
ADVOCACY for HEPATITIS CARE and SUPPORT

**BASIC ADVOCACY SKILLS
Workshop Participant's Handbook**



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Workshop Leader Contact Information:

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Telephone: _____

E-mail: _____



Advocacy for Hepatitis Care and Support A Workshop Kit for Basic Advocacy Skills Development

INTRODUCTION

Advocacy skills have become more important as health and social services have become more complex. Living with hepatitis and getting the necessary services may require negotiation with many professionals and organizations. In talking with many people infected with and affected by hepatitis, we learned they had developed their advocacy skills mainly through painfully prolonged trial and error. They adamantly believed and recommended that people should be taught these skills. It is through their efforts and the desire to reduce the frustrations and stresses of managing chronic hepatitis that this project came to life.

The development of the Workshop Kit for Basic Advocacy Skills is part of an ongoing effort by the staff at BC Hepatitis Services to collaborate with the many hepatitis stakeholders to develop and provide programs that will assist people infected with and affected by hepatitis to not only manage but ultimately to prevent this infectious disease.

Purpose of the workshop:

The Advocacy for Hepatitis Care and Support Workshop Kit provides a step-by-step guide for learning and practicing advocacy skills. The workshop will provide a safe place for participants to practice talking openly about what they need. Through practice participants can gain the confidence needed to communicate effectively with health and social service professionals. Asking for things in a way that doesn't turn others off is more likely to result in getting the desired information, services and resources.

The kit includes a detailed handbook and slide presentation for the workshop leader and a personal workbook for workshop participants. The workshop may be

provided in one day or broken into smaller segments that are provided over a longer period of time.



Acknowledgements:

The development of the workshop kit for basic advocacy was led by Gail Butt, Associate Director, BC Hepatitis Services and Barbara Paterson, Professor, University of British Columbia, School of Nursing with assistance from Liza McGuinness, Research Program Manager, and Warren Hill, Research Analyst, BC Hepatitis Services. Funding for the project was provided by Health Canada, Hepatitis C Community-Based Support Program and BC Hepatitis Services, a Division of the BC Centre for Disease Control. A special thank you to the Manitoba Brain Injury Association who generously granted us permission to modify the advocacy training program they developed in earlier work with Barbara Paterson. We would also like to acknowledge the time and contributions made by the many people who assisted us with gathering and refining the information contained in the kit, the people infected with and affected by hepatitis, service providers, advocates and nurse experts from across Canada.

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

For further information contact:

BC Hepatitis Services, BC Centre for Disease Control, 655 West 12th Avenue, Vancouver, BC, V5Z 4R4
or call 1 888 660 1676

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BASIC ADVOCACY

1 Day Workshop Agenda:

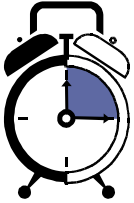
Time	Activity
9:00 A.M.	Introductions
9:30 A.M.	Part 1: General Principles of Effective Advocacy
10:30 A.M.	Nutrition Break
10:45 A.M.	Part 2: Overcoming Barriers in Advocacy
12:00 Noon	Lunch
12:45 P.M.	Recap
1:00 P.M.	Part 3: Applying Advocacy Skills
2:00 P.M.	Nutrition Break
2:30 P.M.	Case Study #3
3:00 P.M.	Wrap-up and Evaluation





General Principles of Effective Advocacy

A. Principles



Advocacy is:

When people support, speak, or act on their own behalf, or on behalf of someone who asks for assistance.

Not an adversarial approach, but an assertive and cooperative strategy.

A means to obtain information, services and resources, as well as the cooperation of health and social service professionals.

Notes

Attitudes:

Skills:

Resources:

Knowledge:

Notes

Notes area with a yellow background.

The Rewards of Advocacy:

Being able to influence other decision makers such as health and social service providers, and family members.

Conserving personal time and energy.

Learning new techniques to improve your people skills.

