

Tools and Strategies: Level 2



HIV/AIDS Treatment Access Advocacy Workshop Series



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Workshop Overview

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1. Introductions
2. The 5 principles of advocacy
3. Lipodystrophy: Who are the Key Players?
4. Making a plan: Private and public strategies
5. Carrying out a plan
6. Close of workshop



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Review

What does *Advocacy* mean?

The act of speaking out for a cause or course of action



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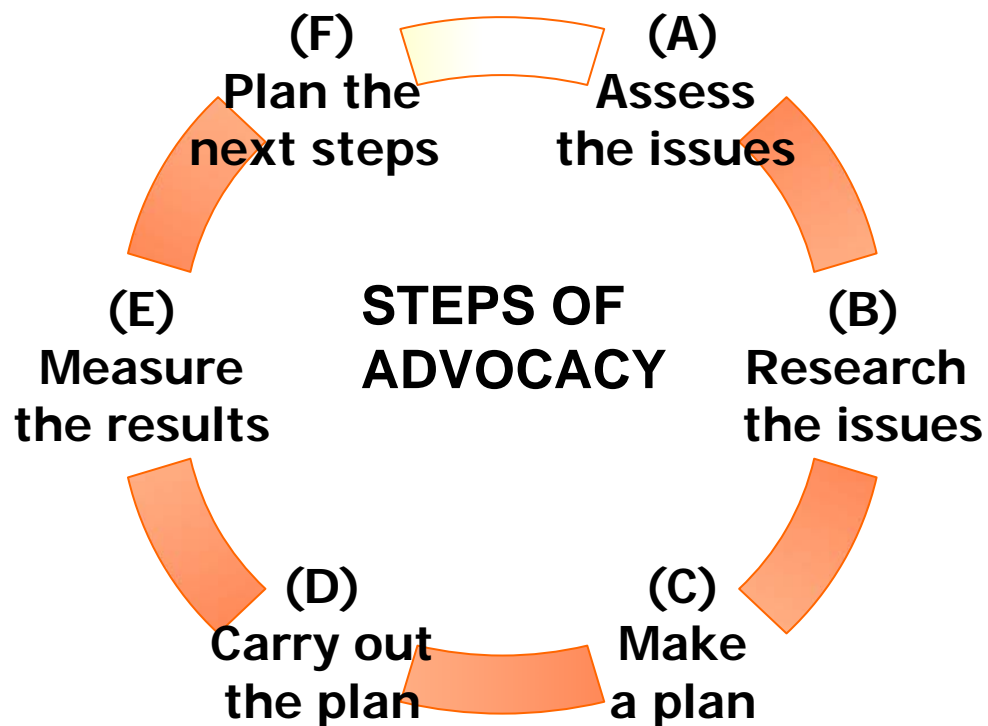
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The 5 Principles of Advocacy

1. Be a voice for other people.
2. Do your research.
3. Respect privacy and confidentiality.
4. Use the style that you are most comfortable with.
5. Create the environment to empower those around you.



What is *Advocacy*?



What is lipodystrophy?

It is defined as a metabolic syndrome with various possible origins:

- Highly active anti-retrovirals (HAART)
- Length of time on HAART
- HIV disease itself



Why do advocacy around lipodystrophy?

- ✓ Who are you advocating for?
- ✓ Do you understand the issue(s)?
- ✓ What do you want to achieve?
 - ✓ Who are the key players?



Who are the Key Players?

Decision makers
Friends and allies
Opponents
Undecided
Media
Other key players



Lipodystrophy: Who are the key players?

*Who are the **Decision makers?***

Government:

Health Canada approval

Policy bureaucrats

Provincial reimbursement plans



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Lipodystrophy: Who are the key players?

*Who are our **Friends and Allies?***

People affected and loved ones

Community

Some politicians

Health care workers (Dr's, R.N's, CHR's, CHN's)

Pharmacists

General public



Lipodystrophy: Who are the key players?

*Who are our **Opponents**?*

Health care system

Some politicians

Formularies

Ignorance, stigma and discrimination

General public



Lipodystrophy: Who are the key players?

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*Who are the **Undecided**?*

Pharmaceutical companies

General public



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Lipodystrophy: Who are the key players?

Who are the **Media**?

Print, television, radio and internet
Private companies and communities
stations

Who else?



Lipodystrophy: Who are the key players?

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Who are the **Other Key Players?**

Faith communities

Psychiatrists and psychologists

Experts in PK economics



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Making a Plan

What is a *Plan for Action*?



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What is a Plan for Action?

A plan for action shows who is involved at each stage of planning, carrying out and evaluating the plan



Making a Plan

- What are we trying to do?
- Who is responsible for the plan?
 - Who are we trying to reach?
 - What is our time-frame?
 - How much will it cost?
- What background information do we need?
 - What's next?



Making a Plan

What is a budget?

Why should you develop a budget as part of your plan for action?



Developing a Budget

For larger activities, identify what costs are involved in your plan, (such as photocopying, travel, postage and food for an event). Do this early in the planning stage and decide who is responsible for paying for what.



Making a Plan

Will a **public** or **private** plan help you to achieve your goal?

What does the person/group that you are advocating for want?



Lipo-Action! Private and Public Plans²¹

Private

Lobbying Politicians

Public

Press conferences and demonstrations



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Carrying out a Plan

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Example of a Private Plan: Face-to-face meeting

- Write out the purpose and what you will say.
- Do you need any background information?
- Practice responses to possible questions.



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Lipo-Action! : Private Plan Example

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Private Plan: Lobbying Politicians

Lipo-Action! prepared and submitted a brief to the Minister of Health and Social Services of Quebec, as well as started a letter-writing campaign to the Minister to mobilize decision-makers into action.



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Carrying out a Plan

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Example of a Public Plan: Information Session

Who should be involved with the planning?

Who should attend the session?

What promotion needs to be done, and how?

How much will it cost? How much will it save?

What message(s) do you want to get across?



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Lipo-Action! : Public Plan Example

Public Plan: Demonstrations

Lipo-Action! has successfully used strategies of “guerilla theatre”: A troop of “HIV Mutants” and other characters performing in public spaces has helped to raise awareness of lipodystrophy and mobilize the general public into action.



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