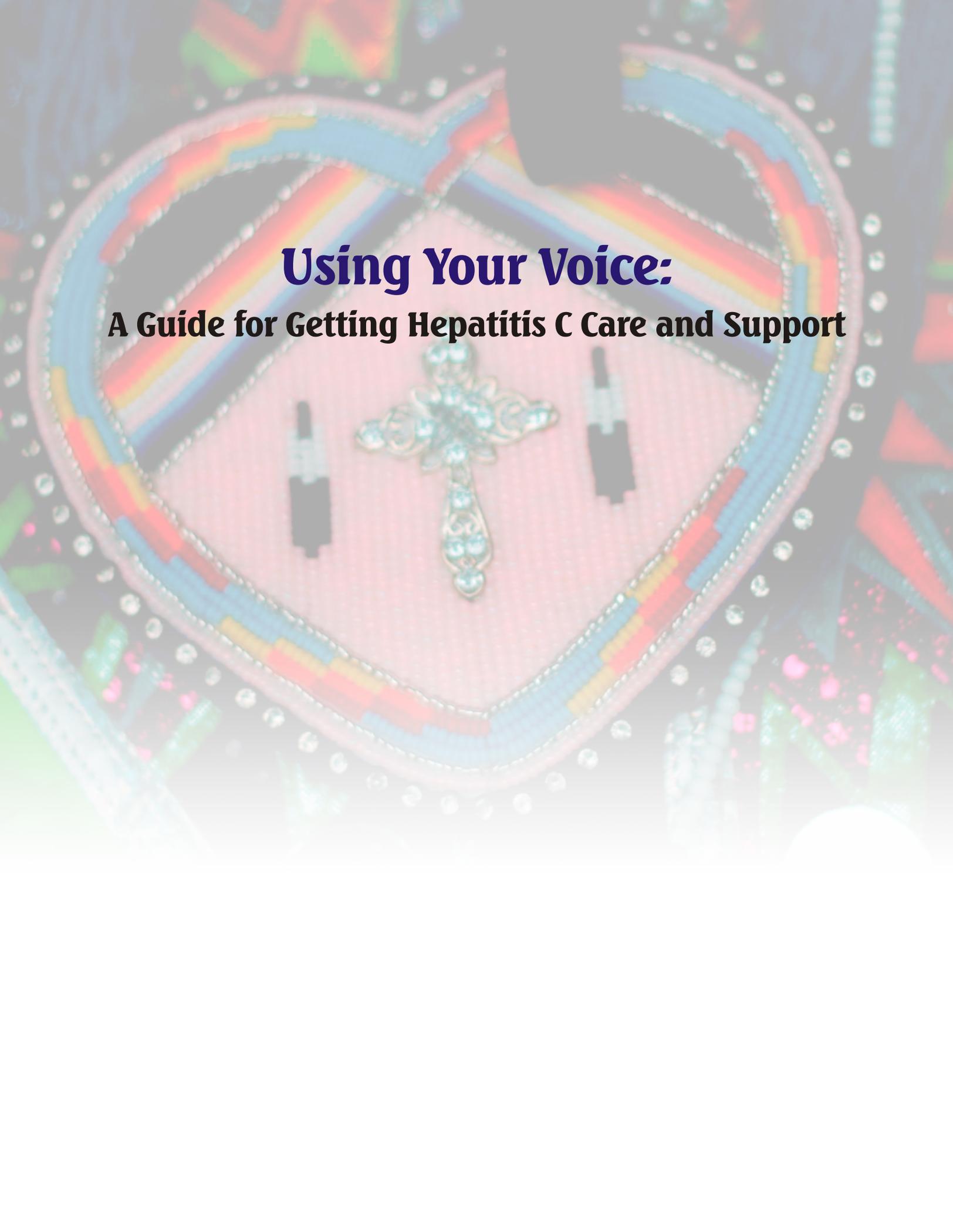


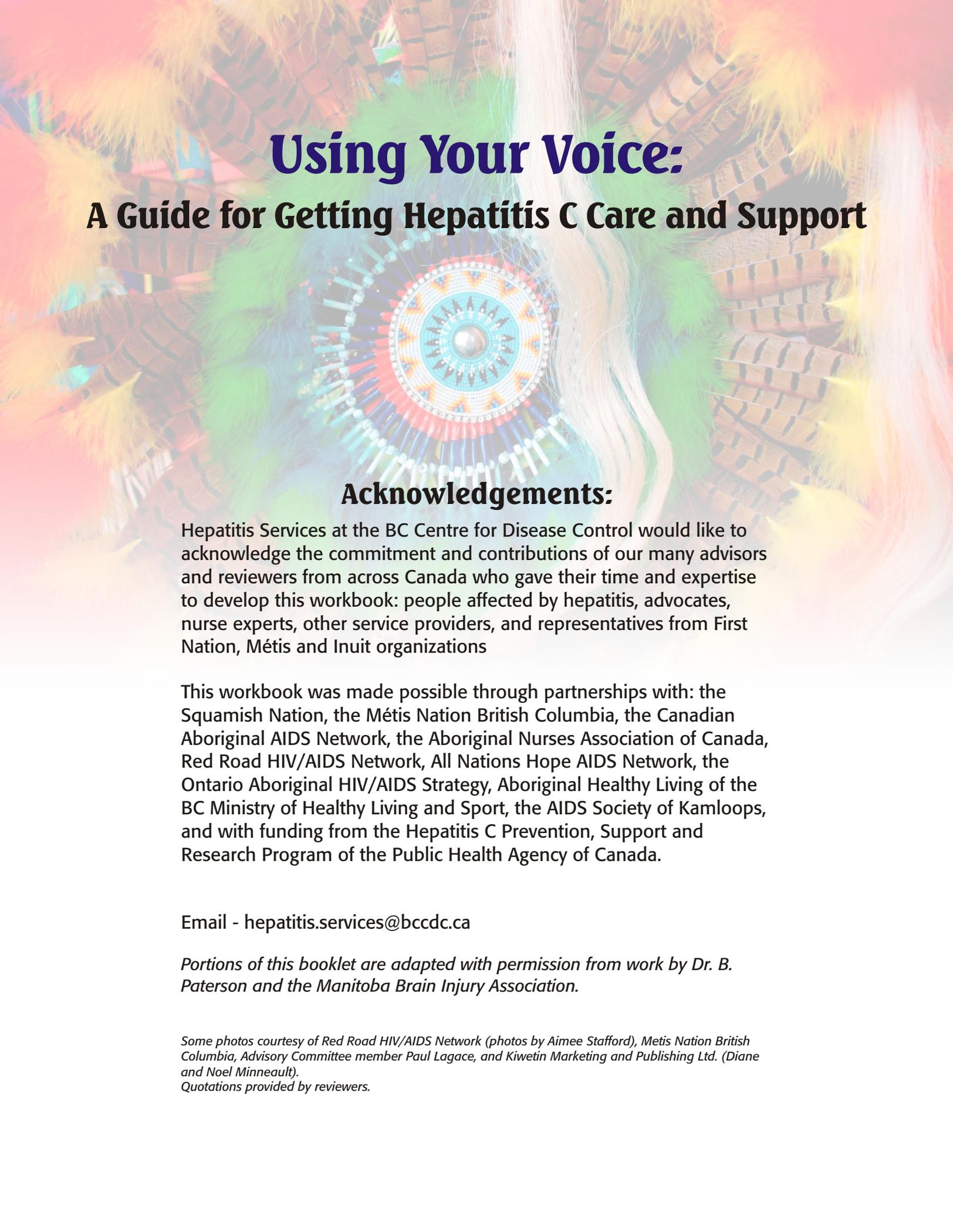
Using Your Voice:

A Guide for Getting Hepatitis C Care and Support



The background of the page is a close-up of a heart-shaped embroidery hoop. The hoop's border is decorated with a vibrant rainbow pattern. Inside the hoop, on a pink fabric, lies a silver cross with clear crystals and two syringes. The entire scene is set against a dark, patterned background with colorful geometric shapes and small white dots.

