

One Foot Forward

A GIPA Training Toolkit

*Designed by and
for People Living
with HIV/AIDS*

MODULE

8

**CAN WE TALK? TREATMENT AND
OPTIONS, A NEW DIALOGUE**

CANADIAN
AIDS
SOCIETY



SOCIÉTÉ
CANADIENNE
DU SIDA



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janssen 

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Canadian AIDS Society
190 O'Connor St. Suite 800
Ottawa, ON K2P 2R3

Telephone : 613-230-3580
Toll Free : 1-800-499-1986
Fax : 613-563-4998

www.cdnaids.ca

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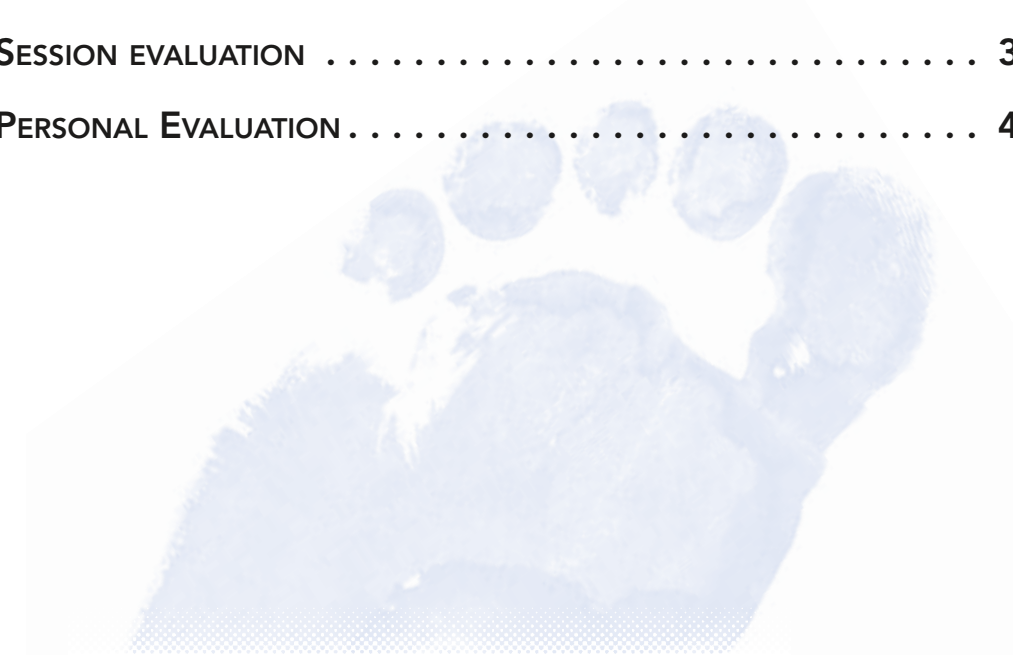
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INTRODUCTION

As people living with HIV/AIDS we are encouraged to maintain treatment regimens. Sometimes we have doctors and specialists that are sensitive to our thoughts and feelings about medications; other times we may encounter medical professionals that believe we don't understand medications enough to make informed decisions about our treatment and health care.

This module will allow you to explore ways you can become more actively involved in assessing your own interests, desires and needs regarding treatments and your personal journey through the Greater Involvement of People With AIDS Principles (GIPA).

The Canadian AIDS Society gratefully acknowledges the participation of Stephen Alexander, National Programs Team Leader and Michael Yoder, Project Consultant. Many thanks as well to Steven Lico and Judy Daniel for their guidance and for funding this module through Janssen.

SECTION ONE**GIPA 101 & THE PATIENT BILL OF RIGHTS**

The following are the GIPA Principles¹. These principles were adopted by the United Nations in 1994 at the Paris Summit. For more information about GIPA read the Module 2 in the One Foot Forward series. This and other modules can be found online at the Canadian AIDS Society website: www.cdnaids.ca.

- To support the greater involvement of people living with HIV and AIDS (PLWHIV/AIDS) through initiatives to strengthen the capacity and coordination of networks of PLWHIV/AIDS and Community Based Organizations (CBOs) stimulating the creation of a supportive political, legal and social environment;
- To involve PLWHIV/AIDS fully in decision making, formulation and implementation of public policies;
- To protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through legal and social environments;
- To make available necessary resources to better combat the pandemic including adequate support for PLWHIV/AIDS, NGOs and CBOs working with vulnerable and marginalized populations;
- To strengthen national and international mechanisms connected to human rights and ethics related to HIV/AIDS.
- To protect and promote human rights in our work.
- To apply public health principles within our work.

For the most part, GIPA Principles apply to organizations and are not applied in the “real world”. Nonetheless, you have the opportunity to become familiar with these principles and find ways to adapt them to your relationship with medical professionals, especially where it involves your treatment options.

For example, The second point about involving people living with HIV/AIDS fully in decision making and public policies could be interpreted as a way in which you can insist on having all the information you need to make decisions regarding your health care, including medications and treatments.

In the end, GIPA is “nothing about us without us.”

¹ Declaration of the Paris AIDS Summit, 1 December 1994.

People Living with HIV/AIDS Patient Bill of Rights²

As persons living with HIV/AIDS we exercise:

- the right to considerate and respectful care regardless of race, ethnicity, national origin, religion, age, sexual orientation, gender;
- the right to obtain current and understandable information concerning diagnosis, treatment and prognosis;
- the right to know the identity of all health care providers involved in our care, including those who are students, residents or trainees;
- the right to work with our health care provider in establishing our plan of care, including the refusal of a recommended treatment, without the fear of reprisal or discrimination;
- the right to privacy and confidentiality pertaining to our HIV sero-status and safety in all environments;
- the right to expect that all records and communications are treated as confidential except in the case of abuse;
- the right to review our own medical records and request copies of them;
- the right to expect that an advance directive (such as a living will, health care power of attorney) will be honoured by the medical staff;
- the right to expect an appropriate amount of time during our medical visit to discuss our concerns and questions;
- the right to expect that our health care providers will follow standard precautions;
- the right to voice our concerns, complaints and questions about care and expect a timely response;
- the right to expect that our health care providers will give the necessary health services to the best of their ability. If a transfer of care is recommended, we should be informed of the benefits and alternatives;
- the right to know the relationships our health care providers have with outside parties (such as insurers) that may have an impact on our treatment and care;
- the right to be told of realistic care alternatives when a current treatment is no longer working;

² Canadian AIDS Society. English: <http://www.cdnaids.ca/web/casmisc.nsf/cl/cas-gen-0171>
français : [http://www.cdnaids.ca/web/setup.nsf/ActiveFiles/MOU+-+Fre/\\$file/MOU%20-%20Fre.pdf](http://www.cdnaids.ca/web/setup.nsf/ActiveFiles/MOU+-+Fre/$file/MOU%20-%20Fre.pdf)

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- the right to expect reasonable assistance to overcome language (including limited English or French proficiency), cultural, physical or communication barriers; and
- the right to avoid lengthy delays in seeing medical providers; when delays occur, we should expect an explanation of why they occurred and, if appropriate, an apology.

