. This protects elbow, wrist or finger joints. When you lift or carry objects, spread the weight of the object over many joints. This prevents you from placing too much stress on one joint.

Avoid holding one position for a long time. Move or change positions often. Keeping joints in the same position adds to joint stiffness and pain.

Balance rest with activity. Learn to understand your body's signals that you're getting tired. Take breaks when you need them. Don't wait for the physical signs of pain before you rest. Plan your routine to alternate activity with rest - even when you are feeling well.

Respect pain. If you have pain that lasts for two hours or more after completing an activity or exercise, then you've done too much. Next time, do a little less or go about it in a way that takes less effort. Simplify your work. Plan ahead, organise and create short cuts. Use labour-saving devices, such as an electric can opener or electric garage door opener, which require less energy on your part and place less stress on your joints.

Ask for help when you need it. Family and friends would rather help you than have you become too tired or ill from doing too much.

Splints

If a joint is very swollen and painful, your doctor or physiotherapist may suggest you use a splint to rest the joint. This helps reduce swelling and pain. Your doctor may recommend that you wear the splint during certain activities, all day or only at night. This depends on how severe the swelling or pain is.

TENS Unit

Some people (especially adults) find these little portable devices very useful in treating both acute and chronic pain. The TENS (Transcutaneous Electrical Nerve Stimulation) unit works by applying brief pulses of electricity under the skin. The machine's different wave lengths and frequencies allow people to experiment in order to obtain pain relief. It is recommended that initially the TENS machine is used under the guidance of your physiotherapist. The device is usually obtained via a loan from the physiotherapy department. It can also be hired or purchased from suppliers of medical equipment.

Sleep

Getting a good night's sleep restores your energy, so you can better cope with pain. It also rests your joints to reduce the pain and swelling. Only you know how much sleep your body needs, so get into the habit of listening to your body. If you feel tired and ache after lunch every day, for example, if possible, take a brief nap. This can help restore your energy and spirits.

If you have trouble sleeping at night, try relaxing quietly in the afternoon rather than taking a nap. Here are some tips to help you sleep better:

- Have a warm bath before going to bed;
- Listen to soothing music or a relaxation tape;
- Spend some quiet time by yourself before you go to bed;
- Read.

Do not take sleeping pills unless your doctor recommends them.

Massage and Topical Lotions^{vii}

Massage increases blood flow and brings warmth to the sore area. You can massage your own muscles or you can ask your doctor to recommend a professional who is trained to give massages. If you have arthritis in your shoulders, elbows, wrists or fingers, you may not be able to give yourself a massage.

When giving yourself a massage, use a lotion or oil to help your hands glide over your skin. Menthol gels also provide a comforting tingle that can further ease the painful area. A rub made from

pure comfrey and beeswax available from health food shops may also be useful in easing joint pain.

Some people find topical sprays such as indomethacin useful for chronic joint or soft tissue pain, but this medication should be used under medical supervision.

Topical "deep-heating" rubs may contain medicine that block the sensation of pain. Or, they may increase blood flow in the skin where they are applied, and distract attention from the painful muscle or joint. However, despite advertising claims that these ointments go directly into the joints and relieve pain, they do not usually penetrate very deeply into the skin.

Tips for safe massage:

- When doing self-massage, stop if you have any pain;
- Don't massage a joint that is very swollen or painful;
- If you use a menthol gel for massage, always remove it before using a heat treatment - otherwise you might burn yourself;
- Deep, aggressive massage is not recommended for treating joint pain;
- If you have a professional massage, make sure the massage therapist has a good understanding of your chronic condition.

Heat or Cold Treatments^{viii}

Using either heat or cold treatments can reduce the stiffness and pain associated with joint damage. Cold packs numb the sore area. They are especially good for severe joint pain and swelling caused by a flare up. Heat treatments relax your muscles. You can use dry heat methods such as a heating pad or health lamp, or moist heat methods, such as a bath pack.