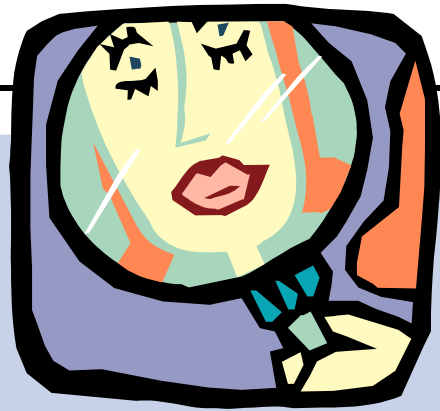
Knowing the difference between what you can and cannot change.



B. Knowing Yourself



Effective advocacy requires you to have three kinds of self-knowledge: how positive you are, when you need to take a break, and when you should not advocate at all.



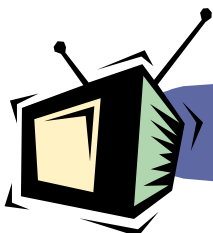
1. Positive Responses

Give three situations that illustrate a positive response.

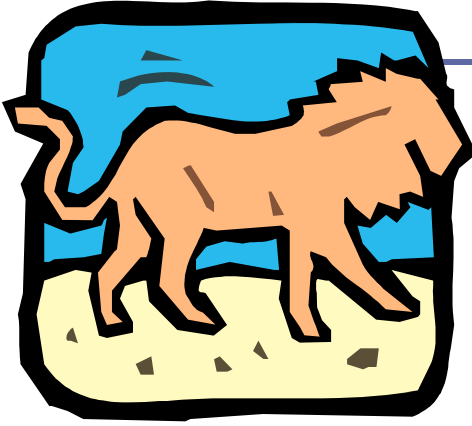
1. _____

2. _____

3. _____



2. Stress and Breaks



Coping with a chronic illness and communicating with health and social service professionals over time is stressful. Often, members of your care team may only see their own small roles. This can possibly lead to frustrating gaps, fragmentation, and unnecessary repetition in care. A natural response to these concerns is anger. Anger is a productive response if it energizes you to get something done or to advocate for your needs.

Anger that builds up over time, however, can produce all sorts of problems for your advocacy efforts. For instance, you could blow up at someone, really hurting your relationship with that person. This buildup is why we stress the need to take a break and re-energize yourself.



You need to take a break if:

You are tired all the time, and sleep does not refresh you.

You cannot sleep.

You find yourself thinking badly of, and criticizing, everyone around you.

You cannot eat, or you eat too much.

You feel that no one understands you, or appreciates the stress you are under.

You have little or no tolerance for frustrating situations.

You feel close to tears most of the time.

REMEMBER

Plan ahead and try to take a break before these symptoms appear.

3. Times Not to Advocate:

When you are very tired, or feeling overwhelmed. At these times, others can take on your advocacy role for you.

When the terms or rules of the health or social service organization are not

delegated to the person you are dealing with. We'll look closer at observing chains of command later in the workshop.

Additional Notes



Overcoming Barriers in Advocacy



It is important to know the common obstacles to effective advocacy so that you can work to overcome them.

These barriers are:

- Being unprepared
- Fearing retaliation, or worrying that others will think you are ridiculous
- Being aggressive
- Being unaware of your rights
- Having unrealistic expectations
- Being unwilling to listen to other people, or to explore alternate solutions
- Feeling inferior or less educated than others
- Having English as your second language

Notes

Ways to eliminate or reduce these barriers

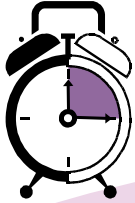
A. Being Assertive, Not Aggressive

Assertiveness is a way of thinking and behaving. It is a key to effective communication. Assertive behavior involves asking for what you want (or saying no) in a simple, direct fashion that does not negate,

attack, or manipulate anyone else. Assertive people stand up for their rights while respecting the rights of others, striking a balance between being aggressive and being passive.

