Taking Care of Yourself: Self Advocacy and Resilience in 2017

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By attending this workshop

1. Discuss the concept of self-advocacy within the context of HIV history
2. Define self-advocacy
3. Describe a number of tools one can use to become a successful self-advocate
What is Self-Advocacy?

- Taking charge
- Not giving away your power
- Being an expert about what you need and what is involved in taking care of yourself
What is Self-Advocacy?
The Denver Principles

1983

Denver, Colorado
The Denver Principles

11 principles
The Denver Principles

People with AIDS have the right:

To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.
The Denver Principles

People with AIDS have the right:

To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
The Denver Principles

People with AIDS have the right:

To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
What is self-advocacy in healthcare?

Taking actions to treat or prevent illness, and promote your own health.
How can I self-advocate for my health?

- Engage in healthcare
- Adhere to HIV treatment
- Reduce health-risking behaviors
- Address other issues connected to health
- Know that there will be “ups” and “downs”
What have you done to self-advocate in healthcare?
Toolbox

- Making decisions
- Medication management
- Managing fatigue
- Action planning
- Exercise
- Working w/ health professionals
- Problem-solving
- Healthy eating
- Using your mind
- Communication
- Evaluating symptoms
- Understanding emotions
Making an Action Plan
Overview

1. What are the parts of an action plan?

2. What do we mean by reasonable and action-specific?

3. What is the difference between a goal and an action?

4. How do we use problem solving techniques?
Parts of an Action Plan- Step One

Choose something **REASONABLE** and **ACTION-SPECIFIC** that **YOU** want to do and **will do**.
What do we mean by reasonable?

Something you believe you can accomplish in the short-term.

For example, walking around the block.

1. Aim for 3-5 days per week, rather than every day to allow for unexpected events.
2. If you say you’ll do 5 and do 7 instead, that’s much better!
3. Is it realistic?

[Handwritten goals:

- Eat
- Fly
- Sleep
- Swim quack
- Mate
- Lay eggs
- Raise chicks
- Learn Taekwondo
- Build a nest.]
What do we mean by action-specific?

What is the difference between a goal and an action?

<table>
<thead>
<tr>
<th>GOAL</th>
<th>ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lose weight</td>
<td>Avoid snacks between meals</td>
</tr>
<tr>
<td>Lower blood pressure</td>
<td>Walk briskly</td>
</tr>
<tr>
<td>Reduce stress</td>
<td>Practice yoga</td>
</tr>
</tbody>
</table>
Parts of an Action Plan- Step 2

Answer the questions:

a. What? (walking fast)
b. How much? (10 blocks)
c. When? (after dinner on Mon, Wed, and Fri)
d. Where? (in the park)
Parts of an Action Plan- Step 3

What is your confidence level?

On a scale from 1 to 10…

Your confidence level should be

7 or greater.
Problem Solving

Maybe you wanted to eat a salad for dinner 3 nights a week, but you only ate it once.

That’s okay!

But how do we try to help you achieve your goal?
Problem Solving

Identifying obstacles
Identifying problems
Talking out your barriers
Adjusting action plan

BE A SELF-ADVOCATE
Problem Solving

MISTAKES IN SETTING GOALS
Brainstorm- “I have no time”

Any ideas on how to solve this problem?

Has anyone else ever had a similar problem?
Make buddies!

Thank goodness we had plans to run together. Left to my own devices, I’d have convinced myself I was deathly ill.
Communicating With Your Medical Provider
Communication and Relationships

✓ Communication is important in all kinds of relationships
✓ It is difficult to have good relationships without good communication skills
Communication and Chronic Conditions

✔ When living with a chronic condition, it is important to:

✔ Seek information about your condition
✔ Keep those people who are close to you informed about your health
Why we communicate with medical providers

It is important that our providers know:

- any changes, improvements, or new issues with our health so that they can provide the best care.

- how we feel about our health. If we do not like a particular treatment or suggestion, we are less likely to adhere.
What do I communicate to medical providers?

- Difficulties with adherence
- Barriers to taking medication, exercising, or anything they recommend
- Concerns about how your health affects your quality of life
- Symptoms

Tip: Track and monitor your symptoms
Do they change? When do they get better or worse?

“80% of the diagnosis is in the story”
Tracking Your Symptoms

10 Question Checklist:

1. What is the symptom? Where?
2. Have you had it before? How long?
3. What is the intensity of the symptom? Better, same, worse?
4. When did it occur? How long?
5. What were you doing when you noticed?
Tracking Your Symptoms

10 Question Checklist:

6. Has anything changed or happened to bring it on?

7. How has it occurred over time? Pattern? Morning/night? After eating?

8. Does it come with other symptoms? Pain? Does it move/radiate?

9. What you have done to manage it? Better or worse?

10. Did you get any advice?
<table>
<thead>
<tr>
<th>Date</th>
<th>Symptom</th>
<th>Intensity Rating</th>
<th>Trigger</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>2/16/17</td>
<td>Headache right in the center of my head; hurts so much it’s hard to think</td>
<td>4</td>
<td>Dry environment</td>
<td>Drank two 8oz glasses of water, took 2 Advil</td>
</tr>
<tr>
<td>2/17/17</td>
<td>Headache in the same spot- hurts a little less but hard to concentrate</td>
<td>3.5</td>
<td>Dry environment</td>
<td>Drank two 8oz glasses of water, took 2 Advil</td>
</tr>
</tbody>
</table>
Prioritize

Unfortunately, we don’t get as much time with medical providers as we might like. Before you go to your appointment, write down the most important things to discuss with them so you remember it.
Communication

Medical provider: “How are you?”

Patient:

“I’m about the same.”

“I’m okay!”
Practice!

Who will volunteer to practice talking to your medical provider?
Summary

• People who are self-advocates take charge of their life. They know what they need to take care of themselves.
• The Denver Principles state that people with HIV have rights.
• Self-advocacy means taking actions to promote your health.
• The four most important things you can do to improve your health are:
  - Engage in health care
  - Reduce health risking behaviors
  - Adhere to your HIV treatment
  - Address other issues connected to health
Summary

• Goal setting is important to self-advocacy.

• There are three parts to an action plan:
  • Something you want to do
  • Answers questions like, “What are you going to do?” and “How often?”
  • You have a confidence level of 7 or more that you will complete it

• In action planning, it is important to set realistic goals.

• Develop an *action plan* to help you achieve your *goal*
Summary

1. To be a good self-advocate, learn how to communicate effectively.

2. Tell your medical providers about any new symptoms or changes in your health.

3. Talk to your providers about how you feel about your health, not just in general.

4. Make a list of things you want to talk about before your appointment so you remember to discuss them.
Discussion/Questions