Here are some more ways you can use heat or cold treatments:

- Soak in a warm bath, shower or spa;
- Place a heating pad on the painful area. Don't sleep with the heating pad on because you may burn yourself;

- Use an electric blanket. Turn it on before you get up to fight off morning stiffness;
- Use flannelette sheets. They feel warmer against your skin;
- Use a hot water bottle wrapped in a towel to keep your feet, back or hands warm;
- Before getting dressed, warm your clothes by placing them on top of the dryer, electric blanket, or heating vent for a few minutes;
- Place hot packs on the painful area. These are filled bags that are heated in water and covered with a towel. Be careful not to let the pack get too hot;
- Ask your doctor or physiotherapist about a paraffin bath. This involves dipping your hands in a mixture of melted paraffin and mineral oil. The warm coating soothes stiff, painful fingers;
- Use a combination of heat and cold. This is called a contrast bath. Soak your hand or foot in warm water, then cold water, then warm water again;
- Place a cold pack or ice bag on the painful area. You can buy these at the chemist or you can make one by wrapping a towel around a bag of frozen vegetables.

Before using:

Your skin should be dry and healthy;
Protect the skin over any bone that is close to the surface of your skin. Place extra padding over the area to prevent burning or freezing your skin.

After using:

Check the area for any swelling or discolouration;
Carefully dry the area;
Gently move your joint to reduce stiffness;
Allow your skin to return to normal temperature before using another treatment.

Use Heat or Cold Safely**Do:**

- Use either heat or cold for only 10-15 minutes at a time. Then wait for at least 30 minutes to let your skin return to its normal temperature before using another application;
- Always put a towel between your skin and any type of pack;

- Always follow the advice of your physiotherapist or doctor carefully when using these methods, especially heat;
- Check your skin before and after using heat or cold;
- Use milder temperatures for a child's skin, because it is more sensitive than an adult's skin.

Don't:

- Use either heat or cold if you have open cuts or sores;
- Use a cold pack if you have poor circulation or vasculitis;
- Use heat that is too hot or cold that is too cold. It is normal for your skin to appear pink after using a hot or cold pack. If an area appears dark red or spotty red and white, there may be some skin damage. Blisters may also appear if the pack is too hot or too cold;
- Use creams, heat rubs or lotions on your skin while using a hot or cold treatment;
- Make your bath or shower water too hot. This may cause dizziness or fatigue;
- Use an electrical device unless approved by your physiotherapist. The device must be in good working order.

Relaxation^{ix}

People who are in pain experience both physical and emotional distress. Pain and stress both have similar effects on the body. Muscles become tight and breathing becomes fast and shallow. Heart rate and blood pressure go up. Relaxing can help you reverse these effects. It gives you a sense of control and well-being and makes it easier to manage pain. Relaxation is more than just sitting back, reading or watching TV. It involves learning ways to calm and control your body and mind. Relaxation does not come easily, especially if you are in pain. It takes practice. The best time to use relaxation skills to manage your pain is before the pain becomes too intense.



Everyone responds differently to different relaxation techniques. Try some of the methods below until you find what works for you:

Guided imagery uses your mind to focus on pleasant images. First, begin by breathing slowly and gently. Think of yourself in a place where you feel comfortable, safe and relaxed. Examples include a favourite holiday spot or under a tree in your backyard. Create all the details - the colours, sounds, smells and how it feels. These images take your mind away from pain and focus it on something more pleasant.

Prayers are very relaxing and comforting for some people. You may want to make a tape recording of a soothing inspirational message.

Hypnosis is a form of deep relaxation in which your attention is focused internally - away from the usual thoughts and anxieties. You will need to work with a professional trained in hypnosis who is recommended by your physiotherapist or counsellor. Suggestions for positive change seem to be more easily accepted while a person is quiet and relaxed. Most people who find hypnosis helpful in relieving pain, report it as soothing and enjoyable as well.