All patients have rights, including those living with HIV/AIDS. As people living with HIV/AIDS we claim our right to universal access and choice to a full continuum of care which allows us to live and die with dignity and grace. Being aware of our rights and responsibilities ensures that we are better equipped to navigate the health care system.

As people living with HIV/AIDS we have rights and responsibilities. Simply requesting that medical professionals follow our lead is not the most effective. We have our part to play in our health care. The following is an agreement we can make with our health care providers that acknowledges we are in a partnership about our treatment, care and support.

PATIENTS AND HEALTH CARE PROVIDERS AGREEMENT³

Introduction

As people living with HIV/AIDS we have the right to full and equal health care, without prejudice and under all circumstances. This agreement is based on *The Mutual Participation Model*, in which we as patients share the responsibility with our health care providers for making decisions and planning the course of our treatment. We are respectful of each other's expectations and values.

The changes in the course of chronic conditions require that we as patients have an open line of communication with our health care providers to be able to determine the success of a treatment plan. This model for communication requires that clear information be provided to us, that there is a common ground with regards to goals, that there is an active role for us to play in our health care, and positive affect, concern, and support from our health care providers.

³ Canadian AIDS Society. English: <http://www.cdnaids.ca/web/casmisc.nsf/cl/cas-gen-0171>
français : [http://www.cdnaids.ca/web/setup.nsf/ActiveFiles/MOU+-+Fre/\\$file/MOU%20-%20Fre.pdf](http://www.cdnaids.ca/web/setup.nsf/ActiveFiles/MOU+-+Fre/$file/MOU%20-%20Fre.pdf)

We as persons living with HIV/AIDS expect:

- to be treated with dignity and respect;
- to be able to trust the competence and effectiveness of our caregivers;
- to be able to effectively navigate the health care system;
- to understand how living with HIV/AIDS and our treatment will affect our lives;
- to discuss how living with HIV/AIDS will affect our family, friends, and finances;
- to be able to look to the future;
- to learn how to care for ourselves away from the clinical setting; and
- to have health care providers focus on our:
 - pain
 - physical discomfort
 - functional disabilities

As people living with HIV/AIDS we promote the principle of greater involvement (GIPA) and claim the right to full involvement in any decision making process affecting our lives. We therefore expect:

- to be fully informed about our diagnosis and all aspects of our care;
- to know our treatment options and alternatives;
- to give informed consent to decisions regarding our care;
- to refuse treatment to the extent permitted by law;
- to refuse to participate in research or experimental projects without fear of prejudice;
- to choose the hospital where we are cared for;
- to make an Advance Directive (Living Will) and appoint a person to make health care decisions for us, in case we become unable to speak for ourselves; and
- to receive explanations about withholding or withdrawing life sustaining treatment.

As people living with HIV/AIDS, our responsibilities include, but are not limited to:

- following the treatment plan agreed upon by ourselves and our health care providers;
- providing accurate and complete information to our health care providers, including known food or medication allergies, and any changes in our condition

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- asking questions if we do not understand any aspect of our care;
- informing our health care providers of an Advance Directive (Living Will), if we have one;
- asking what to expect regarding pain and pain management;
- discussing pain relief options;
- helping health care providers assess our pain and to tell them if our pain is not relieved; and
- being responsible for our actions and condition if we choose to refuse treatment or do not follow our health care provider's instructions.

Being meaningfully involved in our health care means that we must take responsibility to inform ourselves about our treatment and care options as well as listen to our health care providers. Then we will have enough information to make informed decisions that respects the unique relationship between us and medical professionals and we can take control of our health.

Later in the module, we'll explore the Patient's Bill of Rights and pose some questions you can explore.



SECTION TWO

YOUR JOURNEY...

Each of us has a personal journey that we undertake regarding our treatment and care. There is no clear path here, but there are many opportunities.

When we're first diagnosed there is often a lot of information to take in as well as the psychological issues we face. Sometimes, we may be persuaded to act quickly on starting treatments. Our specialists or family doctor may suggest certain treatment regimens based on their experience.

Even later in the progression of HIV, we may find that treatments fail and we need to change medications. In some ways it's like starting all over again – we're faced with making more decisions about how we proceed.

Remember, only you have the decision to make about when or if you start treatment. It's your body and your life and you are in control.

Talking with others

When you're starting a new treatment regimen you might have a lot of questions. Your doctor may have some information, but unless he or she is taking the medications themselves, they won't have the lived experience of dealing with the potential side effects or even the fears of changing medications.

Before you take the leap into a new treatment you have options.

Talking with others about their experiences is one way that you can gather information. If you are accessing services at a local agency, there are probably other people who have been on the same medications as you. If you are not connected to an agency there are online resources and chat groups where you can pose questions to people living with HIV/AIDS about their experience.

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Consider these potential questions for others...

- When you started the medication what side effects did you have?
- How did you deal with the side effects?
- What have you heard from others about the medication?
- Have you heard anything from pharmacists about the medication side effects?

Consider these questions for yourself...

- If I start this new medication will I anticipate side effects?
- How will I cope with the side effects if I have any?
- What will I do to get more information about the medication?
- Are there other medications with fewer side effects that better suit my lifestyle?

Starting or changing medications can be scary. Often we hear about HIV treatment “cocktails”. A martini is a cocktail. This is chemotherapy. Some people have side effects and others have few or no side effects. Everyone’s body is different and your reaction to treatments will be different from another person.

Talking may ease some of your concerns about starting or changing a medication and it gives you more tools to make an informed decision.

Weighing your options and taking your time

The pressure we might feel about needing to start or change medication can be depressing or cause us anxiety. Unless your viral load is extremely high and your CD4 count is dangerously low, you have time to weigh your options.

Stop and breathe!

There are many classes of drugs now available to people living with HIV/AIDS. Each of these classes attacks the virus at different stages of replication. If your specialist or family doctor suggests a particular class of treatment for you, you have the right to get as much information about the medication and the potential side effects and/or effectiveness of the drug.

Never feel pressured into starting a new medication until you feel fully informed about how the medication reacts in the body, the potential for side effects (including longer term side effects/illness).

CAN WE TALK?.....

TREATMENT AND OPTIONS, A NEW DIALOGUE

Treatments are becoming increasingly “user friendly”: there are fewer restrictions regarding food or complicated timing issues than with previous medications. There are options for once per day treatments and the number of combinations is not limited as they were in the past.

However, there are also potential interactions with other medications or alternative therapies. You need to be clear with your medical professionals about your lifestyle, alternate therapies you’re using and ask questions about drug interactions.

