
Speaking Up for Hepatitis Care and Support

A Skills Building Workbook



SPEAKING UP for HEPATITIS CARE and SUPPORT

**A Skills Building
Workbook**





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All characters depicted in this workbook are fictitious and any resemblance they may have to any person living or dead is purely coincidental.

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Speaking up for Hepatitis Care and Support: A Skills Building Workbook

Introduction

Living with hepatitis and getting the necessary services may require negotiation with many professionals and organizations. This workbook contains tips on how to prepare yourself so that you can speak on your own behalf and negotiate for what you need.

Who is this book 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 speak up for what they need

What's in the book?

The Speaking up for Hepatitis Care and Support self-learning workbook provides a step-by-step guide for learning and practicing advocacy skills at home at your own pace.

The workbook has exercises to help you plan, practice, and gain the confidence 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.

REMEMBER

You are the only person who knows what your needs are.
You are the expert about your situation.

This workbook is available online:

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



Getting Started

A. What is Self-Advocacy?

Self-advocacy is:

- 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

**Chances are advocacy is something you have done before.
Have you ever:**

- Informed a cashier that the price was wrong?
- Asked for help to understand something better?
- Disputed a grade with a teacher for yourself or your child?
- Asked to have the rules changed?
- Negotiated with a landlord or an employer?

Think about the times when you have spoken up for yourself.
Describe a time when you advocated for yourself.

Circle the words below that best describe the knowledge, skills, resources and attitudes you used when you advocated.

Knowledge of:

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

Resources:

- Family
- Elders
- Social support network (e.g. friends, relatives and support groups)
- Spiritual Communities
- Access to internet and other information sources (e.g. public health services)

Skills:

- Listening
- Communication
- Resourcefulness
- Assertiveness
- Self-care, such as taking holidays as needed

Attitudes:

- Cooperation
- Flexibility
- Patience
- Positive thinking
- Persistence

Rewards of Advocacy

- Being able to ask for and get what you need
- Saving your time and energy
- Learning new ways to improve your people skills
- Learning the difference between what you can and cannot change

B. Things to Think About

Speaking up for yourself can be difficult and tiring. Three things to think about before you advocate for yourself are:

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

1. Positive Thinking

- Write down a time you felt good about asking for what you needed

2. Stress and Taking Breaks

- Describe a time when you put off asking for something you needed

3. Getting Help

- Describe a situation when you asked or allowed someone to help you ask for what you needed



Stress and Taking Breaks

To manage your chronic illness, you may need help from health and social service providers. You may find that 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 you. For instance, you could lose your temper and blow up at someone. This could hurt your relationship with that person.

Anger that builds up over time might also drain your energy. This is why it is wise to plan to take breaks and re-energize yourself.



You may 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.
- You cannot sleep.

REMEMBER

If you've been feeling frustrated, angry or out of energy lately you may need to take a break.



Getting Help to Advocate

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.
What did you learn from that experience?



Learning How to Overcome Obstacles

It is important to learn about common obstacles to effective advocacy so you can work around them.

Check the obstacles that apply to your situation

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



Have you experienced any other obstacles?

A. Try Being Assertive



Assertiveness is a way of thinking and behaving. Assertiveness means asking for what you want in a simple, direct way. This is key to effective communication. 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 can be as simple as saying something such as, “I would rather go to your office for the meeting,” or as forceful as, “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 the situation and the person you are talking to.

Are there times when you would 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 your body language

Look toward the person you are speaking to and talk 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.

Notes

Be Aware of Unhelpful Ways of Speaking Up

Learn how to spot these ways of speaking up (in others or even in yourself) and why they 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 that 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.

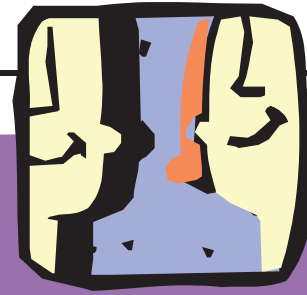


- **Passive-Aggressive:** Angry or aggressive feelings are hidden but come out in behaviours like ignoring or not responding to requests. People who act this way don't get their needs met because other people don't understand what their needs are.



- **Manipulative:** Trying to get needs met by making others feel guilty or sorry for you. 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



Try to Stay Positive

Take a moment to think and take stock of how you are feeling. If you have negative thoughts try to 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. What obstacles does she face?
4. How can she overcome these obstacles?

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, when you can.)
2. Ask the person what advice he or she could give you to achieve 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, when you can.)
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, and 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

Listen carefully. A person may be willing to compromise 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! Negotiation is a process, not a one-time event.

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



Always try to deal directly with the person who is responsible for solving the problem. You will get answers to your questions and quicker help for your problem than if you meet with people who don't have the ability to make changes or who don't have the right information. 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	People
1. Is there a special diet that will help me?	
2. What are my blood test results?	A. Nurse
3. Who do I talk to about getting a TV hooked up in the hospital?	B. Doctor
4. I'm running out of sick time and my bills are piling up. Who should I talk to?	C. Physiotherapist or Occupational Therapist
5. I am tired all the time. How can I get more energy?	D. Lab Technician
6. Who could I talk to about feeling so depressed?	E. Dietician
7. Why don't they wear gloves when they take my blood?	F. Social Worker
8. How long will I be in the hospital?	G. Psychologist
9. I have a lot of brain fog and I need help making financial decisions. Who should I talk to?	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 |
| 2. A, B | 4. F |
| 1. A, B & E | 5. A, B, C & E |
| 6. A, B, F & G | |
| 7. D, A & B | |
| 8. A & B | |
| 9. F, G, A & B | |



Applying Skills from the Workbook

A. Preparing to Speak Up

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.

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. Try to 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. Try to 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?

Try discussing 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

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

Advocacy Resources:

Being an Effective Self-Advocate

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

Stigma & Hepatitis C

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

Managing Your Own Health Care

<http://www.mainstream-mag.com/health.html>

Mental Health/Aging Advocacy Project

<http://www.mhaging.org/help/bill-of-rights.html>

Negotiation Styles in Mediation

<http://adrr.com/adr1/essayb.htm>

Self-Advocacy:

Self-Advocacy Through Negotiation

http://www.arcmi.org/self_adv_tips.htm

The Abbotsford Self Advocacy Group

<http://www.selfadvocatenet.com>

Your Rights:

Hepatitis C in the Workplace, Canadian Hepatitis C Information Centre

<http://pubs.cpha.ca/PDF/P35/23079e.pdf>

Canadian Charter of Rights and Freedoms

<http://laws.justice.gc.ca/en/charter/1.html>

Canadian Human Rights Commission

<http://www.chrc-ccdp.ca/default-en.asp>

Provincial and Territorial Human Rights Agencies

<http://www.chrc-ccdp.ca/links/default-en.asp>

Living with Hepatitis C:

Healthy Living with Hepatitis C, Canadian Liver Foundation

http://liver.ca/files/Brochures/Eng_Hep_C_WEB.pdf

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

<http://www.hepcinfo.ca/>

Hepatitis Outreach Society for Atlantic Canada

<http://www.hepatitisoutreachsociety.com/>

Hepatitis C Council of British Columbia

<http://www.bchepcouncil.ca>