Being assertive is:

- Knowing your limitations but focusing on your strengths
- Being your real self
- Labelling your feelings
- Identifying and breaking down your own defences



When to be Assertive

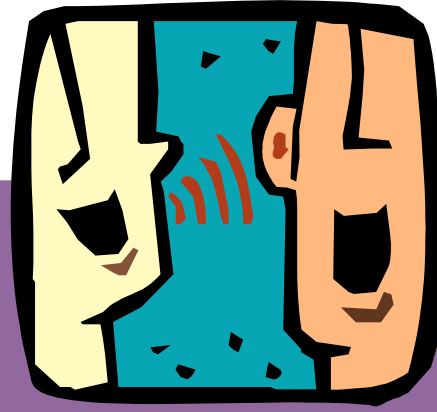
Becoming assertive requires you to know what you want. Think of the situations in which you would like to be more assertive, and make a written list of these situations.

A large, light purple rounded rectangular area containing ten horizontal lines for writing.

Assertiveness can be as simple as saying something such as, "I would rather go to your office for the meeting," or as confrontational 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." The effective level of assertiveness depends on the nature of the situation and the person with whom you are talking.

Assertiveness training involves such specific skills as:



Listening. Clarify by repeating what you have just heard for confirmation (“What I heard you say is ...”).

Being aware of your body language. Make eye contact, maintain erect posture, and speak clearly and audibly.

Connecting feelings with behaviours (“I am frustrated because you did not remember what I told you”).

Expressing your feelings. 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”) rather than “you” statements (“You make me angry

because you call me when I’m too busy to have a proper conversation with you”).

Avoiding sarcasm, character assassination, or absolutes (“You never listen” or “I always have to —”).

Giving alternate behaviours (“Next time, you could call me after 1:00”).

Learning to say no.

Learning to avoid manipulation (for example, the “broken record” technique).

Learning to see how others evade your assertive requests (such as laughing them off).

Notes

Be Aware of the Following Unproductive Advocacy Styles:

It will help if you are able to identify these typical ways of communicating needs when you see them (whether in others or even in

yourself), and also to understand why they are not productive means of getting needs met.



Passive or Submissive: Yielding to someone else's preferences while discounting your rights and needs. Passive people are overly nice and interested in pleasing others to the detriment of their own needs.



Aggressive: Communicating in an openly demanding, forceful, or hostile way. Aggressive people tend to be insensitive to the rights and feelings of others; this style of interacting often creates needless conflict.



Passive-Aggressive: Expressing angry, aggressive feelings in a hidden fashion through passive resistance. Passive-aggressive people seldom get their needs met because others often don't understand what their needs are.

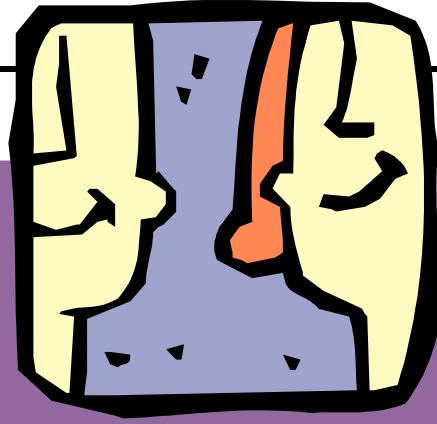


Manipulative: Trying to have needs met by making others feel guilty or sorry for you. This style of interacting only works as long as the other person does not realize they are being manipulated.

B. Controlling Your Feelings

Be Positive

Cultivate a generally positive opinion of health and social service professionals. Remind yourself that these people want to help you, not stand in your way. If you can come to see them as helpers and not as barriers, you might be surprised at how people's language and approach will change for the better.



Inventory Your Feelings

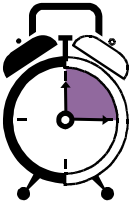
Do an inventory of your thoughts and feelings before you act as an advocate, as some of them can handicap your efforts by detracting from your confidence. Replace negative

thoughts with more positive ones. For example, rephrase "He will never listen to me. He never does" to "Although he hasn't listened to me in the past, I will change the way I approach him and he will listen to me then."