The journey...⁴

We may have apprehension when we’re starting or changing treatments. It’s common and normal. The fear of immediate and long term side effects can be scary. Wondering how our viral load and CD4 counts will be affected can also add to our anxiety.

There’s a common theme for all of us as we move through our fears about treatment. It goes something like this...

1. We are faced with a dilemma: to change or not to change? To start or not to start? Those are the questions...
2. We explore and debate internally about what we have to do to move forward.
3. We fear the potential outcomes of starting or changing medications. We must confront our inner turmoil and apprehension.
4. We make a decision. Whatever our decision is there is no right or wrong. We choose.
5. We come out on the other end as a person who has taken control of our unique situation.

This can be referred to as “the hero’s journey”. It’s a common story for all people, whether they are living with HIV or not. We go “into the woods” or the dark place, confront our inner demons and emerge a stronger person.

Let’s explore this story more closely. You can ask yourself some questions and prepare questions for your health care provider.

⁴ Adapted from *Can We Talk?* Canadian AIDS Society

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The dilemma...

You are being called to start or change medications. You might be feeling uncertain because you've heard a lot about side effects and how the treatment regimen can change how you live.

What are your current fears about treatment?

What have you heard about side effects from the medications?

What can you ask your doctor about the potential side effects?

What could you ask a pharmacist about the potential side effects?

Internal dialogue...

You have more information about the treatment, but inside, what are you thinking and feeling about starting or changing medications?

I feel...

- Worried about the potential side effects
- Comfortable with the results of treatments I currently take
- Sure of myself and the information I have gathered
- Concerned the treatment will disrupt my life
- Confident that treatments will improve my quality of life
- Confident that my health care provider will offer me the most effective options
- Upset that I have to start/change treatments

I think...

- I have enough information to make an informed decision
- I am in control of my health care and treatment options
- I have been heard by my specialist and/or doctor
- I have the support I need to assist me through this journey
- I need to think about it more

The dark place...

Even when we have enough information, there comes the point where we must make a decision: do we start the treatment or not?

It's a scary place full of unknowns. We don't know how our bodies will react to the treatment. We don't know if the treatment will positively affect our viral load or CD4 counts. We don't know whether we'll have side effects or how severe they might be. We don't know if we can tolerate the treatment. And the list goes on.

Is it okay to ask to change medication(s)?

The only certainty is uncertainty. How will you prepare for the uncertainty?

What can you do to prepare for potential side effects?

Who can support you if you do experience side effects?

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What can you do to care for yourself during the initial days or weeks of starting the treatment?

What can you do to alleviate your fear?

The other side...

So, you've made the decision to start or not start the treatment. The decision is completely up to you. No one can make you take medications, but if you choose to take the medications you must also take responsibility for how you react to your situation.

Once you have started the treatment you need to ensure that you can stick with it. If you have problems (side effects or other concerns) you need to talk with your medical support people. You can also talk with your peers. Taking control of your care and treatment also means seeking the support you need to work through the tough times. But you've also learned that you can do it.

If you choose that now is not the time to start a new treatment, the decision is yours. You can look for more options if you decide that you need more information and you can talk it through with your peers and with your medical professionals.

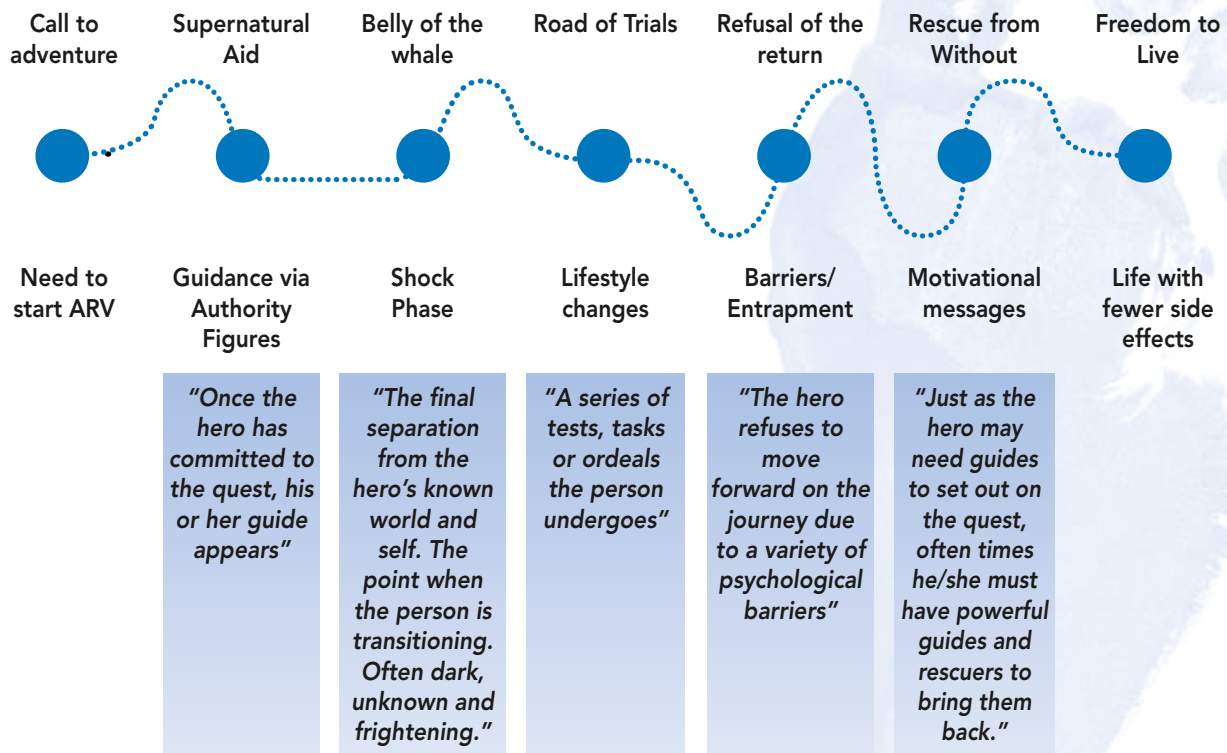
Whatever your choice you remain in the driver's seat!

Another way to look at this journey can be illustrated in the following diagram.⁵

⁵ From Can We Talk PowerPoint Presentation. Canadian AIDS Society

CAN WE TALK?

TREATMENT AND OPTIONS, A NEW DIALOGUE



Getting involved

There are a number of ways in which you can be actively involved in both your own treatment and care as well as assisting others. The following is a pyramid of involvement⁶ that might give you ideas about ways to become active in treatment issues.

PERSONAL INVOLVEMENT: actively involved in their own health and welfare. Educate themselves about therapies, including complementary therapies. Take an active role in decisions about treatment. Become subject rather than object.

You are personally engaged in your own treatment and care. Being actively involved means arming yourself with information.