Using Your Voice:
A Guide for Getting Hepatitis C Care and Support



Using Your Voice:

A Guide for Getting Hepatitis C Care and Support

Acknowledgements:

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Email - hepatitis.services@bccdc.ca

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Quotations provided by reviewers.

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Using Your Voice:

A Guide for Getting Hepatitis C Care and Support

Introduction

Living with hepatitis and getting services may require negotiation with many professionals and organizations. This guide contains tips on how to prepare yourself so you can use your voice to get what you need.

Who is this guide for?

- People living with or affected by hepatitis C
- People affected by other chronic illnesses such as HIV/AIDS
- People who want to learn how to use their voice to get what they need

What's in the guide?

This is a step-by-step guide for learning and practicing advocacy skills.

The guide will help you plan, practice and gain confidence to use your voice to speak up for what you want. You will learn how to talk with health and social service workers in ways that will get you the information and services you are looking for.

Where can I get this guide?

This workbook is available online:

http://www.bccdc.ca/dis-cond/a-z/_h/Hepatitis-/overview/AdvocacyHepatitisCareSupport.htm

REMEMBER

**You are the person who knows best what your needs are.
You are the expert about your life.**





KNOWLEDGE

Part 1: Getting Started

A. What is Advocacy?

Have you ever:

- Told a cashier that the price was wrong?
- Asked for help to understand instructions better?
- Reminded a friend to return a borrowed five dollars?

Advocacy is:

- Looking after yourself
- Speaking up for yourself
- Deciding what is best for you and taking charge of getting it
- Asking for what you need from the people that can help you
- Standing up for your rights

“Even if you have never spoken up and you are afraid, speak up for yourself. The more you use your voice the easier it gets.”



Think about the times when you have spoken up for yourself. Circle the words below that best describe the knowledge, skills, resources and attitudes you used to speak up for yourself.



Resources:

- Family
- Friends
- Elders
- Social support network (e.g. gatherings, drum groups)
- Ceremonies
- Churches
- Cultural and traditional teachings (Medicine Wheel, the Seven Teachings)
- Other information sources (e.g. internet, public health services)



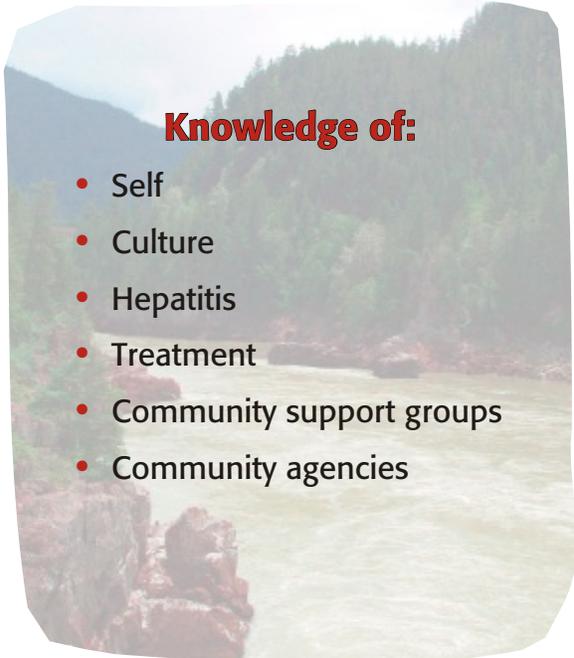
Skills:

- Listening
- Talking or sharing with others
- Resourcefulness (using creativity to overcome obstacles)
- Assertiveness
- Caring for yourself (e.g. knowing when to sleep and eat, being kind to yourself)



Attitudes:

- Positive thinking
- Patience
- Persistence
- Flexibility
- Respect



Knowledge of:

- Self
- Culture
- Hepatitis
- Treatment
- Community support groups
- Community agencies

“Respect your need to laugh or cry”



B. Things to Think About

Speaking up for yourself is sometimes not easy. Three things to think about before you advocate are:

- Do you feel positive?
- Do you need to take a break?
- Do you want someone to support you?