Relaxation audio tapes help guide you through the relaxation process. These tapes provide directions for relaxation, so you don't have to

concentrate on remembering the instructions. Many professional tapes are available for purchase. You might also want to make your own tape of your favourite relaxation routine.

Tips for relaxing:

- Take the phone off the hook;
- Put a note on the front door saying "Do Not Knock";
- Pick a quiet place and time. Take at least 10 minutes for yourself with no noise from TV, radio or other people. Use soft music to muffle other noises;
- Sit or lay in a comfortable position with your head supported and your eyes closed;
- Take slow, gentle breaths. Feel your stomach move in and out with each breath;
- Continue to breathe slowly and rhythmically focusing on just your breathing;
- Think about words such as "peace" or "calm";
- Don't worry about whether you reach a deep level of relaxation. Allow the relaxation to go at its own pace;
- Other thoughts will come into mind. Just notice them and quietly go back to your breathing. Concentrate on relaxing and staying calm;
- Do not practise right after a meal. If you fall asleep, don't worry. Next time, try to stay awake the entire time;
- Set aside time regularly to practise. Then, relaxation will become easier.

Some people find it very difficult to relax. They think they don't have time to practise or they don't believe it will help them. Others feel embarrassed for taking the time. With a little practice, most people get some relief from relaxation. There are many books and tapes available on relaxation in most bookshops.

Taking Control^x

Your mind plays an important role in how you feel pain and how you respond to illness. People with chronic pain often feel helpless and depressed about their condition. With these feelings comes decreased activity, poor self-esteem, and increased pain. So, building a sense of control by changing

your thoughts and actions is an important part of pain management.

Following are some ways you can take control of your thoughts and actions to help control your pain. Thinking differently may not get rid of your pain entirely, but having a more positive attitude can help. Many of these methods are easier said than done - practice and patience are needed.

- Keep a positive attitude. One way to reduce your pain is to build your life around wellness, not pain and sickness. Live what is called a "wellness lifestyle". This means to think positive thoughts, keep a sense of humour, eat a balanced diet. (The key to healthy eating is lots of fresh vegetables, fruit, bread, rice, and other grain products, along with fish, lean meat, poultry and reduced-fat dairy products.^{xi}) Do some form of exercise every day, and enjoy activities with others. It also means following your treatment plan, taking any medication properly, and practising relaxation.
- Chronic pain can limit you, but it doesn't have to control your life. Talk to your doctor, nurse or physiotherapist about how you can make your life more healthy. Get involved in a favourite activity or hobby, or try a new one. Remind yourself of what you can do rather than what you can't do. You'll feel better, and your pain will not seem so severe.
- Don't dwell on pain. How often do you think about your pain? The amount of time you spend focusing on it has a great deal to do with how much discomfort you feel. People who dwell on their pain usually say their pain is worse than those who don't dwell on it. One way to take your mind off the pain is to focus positively on someone else or something else.
- Everyone has the ability to be distracted. The more you focus your attention on something outside of your body, the less you will be aware of physical discomfort. For example, get involved in an activity or hobby you enjoy, develop a new interest or get involved with helping others. If you can't help but think about pain, try to think about it differently. Think of the pain as your body's message to do something different. Arthritis Foundations

run self-management courses which may assist you.

Sex^{xii}

While the saying "pain is a great contraception" is a popular one - don't accept stereotypes. If you live with chronic pain, some people may mistakenly assume you're not interested in sex. You definitely don't have to accept this view of yourself. People with chronic pain can and do have satisfying sexual relationships.

Satisfying sex can help you accept changes in your body, enhance your confidence in your own sexuality, and help you feel better physically.

A satisfying sexual relationship depends on open communication with your partner. It is important to find a time and private place, free from distractions, to talk about the sexual needs, desires, and ideas you both have.