PEER SUPPORT MEMBER: join peer support group as active member, share experience and knowledge with others.

Being involved with peers is a way to find support for yourself, and in turn support others. Sharing experiences is one of the best ways to learn and make informed decisions about your treatment and care.

⁶ Adapted from GNP+ 2 Pyramids of Involvement

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PEER SUPPORT GROUP LEADER: take leadership in the organization of the peer support group. Encourage participation by new members and seek outside support resources.

If you're comfortable taking the lead, you might consider being a peer support group leader. You'll have the opportunity to bring new members into the conversation and really encourage involvement and empowerment.

PEER SUPPORT ORGANIZER: encourage formation of new support groups, identify resources, including fund-raising and promote sustainability. Offer support to peer support group leaders.

As an organizer you have the opportunity to work with your peers to identify the most effective ways to get people involved and engaged in talking about their experiences. You can work with others to develop new groups that are the most beneficial to members.

PREVENTION/CARE: encourage integration of care with prevention through involvement with prevention organizations.

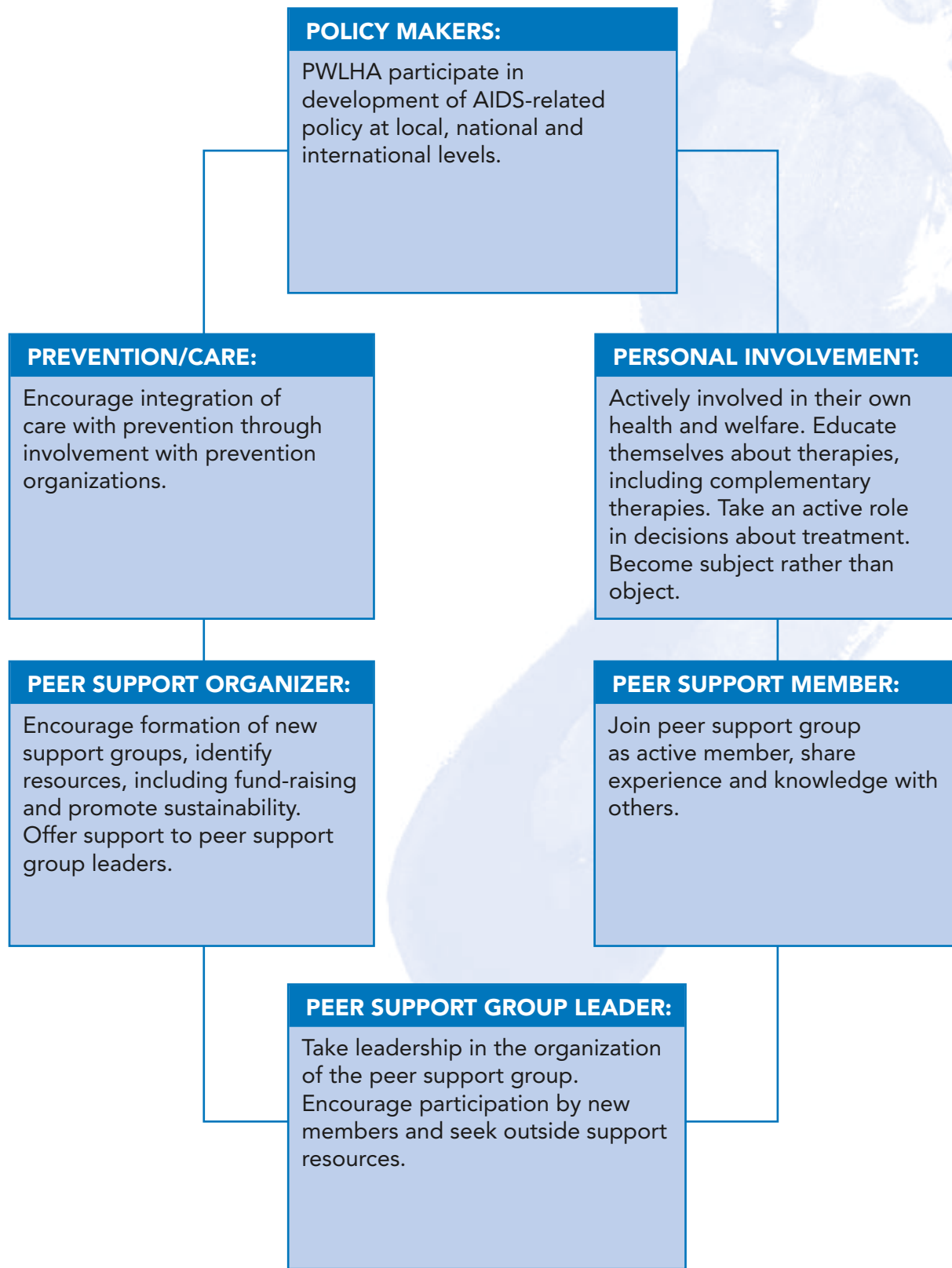
When you are involved in care issues and prevention initiatives you have the opportunity to become a person who can influence organizations to integrate care and treatment issues that provide support to people living with HIV/AIDS.

POLICY MAKERS: PWLHA participate in development of AIDS-related policy at local, national and international levels.

If you decide that you are interested in assisting with policy development, you can influence the way organizations incorporate the GIPA Principles in their daily activities as well as overall policies that affect people living with HIV/AIDS.

In a diagram it might look like the one below. There is no real hierarchy of levels of contribution. We are all involved to the level of our interest and need.





VIRAL REPLICATION, HIV TREATMENTS & POTENTIAL SIDE EFFECTS

Viral Replication

Every virus must enter a cell in order to replicate. A virus is a protein coat with RNA: it doesn't think, but stumbles around the blood stream until it finds a cell for which it has receptors.

When HIV finds a CD4 cell, it attaches itself to the outside of the cell and inserts its RNA into the cell's DNA, causing the cell to make more virus: essentially making the cell a virus "factory". Different treatments are intended to attack the replication process at different points.

Below are the classes of medications and a brief description of how each medication works to combat HIV.⁷

Some words you need to know:

DNA: DNA is like the "blueprint" for building living cells.

Enzymes: Enzymes are like the workers of a cell. They build new proteins, transport materials around the cell, and carry out other important cellular functions.

RNA: RNA is like the construction boss. Cells use RNA to tell enzymes how to build a specific part of a cell. To make a new protein, enzymes will copy a specific part of the DNA into a piece of RNA. This RNA is then used by other enzymes to build a new protein or enzyme.