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 could cope with because her welfare case worker is encouraging her to go back to school full time. Mary is tired all the time, has trouble concentrating and has to write things down or she forgets. She thinks her symptoms 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. State Mary's problem in one sentence.
2. What should her goal be in her next interaction with Dr. Allen?
3. What barriers exist to her advocacy efforts and how can she eliminate or reduce them?
4. What strategies or resources could she use to make this advocacy effort effective?
5. What should she do if Dr. Allen again refuses to give her this information during their next conversation?

C. Understanding Negotiating Styles

Many styles of negotiation are not particularly effective in advocacy. Knowing about these unproductive styles will give you clues as to how to negotiate with a number of different

people. Besides, these descriptions may reveal something about the way you yourself have negotiated in the past.



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



Appeasers or converters: They seek to make you happy by appeasing you or converting you to their way of seeing things. They value a fair agreement between both sides and a positive relationship between all people involved.



Those who flee or dither: Their goal is sheer survival. They fluctuate between attacking, hiding and delaying, and appeasing. They are often unwilling to take a stand. Overall, they would probably like not to be there.



Analysts: Their goal is to understand and to solve the problem whether it meets the needs of the people involved or not. They rely on objective facts, not on emotional appeal.

Truth seekers: They are committed to the “truth”, often despite evidence to the contrary. They are often honest and sincere but inflexible and intense.

The secret in negotiating with anyone who has any of these styles is to separate the style from the process, reducing the negotiation to a discussion of goals and solutions.

REMEMBER

Be Willing To Listen

A person may be willing to compromise or give you something that you need under certain circumstances if you can make what they have to offer match what you need. If you listen carefully to what he or she has to say, you may be able to detect what these circumstances are. Don't assume you already know a person's reaction to what you will propose. As part of your listening, ask them for clarification: "It would help me if you could put in a nutshell your thoughts on what I've just said?"

Notes

D. Negotiating Methodically



Here is a process to negotiate a solution adapted from the Website Self-Advocacy Through Negotiation and Negotiation Tips:

http://www.arcmi.org/self-advocacy_through_nogatiation.htm

Ask the person why he or she has said no to your request, and ask him or her to write the reason down for you on paper.

Ask the person what advice he or she would give you to achieve the solution you want.

Ask the person what solution he or she would recommend as an alternative.

If this alternative is acceptable, ask him or her when you can expect it to happen and ask him or her to write the solution and date it is expected to happen down for you.

If you disagree with the solution, tell the person your own ideas. If the other person disagrees with your ideas, return to #1.

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.

Ask 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 will later feel resentful and angry.

Stick to the problem, and to the facts of the situation. Do not attack the person's intelligence, competence, or sense of fairness.

If you find yourself becoming argumentative, angry, or withdrawn, leave 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?"

Ask for a second opinion. If the other person agrees with the solution, ask him or her to write it down, including an expected date for it to occur.

Document all your meetings and telephone calls, including the date, to whom you spoke, and what was said.

REMEMBER

Don't give up because one person says no. Review your documents and determine if you need to change something in your plan. You may have to change your plan several times, but keep focussing on your goal! Negotiation is a process, not a one-time event.

Notes

This example demonstrates how many of the negotiating skills in this module can work in a given situation:

Problem:	Linda had a liver transplant 3 months ago and is on drug therapy for Hepatitis C. Lately Linda has had too much turnover of home care nurses. Just when a nurse knows about her fatigue, myalgia, and deepening depression, he or she leaves, and Linda has to find the strength to start all over again.
Plan:	Linda will call Betty McCall, the Home Care Supervisor, and request more continuity in the nurses by July 1.
Barriers:	Betty may not have the authority to change the scheduling.
Strategy:	Linda may have to go to her immediate superior. If Betty cannot resolve the situation by July 1, Linda will call or meet with Wilma Ready, her immediate superior, to review the situation.
Documentation:	Any errors or omissions in Linda's care every time a nurse was new to her care; all the names of the nurses who had cared for Linda since she began home care.
Who Can Help:	Linda's physician who has expressed concern about her worsening depression and lack of energy, the specialist who commented that maintaining quality of life was important in helping people recover and take hepatitis drug therapy.
Linda's position:	Linda expects Betty to assign one nurse to her care with only holiday or sick time relief, and to assist with a quick orientation of relief staff, perhaps providing some additional clinical information to staff about liver transplantation, hepatitis and the effects of drug therapy.