1. Positive Thinking Helps

- Write down how good friends describe you. Keep these words with you for strength.

2. Taking Breaks

- Think of a time when you let yourself take a break. What were the signs you needed to take a break?

3. Getting Help

- Describe a time when you let someone help you.

Taking Breaks



Managing a chronic illness is stressful. You may need help from health and social service providers. You may find the person you go to is not able to help you. You may need to tell your story over and over before you find the right person to help you. Telling your story over and over can lead to frustration and anger.

Anger can be useful if it gives you energy to speak up for yourself. However, anger that builds up over time can create problems. For instance, you could lose your temper and blow up at someone, hurting your relationship with that person.

Anger that builds up over time can also drain your energy. This is why it is wise to plan to re-energize yourself. Support to stay balanced can include elders and traditional and cultural practices.

Signs you need to take a break if:

- You find yourself thinking badly of, and criticizing, everyone around you.
- You cannot eat or you eat too much.
- You feel like no one understands you, or knows the stress you are under.
- You can't handle frustrating situations.
- You feel like you are going to cry most of the time.
- You are tired all the time and sleep does not refresh you.



Getting Help

When you are feeling tired or weighed down you may want to ask a friend, family member, or someone else you trust to advocate for you.



Think of a time when you got someone to help you advocate.
Why did you choose that person?

Self Advocacy Can:

- Help you ask for and get what you need
- Save your time and energy
- Open doors
- Improve your people skills
- Reveal the difference between what you can and cannot change
- Change your life



STRENGTH

Part 2: Steps to Overcoming Obstacles

Here are some common obstacles to effective advocacy.

- Being afraid that if you speak up things will get worse
- Not being prepared
- Being spoken to in a harsh or aggressive manner
- Speaking in a harsh or aggressive manner
- Not knowing your rights
- Expecting too little
- Expecting too much
- Not listening to others
- Others not listening to you
- Feeling like you don't count
- Feeling like you are less educated than others
- Not knowing your supports

A. Be Assertive



Assertiveness is key to good communication. Assertiveness means asking for what you want in a simple, direct way. When you are assertive you stand up for your rights and at the same time respect the rights of others. To be assertive you will need to find the balance between being overly pushy (aggressive) and not speaking up (passive).

Assertiveness means saying something like, "I would rather go to your office for the meeting," or, "I get annoyed when I have to track you down and can't reach you when I am ill because I get scared that I will get worse in the meantime." You can change how assertive you are depending on each situation and who you are.

When would you like to be more assertive?

Assertiveness Tips:



Listen

Check that you understood what the other person said by repeating it in your own words.

What I heard you say is..."

Make "I" statements

"I feel angry when you telephone me in the morning because I am too busy then to have a proper conversation with you."

Avoid "you" statements

"You make me angry because you call me when I'm too busy to have a proper conversation with you."

Tell people what you would like

"Next time, please call me after 1:00."

Be aware of what your body language says

Face the person you are speaking to and speak clearly and loud enough to be heard.

Connect feelings with behaviours

"I am frustrated because you did not remember what I told you."

Be respectful of other people

Avoid blaming and finger pointing or phrases with "always" or "never"

"You never listen!" Or "I always have to..."

Notice

Learn to spot when people avoid your assertive requests so you can adjust your strategy.

Notes

Unhelpful Ways of Speaking Up

Being assertive does not involve being submissive, aggressive, passive-aggressive or manipulative. These ways of speaking up (in others or yourself) are not helpful.



Passive or Submissive: Giving in to someone else's needs or wants while not valuing your rights or needs. Passive people are too nice and want to please other people so much they do not get their own needs met.



Aggressive: Talking in an openly demanding, loud, or threatening way. Aggressive people are not usually sensitive to the rights and feelings of other people. This way of speaking up often creates conflict.