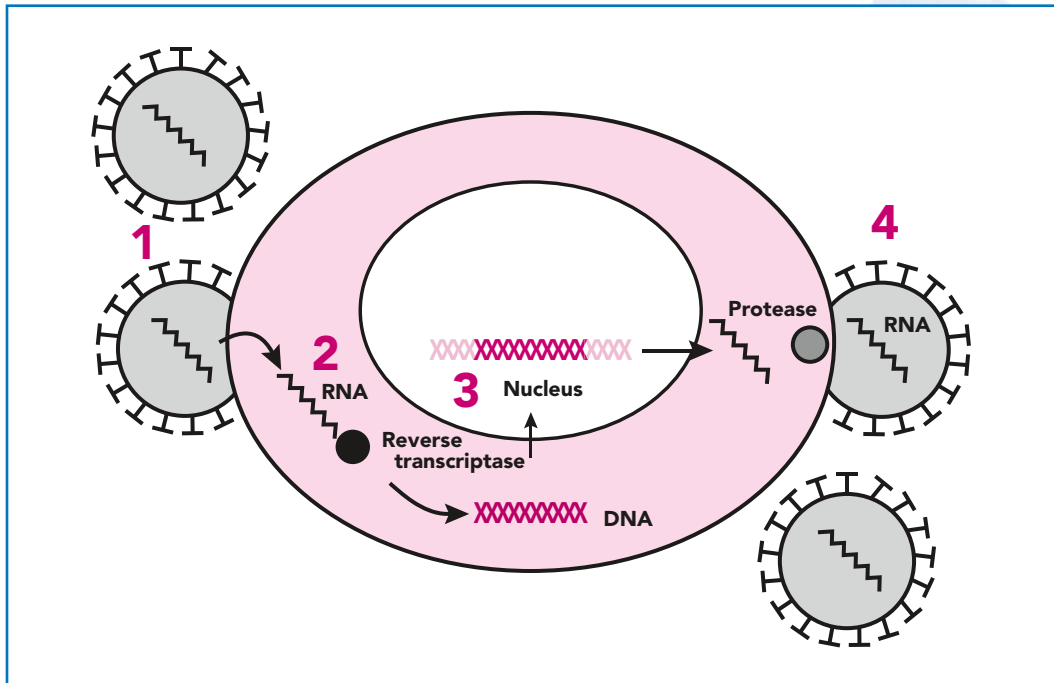
Proteins: The building blocks that are used to make living things.

Nucleus: A small package inside the cell where the genetic material is kept.⁸

⁷ Unless otherwise noted, all treatment descriptions are sourced from http://www.cometonline.org/patient/knowledge.cfm?page=hiv_treating_meds#four

⁸ http://www.aidsmeds.com/articles/hiv_life_cycle_4705.shtml

Below is a diagram of the cycle of viral replication⁹.



Treatments for HIV¹⁰

Starting or changing treatments can be determined for a number of reasons including declining health, increased viral load, CD4 counts (below 350) or an AIDS defining illness. Each person is individual and the reasons for starting or changing medication is a decision made in tandem by you and your health care provider.

The Panel recommends the following as preferred regimens for antiretroviral (ARV)-naïve patients:¹¹

- efavirenz/tenofovir/emtricitabine (EFV/TDF/FTC) (AI)
- ritonavir-boosted atazanavir + tenofovir/emtricitabine (ATV/r + TDF/FTC) (AI)
- ritonavir-boosted darunavir + tenofovir/emtricitabine (DRV/r + TDF/FTC) (AI)
- raltegravir + tenofovir/emtricitabine (RAL + TDF/FTC) (AI)

⁹ <http://www.cipladoc.com/publications/scientificdossier/duovir/duovir1.htm>

¹⁰ Source <http://www.aidsmeds.com/list.shtml>

¹¹ Guidelines for the use of anti-retroviral agents in HIV-1 infected adults and adolescents January 2011

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- Selection of a regimen should be individualized based on virologic efficacy, toxicity, pill burden, dosing frequency, drug-drug interaction potential, resistance-testing results, and co-morbid conditions.
- Based on individual patient characteristics and needs, in some instances, an alternative regimen may actually be a preferred regimen for a patient.

Treatments listed without pictures are experimental

Reverse transcriptase is an HIV enzyme that changes HIV RNA into viral DNA. The viral DNA is then integrated with the genetic material of the CD4+ T-cell. Two classes of medication interfere with the reverse transcription step: Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs) and Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs).

Multi-Class Combination Drugs



Atripla (efavirenz + tenofovir + emtricitabine)

Complera (Rilpivirine + Truvada)


Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs)

HIV creates new double-stranded DNA using its single-stranded RNA as a template. Both DNA and RNA are made up of chains of small molecules. In order to create a strand of DNA from RNA, reverse transcriptase gathers these molecules from the cell and links them one by one into a chain, using its RNA as a template. NRTIs look similar to the molecules used to make DNA, but are modified so that they block viral DNA production and therefore stop HIV replication.

-  Combivir (zidovudine + lamivudine, AZT + 3TC)
-  Emtriva (emtricitabine, FTC)
-  Epivir (lamivudine, 3TC)
-  Epzicom (Kivexa, abacavir + lamivudine, ABC + 3TC)
-  Retrovir (zidovudine, AZT, ZDV)
-  Trizivir (abacavir + zidovudine + lamivudine, ABC + AZT + 3TC)
-  Truvada (tenofovir DF + emtricitabine, TDF + FTC)
-  Videx & Videx EC (didanosine, ddl)
-  Viread (tenofovir disoproxil fumarate, TDF)
-  Zerit (stavudine, d4T)
-  Ziagen (abacavir, ABC)
- Racivir (RCV)
- Amdoxovir (AMDX, DAPD)
- Apricitabine (SPD754, AVX754)
- Elvucitabine (ACH-126,443, Beta-L-Fd4C)

Pharmacokinetic Enhancers

Drugs which are taken to increase the amount of another drug in the bloodstream.¹²








-  Norvir (ritonavir, RTV)
- Cobicistat (GS-9350)
- SPI-452

¹² <http://napwa.org.au/taxonomy/term/871>

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Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)

NNRTIs, also called “non-nukes,” attach directly to HIV reverse transcriptase. When this happens, HIV is unable to convert RNA to DNA, and replication stops.

-  [Intelence](#) (etravirine, ETV, TMC-125)
-  [Rescriptor](#) (delavirdine, DLV)
-  [Sustiva](#) (Stocrin, efavirenz, EFV)
-  [Viramune](#) (nevirapine, NVP)
-  [GSK-2248761](#)
-  [Lersivirine](#) (UK-453061)
-  [Edurant](#) (Rilpivirine)

Protease Inhibitors (PIs)

Once viral DNA is incorporated into the CD4+ T-cell DNA, HIV begins to produce viral proteins that are essential for replication. However, when viral proteins are being produced, they need to go through a final step to be functional. Protease inhibitors block this step.