Think about trying something new: this could provide fresh excitement, comfort, and pleasurable intimacy. Encourage new ideas in one another, without pressing or rushing. For example, you might consider creating a new romantic setting, changing the place where you usually make love, or discovering new and pleasurable ways to touch and hold one another. Consider this an adventure well worth your time and patience.

Let your partner know what feels good to you: you know what you find comfortable, exciting, or painful. Your partner knows what you feel only when you tell him or her. Words are likely to be clearer than smiles or sighs.

Take turns giving each other a gentle massage. This is a good way to learn to talk about body feelings. When your partner's hand gets near a painful area of your body, simply redirect it toward a place where you enjoy the touch most. Continue to share your feelings through words. Have clear, pre-set signals to let your partner know if you experience severe pain. A signal can enable you to continue your lovemaking on a positive level, rather than bringing it to an abrupt end because you both feel anxious.

Talking about your feelings will end the guess work between you and your partner. Support and new understanding which can come from talking may make you feel better than you have ever felt before. Always let your partner know when something really feels good - this is the most helpful guide you can offer.

Pay no attention to the myth that good sex has to be spontaneous and unplanned. You will find that planning is a major help in enjoying sex when pain and fatigue have been constant companions. Here are some general suggestions to think of in your planning:

- Plan for sex at a time of day when you generally feel best;
- Time your dose of pain-relief medication so that its effect will cover the time you have sexual relations;
- Pace your activities during the day to help avoid extreme tiredness;
- Practise prescribed range-of-motion exercises to relax your joints;
- Use a vibrator or lubricant before sex to help produce arousal and make insertion easier;
- Take a warm bath or shower before sex to relax and soothe your joints and muscles;
- Use your imagination: shower or bathe with your partner. Make it a part of the romance. Gently apply lotion to one another, to heighten sexual arousal. You can enjoy pleasant sensations, warmth and affection even if all the pain is not relieved. Gentle touching may feel especially good to one whose body is often a source of pain.

Finding new positions for intercourse can put less strain on painful joints and, in turn, improve your sex life. The common position with the woman on her back, legs spread wide, and the man over her can be very uncomfortable, especially if the woman has arthritis in her hip, or if the man has it in his knee, leg, or arm. If movement causes you pain, have your partner provide most of the body action. You may prefer a position which allows you to move away if you suddenly have joint pain.

Think about what you do to make yourself more comfortable when you are lying in bed. Perhaps these changes of position can be adapted to your lovemaking, for greater comfort and increased pleasure for you and your partner.

There are many satisfying ways, other than intercourse, to make love and to have your body respond to sexual stimulation. Some of these may be familiar to you; others less so. All are normal, natural expressions of human sexuality. These alternate sexual activities can be a welcome solution when you're having joint pain.

Sensation, pleasure and satisfaction do not depend on penetration of the penis deep into the vagina. For example, the end of the penis is its most sensitive part. The clitoris and opening to the vagina are far more sensitive than the interior of the vagina. Men often feel that an erection and penetration of the woman's vagina are necessary to please his partner. But this is not necessarily so. Many women find greater satisfaction through genital stimulation, either manually or orally.

Women may have a problem with decreased lubrication causing the vagina to be dry, which makes intercourse uncomfortable. The decreased lubrication may be caused by certain medications, by some diseases like lupus, scleroderma and Sjogren's Syndrome, or can be a natural change due to ageing. Using a vaginal lubricant will make entry of the penis easier in any position. Petroleum jelly products and other oily substances are not recommended because they may harbour germs which could cause infection. It's best to use a germ-free lubricant, such as K-Y Jelly or Steri-lube. These are available without a prescription.

If you have had joint replacement surgery, talk to your doctor about when to resume sexual activity and which positions will be most comfortable for you.