Passive-Aggressive: Angry or aggressive feelings are hidden but come out in behaviours like ignoring or not responding to requests. People who act this way don't get their needs met because other people don't understand what their needs are.



Manipulative: Trying to get needs met by making others feel guilty or sorry. This style of interacting only works as long as the other person does not realize they are being manipulated.

B. Practice Taking the Positive Path



Stay Positive

Take a moment to think about how you are feeling. If you have negative thoughts, shift them to be positive. For example, change "He never listens to me" to "Although he hasn't listened to me in the past, I will change the way I approach him and then he will listen to me."



Case Study #1.

Mary is a 28 year old single mother of 3 children. She has had hepatitis C for 7 years. Mary went to see Dr. Allen to get his opinion about what she should do because Sally, her welfare case worker is encouraging her to go back to school full-time. Mary doesn't think she can cope with full-time school. She is tired all the time, has trouble concentrating and has to write down things or she forgets. She thinks her problems are from the chronic hepatitis infection. Dr. Allen says, "Yes, you have hepatitis C but don't worry about it. Young mothers are always tired. It's not the hepatitis. There is no reason you can't go back to school. It would do you good to get out of the house."

1. Did Dr. Allen help Mary with her problem?
2. What should she ask for in her next meeting with her case worker?
3. How can she overcome the obstacles she faces?

Discuss the case studies in this book with others to learn how they would approach the problems and overcome barriers.



C. Learning Negotiating Styles

Negotiation is when you know what you want and you try to get another person to give it to you. Below are some styles of negotiating that are challenging to work with. Learn to recognize these styles.



Fighters or attackers: They seek to win. They may threaten, insult, withhold information, and stretch the facts.



Appeasers or converters: They will try to make you happy by offering to do some things for you or by convincing you to see things their way.



Those who flee or dither: They switch between attacking, hiding, delaying and trying to win you over. They do not take a stand on things. For the most part, they would probably not like to be there.



Analysts: They try to ignore feelings and only look at the facts to solve the problem - whether or not it meets peoples' needs. They rely on facts not on emotions.

One-way thinkers: They have already made up their minds and won't change. Often they are honest and well-meaning but are not flexible.

D. A Guide to Negotiating



1. Ask the person why he or she said no to your request. (Write the reason down.)
2. Ask the person what advice he or she could give you to get the solution you want.
3. Ask the person to recommend another option or solution.
4. If this option is okay with you, ask for details of when it will happen. (Write the important details down.)
5. If the option is not okay with you, tell the person your own ideas. If the other person disagrees with your ideas, return to #1.
6. Know your BATNA, or Best Alternative To a Negotiated Agreement. Can you walk away if you don't get this? What other choices do you have? What are the pros and cons of each choice? Also consider what the other person's BATNA might be.
7. Ask yourself what are your best and worst case scenarios. Aim for the area in between during negotiations. Don't drop below your worst, as you may feel resentful and angry later.
8. Stick to the problem, and to the facts of the situation. Do not attack the person's intelligence, competence, or sense of fairness.
9. If you find yourself becoming argumentative, angry, or withdrawn, ask to stop the conversation and come back another time when you are not upset. Say, "I am feeling that a bit of time may be helpful for me to reflect on what we have both said. When can we meet again to talk about this?"
10. Ask for a second opinion. (Write it down, including an expected date for it to occur.)
11. Keep a record of all your meetings and telephone calls, including the date, to whom you spoke, and what was said. Using a health diary will help you keep everything organized and all together.

*Adapted from the website Self-Advocacy Through Negotiation:
http://www.arcmi.org/self_adv_tips.htm*

REMEMBER

Negotiation is a process, not a one-time event.

Listen carefully. A person may be willing to meet you halfway or give you something that you need under certain circumstances. If you listen carefully to what he or she has to say, you may be able to detect what these circumstances are.

Don't give up because one person says no. Review your plan and determine if you need to change something. You may have to change your plan several times, but keep focusing on your goal!