-  [Agenerase](#) (amprenavir, APV)
-  [Aptivus](#) (tipranavir, TPV)
-  [Crixivan](#) (indinavir, IDV)
-  [Invirase](#) (saquinavir, SQV)
-  [Kaletra](#) (Aluvia, lopinavir/ritonavir, LPV/r)
-  [Lexiva](#) (Telzir, fosamprenavir, FPV)
-  [Norvir](#) (ritonavir, RTV)
-  [Prezista](#) (darunavir, DRV)
-  [Reyataz](#) (atazanavir, ATV)
-  [Viracept](#) (nelfinavir, NFV)

Entry Inhibitors (including Fusion Inhibitors)

Entry inhibitors work differently from other HIV medications because they do their job by blocking HIV from entering the CD4+ T-cell.



Fuzeon (enfuvirtide, ENF, T-20)



Selzentry (Celsentri, maraviroc, UK-427,857)

Vicriviroc (SCH-417690, SCH-D)

Ibalizumab (TNX-355)

PRO 140

Integrase Inhibitors

Viral DNA is inserted into the CD4+ T-cell's DNA by the integrase enzyme so it can be copied. Integrase inhibitors block integrase from doing its job.



Isentress (raltegravir, MK-0518)

GSK-572

Elvitegravir (GS-9137)

Maturation Inhibitors

Maturation Inhibitors aim to prevent HIV from properly assembling and maturing, from forming a protective outer coat, or from emerging from human cells. Inhibiting this step is an entirely new way to halt or inhibit HIV replication.¹³

Bevirimat (PA-457)

Cellular Inhibitors

Droxia or Hydrea (hydroxyurea, HU)

¹³ <http://aids.about.com/od/generalinformation/a/maturation.htm>

Immune-Based Therapies

Aralen (Chloroquine phosphate)

DermaVir (therapeutic vaccine)

Interleukin-7 (IL-7)

Lexgenleucel-T (VRX-496; gene therapy)

Plaquenil (hydroxychloroquine)

Proleukin (aldesleukin, Interleukin-2, or IL-2)

SB-728-T (gene therapy)

Vacc-4x (therapeutic vaccine)

Side effects can vary from one medication to another as well as from person to person. Consult with your health care provider or pharmacist about the potential for side effects and what you can do if you experience side effects from the medications.

Many people experience basic side effects such as fatigue, nausea, vomiting and diarrhoea, dizziness, sleep disorders, vivid dreams. Nausea, vomiting and diarrhoea are usually most present at starting or changing a medication and ease over time. Again, remember that everyone is different and will have different reactions to medication. For some, side effects may be severe and prolonged while others may experience only minor side effects that end soon after starting the treatment.

Other side effects may develop over time. Some of these include:

- Risk to your liver
- Risk to your heart
- Risk to your kidneys
- Osteoporosis or osteopenia (bone density issues)
- Musculo-skeletal problems
- Peripheral neuropathy (pins and needles in your hands and feet)
- Lypodystrophy (fat redistribution such as a buffalo hump)
- Lypoatrophy (loss of fat in the face or limbs)
- Diabetes

Again, not everyone will experience all these side effects, but being informed about the potential for side effects can help you in making informed decisions about the medications you take and subsequent treatments to deal with the side effects. You can keep a record of the side effects you experience including the severity and duration and report these to your health care provider; they may be able to help you find ways to minimize or eliminate the effect.

Date	Side effects	Severity & Duration
Jan 1	Nausea	Moderate about 1 hour
Jan 3	Nausea, fatigue	Moderate (1 hr) fatigue all day

SECTION THREE

RESOURCES

Community Resources

In your community there may be resources that can help you in making informed decisions about your treatment and care options.

Larger centres may have treatment information available at an HIV/AIDS agency. Some agencies may have libraries of information that can help you research the medications and weigh your options.

In rural and smaller communities, you may need to speak to your HIV pharmacist or other health care provider. Alternately, you may be able to access information through the internet or an HIV/AIDS group in a community nearby. Remember that not all information on the internet is reliable: make sure you have a source for relevant and reliable information. For more information see Module 5 of the One Foot Forward Series available through the Canadian AIDS Society or the CATIE Resource Centre.

Look around and see where the most accurate and up to date information is and take advantage of those resources (e.g. your local agency, pharmacist or organizations such as CATIE or CTAC). Treatment information changes frequently, so beware of any information that is more than a few years old.

There are several organizations in Canada that are run by and for people living with HIV/AIDS. These groups can offer you treatment information as well as peer support when you are changing or starting medications. Some of the most prominent groups are the Toronto People with AIDS Foundation (www.pwatoronto.org), the Positive Living Society of BC (formerly the BC Persons With AIDS Society www.bcpwa.org, Vancouver, BC) and REZO in Quebec (www.rezosante.org). In other regions there are groups that can assist you in finding the information you seek.

Internet Resources

Searching for information about treatments online is another way you can educate yourself to make informed decisions. But remember that accurate information is the key: not all sources on the internet are reliable.

Pharmaceutical company websites will tell you a lot about the medication, how it works and the potential side effects. However, they won't generally

give you the lived experience. As well, pharmaceutical websites will list all the potential side effects, even those that are experienced by a very small percentage of people.

You may find out more about the medications you are prescribed by searching for people who offer “user reviews”. User reviews are submitted by people who have actually taken the treatment and are offering their personal experience. But some people may only offer a negative experience, even though there are many people who have had a positive experience with the drug in question. You’ll need to sift through the information offered to make up your own mind.

Beware of “snake oil” salesmen! There are many sites that may offer limited information about miracle treatments that they swear have cured HIV/AIDS. These sites may offer testimonials of people who have been “cured” and may have study information that supports their claims.

There is no cure for HIV/AIDS. There are only treatments that assist in maintaining our health as people living with HIV/AIDS. Use good judgment when looking up information online and be a cautious and careful observer of the claims that are being made.

National Resources

There are several groups in Canada that offer treatment information. These groups have websites with searchable information and may have a toll free line that you can call to ask questions about the medication you are being prescribed.

Canadian AIDS Treatment Information Exchange (CATIE) offers online publications, a listing of treatments and information about the treatments as well as a magazine written for people living with HIV/AIDS. You can check out their website at www.catie.ca. CATIE also has a toll free line at 1.800.263.1638. You can call to get information about treatment and where you can find answers for your questions. Information is offered in English and French.

The Canadian Treatment Action Council (CTAC) offers online information about HIV treatments and news about what the agency is doing to improve access to medications and medical services. Their website is www.ctac.ca.

These and other National organizations will also have links on their website to other groups that offer treatment information and support. All national groups offer information in both official languages.

SECTION FOUR

CAN WE TALK? YOU AND THE MEDICAL COMMUNITY

In the early days of the AIDS epidemic, doctors focused on making sense of patients' lab test results along with signs and symptoms so that they could prevent and treat the inevitable life-threatening complications that were the hallmark of AIDS.