People who have bloodborne viruses need to be aware of transmission risks with sexual partners. To avoid transmission of HIV, those who have tested positive to this virus need to wear condoms during intercourse and oral sex, as there is a possibility of transmission via blood, semen and vaginal fluids where skin is broken or sex toys are used. While the risks of transmitting hepatitis C are less clearcut, it is recommended that people who have tested positive for hepatitis C wear condoms in casual sexual relationships, as this will reduce the risk of all infections. If a couple is in a long term relationship, only having sex with each other, they should discuss their need for condom use with their doctor. By wearing condoms people are also protecting themselves and their sexual partners from other sexually transmitted diseases. By taking responsibility in this area, more satisfying and less stressful relationships are developed. Responsibility communicates respect and trust.

Family Issues^{xiii}

Chronic pain affects the whole family. Partners or families of people who have chronic pain often feel as helpless as the person in pain. To make it easier on everyone, both the person living with chronic pain and his/her family members need to have patience and show sensitivity.

How you can assist the person in chronic pain:

- Show that you value his or her company. Everyone likes to hear good things about themselves so be generous with compliments. Keep in mind how helpful kind words are on days when you feel low;
- Offer support in small ways. Corny as the cliché ‘It is the little things that count’ sounds, there is truth in this saying. For example, when you have time, you can give a back rub, run bath water, make a meal, or perhaps, if technically minded, try to create a new adaptive device. You might share a new hobby or suggest a night out, or take a drive to the beach together.
- Try to encourage your relative to achieve new goals and ideas. Over time, you will learn the

difference between helping when it is needed and helping too much. Always pampering your family member living with chronic pain can, in the long run, make him/her see themselves as being worthless and co-dependent. He or she needs to remain as independent as possible.

While the person's pain should not be dismissed, sometimes it can get to be too much for the family. This is especially true when treatment after treatment is ineffective and/or the complaints about being in pain seem never ending. If you feel you need to find new ways to relate to your family member who has chronic pain, consider speaking to your Haemophilia Counsellor. Don't forget to pay attention to your own needs for rest and relaxation. Seek support from friends also. To remain a caring and giving person, you need to receive as well as give.

Stress^{xiv}

The most common signs of stress are:

- tiredness/exhaustion;
- muscle tension;
- anxiety;
- indigestion;
- nervousness/trembling;
- sleeplessness;
- cold, sweaty hands;
- loss of or increased appetite;
- grinding teeth/clenching jaws;
- general body complaints such as weakness, dizziness, headache, stomach ache or pain in the back.

Dealing with Stress

Pain is stressful. If you have increased stress, you may feel more pain. So, learning to reduce stress can also help you to manage your pain.

The key to reducing stress is to get stress to work for you instead of against you.

A complete program for reducing stress has four parts:

- Learn how to reduce stress;
- Learn how to cope with depression and anger;
- Learn how to accept what you can't change;

- Learn how to overcome the harmful effects of stress.



Tips for reducing stress:

Identify the causes of stress in your life.

What causes you the most worry and concern? What situations make you feel anxious, nervous or afraid? Once you know what the stressful aspects of your life are, decide whether or not you can change them.

Keep a "stress diary" to record the events in your life that cause stress.

Record any physical symptoms you have. Try some of the ways to reduce stress suggested in this booklet, noting if they helped you. Soon you will learn what upsets you the most, and which ways help you to cope the best. Then try to prevent those situations from occurring. For example, if watching violent programs on TV upsets you, give them a miss. If important family events usually make you anxious, plan to get extra rest ahead of time so you are better able to cope.

Share your thoughts and feelings.

It's usually helpful to talk to someone about your concerns. Perhaps a family member, friend, member of the clergy or Haemophilia Counsellor can help you see your problems in a different way.

Learn to tell people when you can't do certain things.

Saying "no" to people is important and you shouldn't feel guilty when you do. You may find that turning down extra duties - even for a short period of time - reduces your stress.

Respect your limits of energy, pain, and time.

If you don't, you can become so worn out that you can't be the kind of friend, lover, or parent you want to be.