Notes

Below is an example of how you might use the skills described in this workbook.

Problem: Linda is very weary. She had a liver transplant 3 months ago and is taking therapy for hepatitis C. Lately, Linda has had too many different home care nurses coming to help her. Just when a nurse knows about her tiredness, pain and depression, the nurse leaves and Linda has to find the strength to explain her needs all over again to a new nurse. This is very stressful.

Plan: Linda will call Betty, the Home Care boss and ask that only one or two nurses be assigned to her care by July 1.

Obstacle: Betty may not have the authority to assign the nurses.

Clearing Obstacles: Linda may have to go to Betty's boss. If Betty cannot help by July 1, Linda will call or meet with Wilma, Betty's boss to go over what is happening.

Take Notes: Linda will keep a list of the names of the nurses who cared for her since her home care began. She will also note any errors or problems with her care in her health notebook.

Who Can Help: Linda's doctor who is worried about her deepening depression. The doctor told her that reducing her stress was important for her recovery and for staying on the drug therapy.

What Linda wants: Linda wants Betty to assign only one or two nurses to come to her house.

Notes

E. Knowing Your Rights

The rights listed below belong to you. Keep them in mind when you negotiate for services or resources.



Personal Bill of Rights

1. I have the right to ask for what I want.
2. I have the right to refuse services or resources that don't meet my needs.
3. I have the right to change my mind.
4. I have the right to express my feelings, whether positive or negative.
5. I have the right to determine my priorities.
6. I have the right to advocate for myself.
7. I have the right to feel scared or afraid.
8. I have the right not to justify my decisions.
9. I have the right to be treated with dignity and respect.
10. I have the right to play and be frivolous.
11. I have the right to experience honesty from others.
12. I have the right to take breaks from advocating and ask for help.
13. I have the right to feel angry.
14. I have the right to say that I am not ready or am unable to meet the demands and expectations of others.
15. I have the right to receive copies of anything I sign.
16. I have the right to see my medical records.

Adapted from the Mental Health and Aging Advocacy Project:
www.mhaging.org/help/bill-of-rights.html

You have a right to be involved with health and social service workers in planning your care. Only you can decide how much information you want from them and what role you want to play in your care. Some people like to know all the details, including what is expected to happen in the future: they usually like to be consulted in all decisions. Others prefer only to hear about the general picture: they get involved only when there are problems.

F. Finding the Best Person to Talk to

It's important to try and find the person who could help you with your health needs. You might have to ask around to find out who is the best person to meet with.

Here are some examples of issues you might face where health and social service workers are involved. See if you can match the person who could best help with each issue - you can choose more than one person.



Problem or Issue

1. Is there a special diet that will help me?
2. What are my blood test results?
3. Who do I talk to about getting a TV hooked up in the hospital?
4. I'm running out of sick time and my bills are piling up. Who should I talk to?
5. I am tired all the time. How can I get more energy?
6. Who could I talk to about feeling so depressed?
7. Why don't they wear gloves when they take my blood?
8. How long will I be in the hospital?
9. I have a lot of brain fog and I need help making financial decisions. Who should I talk to?

People

- A. Nurse
- B. Doctor
- C. Physiotherapist or Occupational Therapist
- D. Lab Technician
- E. Dietician
- F. Social Worker
- G. Psychologist
- H. Unit Clerk

(See bottom of next page for answers.)



Case Study #2.

Jason is a 46 year old married man with 2 teenage boys. He regularly donates blood. Recently, after giving blood he received a letter telling him he could not give blood anymore and he should see his doctor. He went to his doctor who said, "You can't give blood because you have hepatitis C. You are OK, go home, don't worry and come again to see me when you have a health problem." Jason asked if there is anything more he should know. The doctor said, "Go to the local Health Unit and get vaccinated for hepatitis A and B, " then left the room.

1. What is Jason's problem?
2. What should Jason do next?
3. What obstacles does he have?
4. How can he get around these obstacles?
5. What should he do if he doesn't get what he needs?