The availability of highly active antiretroviral therapy (HAART) in 1996 transformed AIDS from an eventual death sentence into a chronic health condition that can be controlled by taking medicines every day. HAART's power is so profound that researchers expect that HIV-positive people who start treatment today will likely have near-normal life spans, particularly in high-income countries with their social-welfare systems. Now, as we enter the fourth decade of the AIDS pandemic, most doctor-patient visits still revolve around laboratory testing and signs and symptoms. However, in high-income countries most visits deal with the intersection of one or more of the following themes:

- long-term complications of HIV infection, many of which may be related to ongoing inflammation
- aging-related issues
- co-infections and co-existing complications
- the physical, biological and psychological burden of having a chronic health condition
- medication-related side effects¹⁴

Being assertive with medical professionals

There's a difference between being assertive and being aggressive. Being assertive is a way that you can express your thoughts and opinions and take control of your health care. Aggression may only lead to arguments.

When dealing with medical professionals you are entering a relationship. As in all relationships there's give and take. Hopefully, you have found a specialist or family doctor who listens as much as they talk. Nonetheless, you have the right to be assertive in managing your health care and treatment options.

¹⁴ *Effective communication. The impact of optimal patient-doctor communication for people living with HIV. A special project of the Fugues Magazine produced in cooperation with Tibotec, a division of Janssen-Ortho. July 2010*

CAN WE TALK?.....

TREATMENT AND OPTIONS, A NEW DIALOGUE

Many of us have an idea that the doctor always knows best. They understand the medications and they'll give us the best opinion and most effective course of treatment. While this may be true, you have the responsibility to yourself to talk openly about your concerns and make decisions based on all the information available.

If you are being asked to start or change treatments, you have to make up your own mind. If you are experiencing side effects, and even if your blood work is good, you might consider a different course of treatment to reduce side effects. If your viral load is increasing it may be time to consider treatments. And it's your decision. .

If you are comfortable with how you are managing medications, you have the right to take your time and decide when you are ready. Keep in mind that treatments require commitment: you need to stick with them to see the positive effects over time..Nonetheless, if you aren't feeling ready to start or change your medications this may mean telling the doctor "no". It's easier said than done, especially if we think that we must follow the doctor's lead.

Remember this is a relationship: you have as much input as your health care provider.

Proactive steps you can take

Make a Plan¹⁵

- Concentrate on what is most important to you regarding your health.
- Define your priorities.
- Try to specify main points you want to discuss and how you want to do so.
- Be ready to consult healthcare workers other than your attending physician, specifically nurses, social workers, specialists, pharmacists or community care agents. These professionals may be better placed than your doctor to answer some of your questions.

Prepare yourself by brainstorming with a friend.

¹⁵ *Effective communication. The impact of optimal patient-doctor communication for people living with HIV. A special project of the Fugues Magazine produced in cooperation with Tibotec, a division of Janssen-Ortho. July 2010*

ONE FOOT FORWARD

When you are being asked to start or change a treatment, find out as much as you can before making a decision. This means researching and talking to others, as we've mentioned in previous sections.

1. First you can ask why you are being advised to start or change a treatment. This is step one in understanding the reasons behind the change.
2. Research the medication. Look on the internet, contact local, regional or national resources, and talk with your peers.
3. Bring your questions to the doctor. Writing out the questions and concerns you have will make you better prepared and you won't forget something.
4. Once you have information from the doctor, weigh your options. Are there other medications that might be better for you? Do you need to start or change right now or can you wait – weigh the risks and benefits to treatment? You can continue your research before you make any decisions about your treatment options.
5. Don't make a decision until you're ready and confident that it's right one for you.

Taking and keeping control of your health care: questions you can ask

Taking control of your health care means being an active participant in the process. Considering the patient's bill of rights is one way you can assess the level of control you believe you have over your care.

- *The right to considerate and respectful care regardless of race, ethnicity, national origin, religion, age, sexual orientation, gender.*
Do you believe that your care provider is respectful? What do you need from your care provider?
- *The right to obtain current and understandable information concerning diagnosis, treatment and prognosis.*
Are your questions being answered in a way that you understand? Is print information available to you that is easy to understand?
- *The right to know the identity of all health care providers involved in our care, including those who are students, residents or trainees.*
If your doctor includes a trainee in your visit, are you comfortable with this? If not, how comfortable are you to ask for a private meeting with your doctor?

- *The right to work with our health care provider in establishing our plan of care, including the refusal of a recommended treatment, without the fear of reprisal or discrimination.*

Do you feel comfortable asserting your right to fully participate in your treatment planning, including the right to refuse a treatment or ask for alternatives?

- *The right to privacy and confidentiality pertaining to our HIV sero-status and safety in all environments.*

Are you comfortable that your sero-status is not being discussed with anyone but yourself? What privacy concerns do you have and how are these being addressed?

- *The right to expect that all records and communications are treated as confidential except in the case of abuse.*

How does your doctor maintain your records? Are your records on a computer and if so, what safeguards are in place to maintain confidentiality?

- *The right to review our own medical records and request copies of them.*

Do you feel comfortable asking your doctor for copies of your medical records? If not, do you feel comfortable talking with your doctor about your desire to have copies for your own files?

- *The right to expect that an advance directive (such as a living will, health care power of attorney) will be honoured by the medical staff.*

If you have an advance directive, do you feel comfortable that your doctor or other care providers will honour that directive? What can you do to ensure that your wishes are carried out?

- *The right to expect an appropriate amount of time during our medical visit to discuss our concerns and questions.*

Does your doctor take time to listen as well as review your blood work, or do you feel rushed? Are you comfortable asking your doctor to take more time to discuss your concerns and questions?

ONE FOOT FORWARD

- *The right to expect that our health care providers will follow standard precautions.*

Does your doctor use standard precautions, such as gloves, sterile wipes, etc. in his/her office? Are you confident that the doctor's office is clean and sterile?

- *The right to voice our concerns, complaints and questions about care and expect a timely response.*

Will your doctor respond respectfully to your concerns and questions, or do you feel dismissed? What can you do to ensure that your concerns are addressed?

- *The right to expect that our health care providers will give the necessary health services to the best of their ability. If a transfer of care is recommended, we should be informed of the benefits and alternatives.*

Do you feel confident that your doctor is well-informed and provides you with the best possible care? If your doctor recommends that you see a different doctor, do you feel comfortable talking about your choices in the selection of a different doctor?

- *The right to know the relationships our health care providers have with outside parties (such as insurers) that may have an impact on our treatment and care;*

Is your doctor open to talking about outside relationships with insurers and other authorities? How might these relationships affect your care and treatment?

- *The right to be told of realistic care alternatives when a current treatment is no longer working.*

Does your doctor inform you fully when suggesting alternate treatments? Do you feel comfortable asking for more information when you are not clear about your options?

- *The right to expect reasonable assistance to overcome language (including limited English or French proficiency), cultural, physical or communication barriers.*

Is communication with your doctor or other care providers working for you? If not, what would work better for you to fully understand and communicate?