Realise that you have the right to decide if you want to discuss your chronic illness.

If having haemophilia limits your activity, that may be a good reason to mention it. Otherwise, your haemophilia is a private matter.

Learn to express anger and other negative emotions without hurting others.

It's all right to be angry! However, try to say, "I'm feeling angry", instead of, "You are making me angry." This lets you express your feelings without blaming someone else. "Striking" someone with words will only make that person feel under attack. This can make the conflict harder to resolve. Learning to express your feelings will enable you to improve relationships with the people who are important to you.

Choose a "safety-valve" activity to help you cool off when you're angry.

"Bottled-up" anger can produce stress. Listening to music, singing, or talking to a friend you can trust are good examples of ways to vent feelings. Physical activities such as walking or working in the garden are also good examples.

Try not to get depressed.

Chronic pain can bring about feelings of depression. You may feel sad or "down", or have more serious thoughts of hopelessness and despair. Depression can make you feel miserable and also increase your pain.

Depression often results when a person is unable to express angry feelings and keeps them buried inside. It also can be a side effect of certain medications. In addition, depressed feelings can be triggered by chronic pain, fatigue, too much stress, fear of losing the interest and affection of a loved one, a sense of loss about changes in one's body or lifestyle, or fear of possible future body or lifestyle changes. But, in spite of these many "reasons," not all people with chronic pain get depressed or angry, and many learn to overcome such feelings.

If you are depressed, how does this condition affect your life? Are you irritable with family or friends? Have you stopped taking care of your pain? Are you withdrawing from activities and friends? Are you sleeping less or more, eating less or more, or feeling more pain and fatigue than usual? Are you paying less attention to your personal appearance? Do you find that life has no value and that your thoughts tend to be gloomy and negative? These behaviours are possible symptoms of depression and may require treatment from a professional.

One of the biggest problems with pain is that it is invisible. In our society we are often conditioned to believe only what we can see. This means that sometimes people who are actually in pain have a difficult time being believed, especially if the pain is long-lasting. This can increase your feelings of depression, anger and/or frustration.

Tips for coping with depression and anger:

There are many ways of treating depression. The catch is that depressed people often don't feel like doing the things that will help them get out of their blue moods. If you are depressed, you may have to make yourself do things at first, but it will get easier as time passes. Making the effort to interact with other people, and to leave your house, are good starts towards overcoming depression. Choose activities you enjoy and people who are cheerful and fun to be with. Talking about your feelings and moods with family, friends, or clergy also can be very helpful.

Since anger can build up inside you and cause depression, it's important to learn how to express angry feelings outward in a positive way.

Appropriate ways of releasing angry feelings include exercising, crying, keeping a journal that includes feelings, speaking into a tape recorder about your concerns, and talking to an understanding friend. If the anger is directed toward another person, it may be best to get the matter out in the open and clear the air rather than to keep the feelings inside. This does not necessarily mean having an argument. One can learn how to discuss angry feelings without doing damage to the relationship.

If the depression persists, consider discussing the situation with your doctor. Sometimes treatment involves taking medication. If you are taking tranquillisers or drinking a lot of alcohol, talk with your doctor about their possible effects on your mood. Also consider speaking to your Haemophilia Counsellor about how you feel.

Some people are afraid to admit they need help. They believe that others will think they are crazy if they talk to a professional about their problems. But it is important to get help when you need it. If you have the symptoms of depression - poor sleep, changes in appetite, crying, sad thoughts, consider talking with your Haemophilia Counsellor. The same goes if you feel you are getting angry more often.

Simplify your life as much as possible.

Look at the activities you do. Decide which ones are most valuable and leave out those that aren't. Many tasks or chores may seem necessary. But are they? They may be important only in your mind. Your family and friends enjoy you more when you're rested and healthy. Therefore, don't get worn out trying to do too much. Instead, do a few things well.