E. Knowing Your Rights

We have adapted this personal bill of rights from one identified by the National Mental Health Consumers Self-Help Clearinghouse (see the internet links section for their website address). These rights belong to you. Be aware of them before you enter into any negotiations for better or more services and resources.



You have a right to be involved with health and social service professionals in your care plan. However, it is useful to decide how much information you want from them and what role you yourself want to play in your care. Some people like to know all the details,

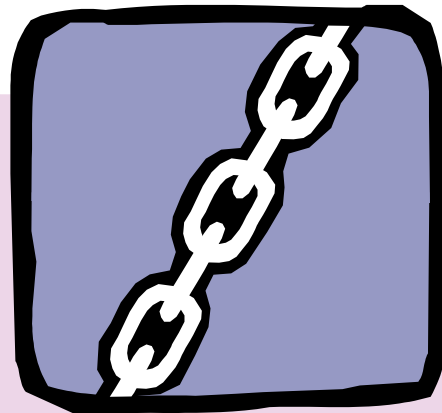
including what is expected to happen in the future: they usually like to be consulted in all decisions. Others prefer only to hear about the general picture: they get involved only when there are problems.

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.

F. Observing Chains of Command

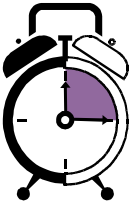
Always try to advocate directly with the person who has direct responsibility for a given problem or issue. This will help you to get questions answered and to arrive at solutions earlier than if you meet with several people without proper authority in the matters at hand. You may have to do a little homework beforehand, by looking at organizational charts and seeing who reports to whom for what.





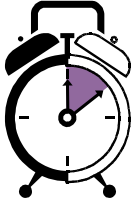
Case Study #2.

Jason is a 46 year old married man with 2 teenage boys. He regularly donates blood. Recently, after giving blood he received a registered 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. Go home, don't worry and come again to see me when you have a medical 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. State Jason's problem in one sentence.
2. What should Jason do next?
3. What barriers exist to his advocacy efforts and how can he eliminate or reduce them?
4. What strategies or resources could he use to advocate effectively with his doctor?
5. What should he do if his attempts are unsuccessful?

Notes



Here are some common examples of issues involving health or social service professionals. See how accurate you are in matching the person best suited to resolving each problem.

Problem or Issue	Answers	People
1. How long will I be in the hospital?		
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. Is there a special diet that will help me?		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

REMEMBER

As you can see here, there is often more than one person you can speak to on a given issue.



Applying Advocacy Skills

3

A. Preparing for Advocacy Situations

Overall Principles:

- Plan ahead
- Research all relevant literature about available 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
- Plan for the worst case scenario
- Remember that you are a valuable member of the team

Notes

B. Before a Meeting

Request a written agenda before any meeting. Once you have seen the agenda, contact the person in charge of the meeting to add your concerns or questions to it.



Inform the group with which you are meeting that you would like to bring a tape recorder or another person with you when you are advocating for yourself. These steps will help you to feel supported, to recall what was said, and to remain calm and focussed on your goal. They will also provide a record that you can refer to later on. Note, however, that some groups may be threatened by an audiotaped session.

Timing is critical. Ask yourself if it would be better to write rather than to meet someone in person. Should you approach a person alone or in the presence of others? In this person's office or in another location? In the morning or the afternoon? Most health and social service professionals have specific times set aside for meetings.