Answers to matching exercise from previous page:

- | | |
|----------------|----------------|
| 5. A, B, C & E | 1. A, B & E |
| 4. F | 2. A, B |
| 3. H | 3. H |
| 8. A & B | 4. F |
| 7. D, A & B | 5. A, B, C & E |
| 6. A, B, F & C | 6. A, B, F & C |
| 9. F, G, A & B | 7. D, A & B |



POWER

Part 3: Applying Skills from the Workbook

Overall Principles:

- Plan ahead
- Gather information about resources
- Write down your important issues and questions in advance
- Be clear about your requests
- Talk to the appropriate people
- Write letters or e-mail
- Make appointments, be on time
- Take notes
- Plan for the worst case scenario
- Negotiation is a process – "no" means try again

Ask Yourself

Would it be better to phone or write rather than meet someone in person?

Should you approach a person alone or in the presence of others?

Where should you meet? In this person's office or in another location? In the morning or the afternoon?

B. Getting Ready for a Meeting

Ask for a written meeting plan (agenda) before the meeting. Once you have seen the plan, ask the person in charge of the meeting to add your questions or concerns to the plan. If there is no agenda, write out your concerns to take to the meeting.



A Record of the Meeting is Helpful

Tell the group you are meeting with that you would like to bring another person with you to the meeting or tape record the meeting. These steps will help you feel supported and remember what was said. Having someone with you will also help you stay calm and remember your goal. If you have someone attend the meeting for you, ask to have a copy of the meeting minutes.

C. Taking Part in a Meeting



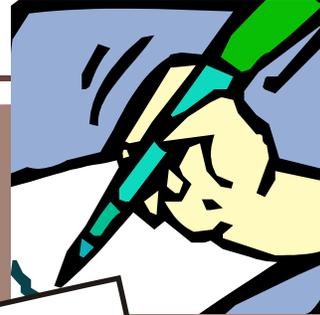
1. Practice what you'll say before the meeting and think about the words you'll use to help you get your point across.
2. Keep your comments short and to the point. Begin by noting something positive about the person or organization and thank everyone for coming. Start with the strongest point of your argument. Use positive words.
3. Relax. If others get angry or annoyed, you will do better if you stay calm.
4. Don't be tempted to fill in silences that happen.
5. Turn off your inner voice and focus on what is being said during the meeting.
6. Be honest, respectful and honour your promises. If you keep your promises, others will see you as trustworthy. You will be able to build a relationship that will help you get what you need over the long term.

Write down a few things that might be difficult for you in a meeting.

Think about how you might get around these obstacles.

D. Writing Letters

You might choose to write a letter to speak up for yourself. Keep the letter short, clear and to the point, as in the example below. Outline your problem and what you would like done about it.



34 Blossom Lane
Blarney, BC V7E 4B4
Phone: 604-575-2222

Ms Fredricka Pullet
Patient Services Manager
4C Bellamy Hospital
2203 Woodward Crescent
Blarney, BC V7E 3B9

Dear Ms. Pullet,

Following our telephone conversation of February 4, 2001 I wish to file the following complaints with your office. They are as follows:

1. On January 29, I was released from the hospital without enough time to schedule home care for the next day.
2. Because there was no home care available, my husband had to take a day off work to look after me, threatening our income and his employment.

I would like your office to make a policy that patients are not discharged until home care is in place.

Please let me know in writing how you plan to resolve this problem.

Signed:

Date:



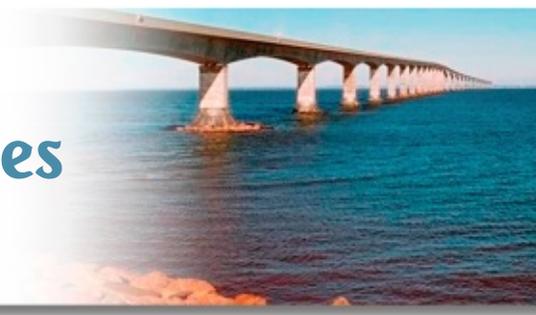
Case Study #3.