- Ask for help when you need it, and accept it gratefully. Allow others the joy of giving.
- Use aids and devices to make your everyday tasks easier.

Manage your time and conserve your energy.

When you usually have pain and limited energy, it's natural to work harder on days you feel well. Instead of getting worn out trying to do everything, organise each day the night before or in the morning.

- Plan to do the most stressful or hardest task early in the day;
- Schedule rest periods, and remember to take them before you get worn out;
- Pace your activities by doing a heavy task and then light ones. Don't try to do too many heavy jobs in one day;
- Combine chores or errands so you can get more done with less effort.

Set short-term and life goals for yourself.

Goals give you something to work for, and they give you satisfaction once you achieve them. Set short-term, achievable goals, taking one day at a time. Remember to include hobbies and friends in your planning. Take some time to think about your life goals. How has your life changed since you last thought about your goals? Has your pain affected them? What is most important to you now? What do you want to achieve? Consider what you want out of life as you answer some of these questions.

Realise that drugs and alcohol don't solve life's problems.

When people who smoke are under stress, they tend to smoke more. Some people use alcohol, marijuana, or other drugs in an attempt to solve or to escape from life's problems. The truth is, these substances can only add to your health problems. They don't help you reduce stress. In fact, in the long run they can increase your stress. Instead, see a counsellor or ask your community health service or hospital about programs offered in stress reduction. (See section on Dependency.)

Try to be as physically and mentally healthy as possible.

Remember that having haemophilia is only one part of your total health picture. Sometimes people feel so overwhelmed trying to manage the pain caused by their haemophilia that they forget about the rest of their health. You suppress pain not only by smoking, drinking, or taking drugs, but also by your weight, exercise, and attitude. By becoming as physically and mentally fit as possible, you can improve your energy, state of mind, and your level of stress.

Develop a sense of humour and make time for fun.

Schedule time for play and become involved in activities that make you laugh. Laughing seems to make everyone feel better. No matter how sad your mood, laughing can make the world look brighter. Laughter eases tension - you can't be "uptight" and laugh at the same time! Joke with friends or see a funny movie. You know yourself - do what is fun for you.

Don't take yourself and the world too seriously, or you'll just become tense and gloomy. Negative feelings can't change your situation. They only increase your level of stress. Instead, practise thinking positively, actively choosing the brighter side rather than the darker side of every issue. Make positive choices a habit, and soon you'll be feeling more hopeful.

Get help to cope with constant, hard-to-solve problems.

For instance, a counsellor or therapist may be able to help you work through a serious relationship problem. He or she might be able to help you find positive ways to express anger, if this has become a major concern.

Accepting what you can't change:

Realise that you can change only yourself, not other people.

Most people spend too much time and energy trying to reform their partners, children or doctors. They want to make them different, or to have them act in a certain way. When these changes don't happen, people tend to feel frustrated, tense, and upset. No one has the power to change another person. When people change, it's generally because they wanted to do so.

Have the courage to be imperfect.

Stop trying to be the ideal parent, partner, child, patient, employee, or boss. No one is perfect! Trying to be perfect is admirable, but doing so takes its toll on your time, energy, and the way you feel about yourself.

Realise that life isn't always fair. Drugs have side effects, doctors may sometimes be grouchy, and families don't always understand.

Overcoming the harmful effects:

Learning how to relax is one of the most important ways to cope with stress in a positive way. Relaxation is more than just sitting back and being quiet. Relaxation is an active process involving methods that calm your body and mind. Learning how to relax takes practice, just as learning how to ride a bicycle takes practice. Once you know how, it becomes "second nature." (See section on Relaxation.)

Complementary Therapies

People often turn to 'natural' methods of relieving pain after a medical approach has not been successful for them. A great deal has been written both for and against complementary therapies. Ultimately, it is up to individuals to decide what they would like to try to ease their pain. However, before you try anything outside your medical treatment plan, do at least a little research on what you are interested in trying. Then talk to your doctor about the natural therapy you are interested in.