CAN WE TALK?

TREATMENT AND OPTIONS, A NEW DIALOGUE

- *The right to avoid lengthy delays in seeing medical providers; when delays occur, we should expect an explanation of why they occurred and, if appropriate, an apology.*

Are your appointments on time, or do you have to wait for long periods to see your doctor? Are your appointments made regularly and within a three to four month period, or are they scheduled too far apart? Do you feel confident in asserting your concerns about your medical appointments?

Always remember that you are in charge of your health care and your options. You have rights and responsibilities and so do your health care providers. By being proactive and involved in the decision making process you will maintain your control over your treatment and care.

It may take some work, but arming yourself with information is the first step toward developing meaningful and respectful relationships with your care providers.

The steps you take are the key to maintaining control. Be true to yourself and you can't go wrong.

ONE FOOT FORWARD

SELF ASSESSMENT

After completing this section I learned:

I still need more information about:

My strongest areas right now are:

My weakest areas right now are:

My next steps will be:

I can complete my next steps by: _____

Rate the statements below by circling the number that you think fits.

	Very confident			Need to work on this	
I spent enough time on this module.	1	2	3	4	5
I'm using my energy wisely.	1	2	3	4	5
I know where to find more information.	1	2	3	4	5
I can find a person to help me out.	1	2	3	4	5
I know how to apply what I learned.	1	2	3	4	5

FACILITATOR'S SECTION

When working with a group, you'll be able to develop your own format for exercises and group activities. This section will give you some suggestions on ways to explore the GIPA Principles as they relate to starting or changing treatments.

SECTION ONE

Review the GIPA Principles and discuss what they mean to group members. Many people will be unfamiliar with the principles and discussing personal meaning may assist participants in understanding their rights.

For the Patient's Bill of Rights and the Care Provider agreement, again reviewing the articles will help participants focus and understand the concept of partnership in their health care.

Remember that Section Four poses specific questions that a person can ask themselves about their relationship with their health care provider. You may want to hold off longer conversations about the Bill of Rights until reviewing Section Four.

SECTION TWO

The Hero's Journey, and indeed anyone's personal journey with treatment will be a diverse discussion. The Canadian AIDS Society has a power point presentation that helps outline the issues faced by people starting or changing treatments. You can also plot the course yourself.

Exercise

Part 1: An imaginary person is being asked to start a new treatment. The previous medications aren't working and the person's blood work is showing an increasing viral load and dropping CD4 counts. You can choose a real medication and participants can do some research as part of the exercise.

Brainstorm: What is this person likely thinking right now after being told to about their situation and the need to start/change treatment?

ONE FOOT FORWARD

Part 2: The person has been given options for a new medication.

Brainstorm: What does this person need to know about the medication? Where will the person find this information?

Part 3: There are potential side effects to the medication including nausea, diarrhea, vomiting, fatigue, and over time the potential for other illnesses to develop (e.g. diabetes).

Brainstorm: What is this person feeling? What could this person do to alleviate any fears? Are there other options?

Part 4: The person decides to start the new medication.

Brainstorm: What does this person need to do to feel okay about their choice? What strategies could this person use to counteract the potential side effects of the medication?

Part 5: Brainstorm: What do you think are the lessons this person may have learned? How can you learn from this exercise when/if you are faced with starting/changing medications?

Discussion: If participants are comfortable, you can ask them to share their experiences about treatments. Invoke confidentiality to ensure group safety; personal stories are not to be shared outside the group unless the person opens the discussion themselves.

Getting involved

For this part of the section, you can open a discussion about levels of involvement on the pyramid. Most participants may not be interested in being involved in policy development, but many may take an interest in assisting others as they move through their personal journey with treatment and care.

Questions you might ask the group:

- What have you found to be the most effective support for you?
- What kind of support do you think you might offer others?
- In your agency, is there adequate support for people who are starting/changing treatments? If not, what kinds of support would be most effective and how might you approach the appropriate staff people to start a support group?

- Are there issues that require different types of support groups (e.g. women, youth, First Nations, gay men, etc). What's the best way to ensure that everyone is getting their needs met?
- What steps would you take to develop and lead a support group?
- What health care policies do you think would be the most beneficial for people who are dealing with new or changing treatment regimens?

SECTION THREE

Accessing resources is dependent on where you live. In some communities there are groups with ample resources about treatments, while other communities may have little to no information about treatments.

Brainstorm/Discussion: What resources are available locally about treatment information? Is this information easy to access and understand? Are there people locally that you can talk to about treatments? If not, is there something that can be arranged to facilitate people talking about treatments?

Brainstorm/Discussion: What resources are available on the internet? How easy is it to find the information you need? (if computers are available, you can ask people to perform searches for information about a particular treatment and report the results)

Brainstorm/Discussion: What resources are available regionally and nationally? How can you access that information? (again, if computers are available, participants can do web searches for regional/national information and support)

SECTION FOUR

Being assertive: Discuss the differences between being assertive and being aggressive. What are the most effective ways that participants have found in communicating with their health care providers? What was least effective? If the health care provider is not listening, what might participants do to change that? You can also consider bringing a trusted friend, family member or advocate to be an extra pair of ears to listen and ask questions you might not have considered.

Patient Bill of Rights

Go over each section of the Patient's Bill of Rights and discuss what each point means to the participants. While questions are provided, you may discover that people have their own questions and concerns.

If participants are comfortable, you can ask them to relate personal experiences with their health care providers. Remember to invoke confidentiality – that no person's personal story is to be shared outside the room, unless the person themselves is the one to open the discussion.

Alternately, you can ask the group to brainstorm what is most effective in their relationship with health care providers using each point of the bill of rights. Discuss the role and responsibility of the patient as well as the role of the health care provider.



SESSION EVALUATION

You can choose to use a standard snapshot evaluation form for each session, but you can also incorporate a discussion piece.

1. How do people feel after the session?
2. Are there any areas where people would like to spend more time?
3. Do participants have a better understanding of their skills and abilities?
4. Do participants have a better understanding of self care and burnout?

Here is a possible evaluation template. Don't hesitate to add other questions to get a more precise evaluation.

1. The information presented was easy to understand? ___yes ___no
2. The allotted time was sufficient? ___yes ___no
3. I had enough opportunity to present my point of view and ideas.
___yes ___no
4. I would have liked to know more about _____

5. The part that I most liked was _____

6. The part that I least liked was _____

7. What could have been done better?

8. Comments: _____

ONE FOOT FORWARD

PERSONAL EVALUATION

1. How do you feel about how you presented the information?
2. Were there any topics or areas that you think you might want to change?
3. Are there any other exercises you think might make the information more tangible?
4. In your estimation, did the group seem to grasp the information and concepts?



NOTES

Lined area for notes