Allison has just completed a difficult year of drug therapy and her doctor says she is cured. However, Allison continues to feel extremely tired, has difficulty cooking nutritious meals and has periods of what she describes as brain fog. She doesn't feel that she is ready to return to work. Her disability insurance has been cut off because the terms of the insurance policy state that there will be no further coverage when treatment results in a cure.

1. What is Allison's problem?
2. What should her goal be?
3. Whom should she involve?
4. What are her obstacles?
5. How can she get around these obstacles?
6. What should Allison do if the insurance adjuster denies her application for return of her coverage?

Discuss the case studies in this book with others to learn how they would approach the problems and overcome barriers.





Internet Resources

BC Hepatitis Services Advocacy Resources

www.bccdc.ca/dis-cond/a-z/_h/Hepatitis-/overview/SpeakingUp.htm

Self Advocacy Resources:

Being an Effective Self-Advocate

www.mentalhelp.net/poc/view_doc.php?type=doc&id=4784&cn=74

First Nations Health and You

www.fnhc.ca/pdf/fnhc-health-and-you.pdf

Managing Your Own Health Care

www.mainstream-mag.com/health.html

Negotiation Styles in Mediation

www.adrr.com/adr1/essayb.ht

Patient's Bill of Rights

www.mhaging.org/help/bill-of-rights.html

Self-Advocacy Through Negotiation

www.arcmi.org/self_adv_tips.htm

Stigma & Hepatitis C

www.bccdc.ca/dis-cond/a-z/_h/Hepatitis /educmat/StigmaHepatitisC.htm

The Abbotsford Self Advocacy Group

www.selfadvocatenet.com

Your Rights:

Canadian Charter of Rights and Freedoms

www.laws.justice.gc.ca/en/charter/1.html

Canadian Human Rights Commission

www.chrc-ccdp.ca/default-en.asp

Hepatitis C in the Workplace, Canadian Hepatitis C Information Centre

www.pubs.cpha.ca/PDF/P35/23079e.pdf

Provincial and Territorial Human Rights Agencies

www.chrc-ccdp.ca/links/default-en.asp

UN Declaration on the Rights of Indigenous Peoples

www.un.org/esa/socdev/unpfii/en/drip.html

Living with Hepatitis C:

AIDS Society of Kamloops (ASK) (BC Interior)

www.askwellness.ca

All Nations Hope AIDS Network (Saskatchewan)

www.allnationshope.ca **Canadian Aboriginal AIDS Network (CAAN)**

www.caan.ca

Blood Ties Four Directions Centre (Yukon)

www.bloodties.ca

Canadian AIDS Treatment Information Exchange (CATIE), Hepatitis C website

www.hepcinfo.ca

Canadian Inuit HIV/AIDS Network (CIHAN)

www.pauktuutit.ca/hiv/main.html

Centre d'action communautaire auprès des toxicomanes utilisateurs de seringues (CACTUS) (Quebec)

www.cactusmontreal.org

First Nations, Inuit, and Aboriginal Health, Health Canada

www.hc-sc.gc.ca/fniah-spnia

Healing Our Spirit BC Aboriginal HIV/AIDS Society (BC)

www.healingourspirit.org

Healthy Living with Hepatitis C, Canadian Liver Foundation

liver.ca/files/Brochures/Eng_Hep_C_WEB.pdf

Hep'd Up On Life Native Council of PEI

www.upei.ca/si/files/si/2008_Poster4_PamONeill_EN.pdf

Living Positive Resource Centre (BC)

livingpositive.ca/

Métis Nation British Columbia

www.mnbc.ca/health/index.asp

National Aboriginal Health Organization (NAHO)

www.naho.ca

Ontario Aboriginal Health Advocacy Initiative (OAHA)

www.ofifc.org/oahai

Ontario Aboriginal HIV/AIDS Strategy

www.oahas.org

Red Road HIV/AIDS Network (BC)

www.red-road.org