Following, in alphabetical order, is a run-down of some of the popular forms of complementary therapies used to help treat chronic pain:

**Alexander Technique**

This approach was developed by the Australian actor F. M. Alexander and focuses on improving body awareness, which leads, it is asserted, to the release of the chronic tension that has become part of the way we move and act.

Aromatherapy

Aromatherapy is another traditional healing therapy. It uses oils extracted from aromatic plants such as lavender and geranium. One use for essential oils is to enhance health. Apart from the physical benefits, essential oils are said to have subtle effects on the mind and emotions. These oils are used in massages, baths, compresses, inhalations and vaporisation.

To help ease the pain associated with joint damage, one suggestion is to prepare a bath oil mixture which contains: 25 drops fennel oil, 15 drops of juniper oil and 15 drops of cypress oil. Four drops of this mixture should be added to the bath water, along with two handfuls of Epsom salts. This preparation will be enough for approximately 10 baths.

To help achieve relaxation any of the following oils may be beneficial: chamomile, clary sage, lavender, sandalwood.

Use essential oils only as directed by your naturopath.

Feldenkrais Method

This approach was developed by Moshe Feldenkrais, a Russian-born Israeli educator. It uses physical movement to focus on learning about the connection between thought and action. This approach is said to improve posture and flexibility and ease muscular tension and pain.

Massage Therapy

Hands-on manipulation is an old healing tradition, with written records of massage going back three thousand years to China. There are a variety of forms of massage therapy and bodywork, all with their own specific philosophy. However, what they do have in common are the beliefs that massage may assist in release of tensions and toxins, reduction of stress and enhancement of all

bodily systems. If you decide you would like to try this therapy, ensure the person you choose is a qualified masseur.

Meditation

This is a term that refers to a wide variety of mind control techniques that aim to provide a feeling of inner calm and peacefulness. Many people who meditate do so by sitting and concentrating on their breathing, an image, or a mantra (word that is repeated in your mind).

Reflexology

This approach involves the manual stimulation of reflex points on the ears, hands and feet. The pressure on these reflex points is believed to relieve stress and tension, to improve blood supply, to promote the unblocking of nerve impulses and to help restore balance in the body.

Reiki

This is the Japanese word for "universal life force energy". It is an ancient approach where, it is alleged, the reiki energy enters the practitioner through the top of his/her head and exits through the hands, being directed into the body or energy field. This form of healing may be done through clothing and without any physical contact between practitioner and client.

Issues relating to using complementary therapies:

- One problem with using complementary therapies has been the costs involved. However, some private health insurance companies may include recognised natural therapies as one of its optional special benefits. Also, you may be able to negotiate an amount to suit your budget.
- Living with chronic pain does tend to tempt many people to try unproven remedies. Possibly harmful remedies include lasers, large doses of vitamins, snake venom and drugs with hidden or unknown ingredients. At first glance it may not be easy to spot an unproven remedy. Often the only source of information about a remedy may be what's given out by its promoters. Suspect some sort of con when you see any of these claims for a remedy: 'will work fast', 'will cure your pain',

'is inexpensive', 'will work on everyone'. If you are in doubt about the qualifications of the practitioner of a particular natural therapy, your local Natural Therapists' Association may be able to assist you.

Support Groups

Sharing your feelings and experiences with a group can make living with chronic pain easier. The basic goal of a support group is to give you a way to share and learn about your disorder and the pain which results from it. A group may also help you to feel understood and can give you new ideas to help cope with problems. It can also help you feel good about yourself because you'll be assisting others in the group.

Groups may be run by professionals or they may be self-help groups led by people with chronic pain. Others have no specific topic but work with people who have different types of problems. Speak to your Haemophilia Counsellor to find out whether there is an existing group you can tap into.



Illustrator: Jason Davis

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