Notes

C. During a Meeting

Keep meetings short and to the point. Begin with a generally positive statement about the person or organization. Begin with the strongest point of your argument. Avoid using negative language: rehearse what you might say beforehand and consider your words before speaking. Be aware of your body language. While others may get angry or annoyed, you will benefit by keeping calm.



Say what you have to say and then stop. Don't be tempted to fill in the silences that happen in conversation, as they can work to your advantage by giving you time to think about other people's statements and to prepare your response. For that matter, turn off your inner voice and force yourself to concentrate on what other people are saying and how they are saying it. Most people carry on an inner dialogue with themselves as they listen to others. They are usually planning how they will respond as the other

talks, but they don't necessarily hear everything the person says.

Be trustworthy, tell the truth, keep confidences, and honour your promises. Without other peoples' trust, negotiation is difficult, if not impossible. If you lie or break promises, others will see you as manipulative and conniving, not as trustworthy. You may get what you want once, but you will have a difficult relationship with these people afterwards.

Notes

D. Writing Letters

These same strategies also apply in writing effective letters. If you are writing, follow this guideline, making the letter factual and clear.



To: 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 sufficient notice to schedule home care for the next day.
2. Because there was no home care available, my husband had to miss a day of work to look after me, jeopardizing our income and his employment.

My desired resolution is:

1. Your office will institute a policy that patients such as me are not to be discharged until home care arrangements are in place.
2. A letter will be sent to my husband's boss (his name and address are attached) to explain why he was unable to attend work that day.

I request that you acknowledge to me in writing your willingness to resolve the issue as I have indicated above.

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

Signed:

Date:



Case Study #3.



She 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. State Allison's problem in one sentence.
2. What should her goal be?
3. Whom should she involve?
4. What barriers exist to her advocacy efforts and how can she eliminate or reduce them?
5. What strategies or resources could she use to make this advocacy effort effective?
6. What should she do if the insurance adjuster denies Allison's application for return of her coverage? What information would you include in a letter?

Notes



Internet Links and References

Links

Hepatitis Resources:

BCCDC Hepatitis Diseases Reports.

<http://www.bccdc.org/content.php?item=34>

Vaccine Issues.

<http://www.bccdc.org/content.php?item=115>

Hepatitis Division.

<http://www.bccdc.org/division.php?=5>

Advocacy Resources:

Office for Children and Youth - Advocacy Information.

<http://www.gov.bc.ca/officeforchildrenandyouth/popt/advocacy.htm>

Anger and Aggressiveness.

<http://www.mentalhelp.net>

Assertiveness.

<http://www.uwlax.edu/SAC/Leadership/briefs/VirtLib/Assertiveness.html>

Creating Your Own Self-Advocacy Plan.

http://www.arcmi.org/creating_your_own_self-advocacy_plan.htm

Managing Your Own Health Care.

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

National Mental Health Consumers Self-Help Clearinghouse's Website.

<http://www.mhselfhelp.org>

Negotiation Styles in Mediation.

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

Negotiation Tips.

<http://www.bbraham.com/html/negotiation.html>

Self-Advocacy:

Robb, W. (1998). Four steps to self-advocacy.
<http://www.i5ive.com/article.cfm/669/6244>

Self-Advocacy Through Negotiation.
http://www.arcmi.org/self-advocacy_through_nogatiation.htm

The Abbotsford Self Advocacy Group.
[http:// www.selfadvocatenet.com](http://www.selfadvocatenet.com)

The Prince Rupert Self-Advocacy Group
<http://www.princerupertlibrary.ca/selfadvo/>

Systems Advocacy:

Minnesota AIDS Project.
<http://www.mnaidsproject.org>

Brain Injury Resource Center.
[http:// www.headinjury.com/advosystem.html](http://www.headinjury.com/advosystem.html)

The National Aids Treatment Advocacy Program (Hepatitis)
<http://www.natap.org/hepc.htm>

NHCAC-National Hepatitis C Advocacy Council (U.S.)
<http://www.hepcnetwork.org>

Frontline Hepatitis Awareness.
<http://www.frontline-hepatitis-awareness.com>



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