



**THE HUDDLE**

# **PATIENT SUPPORT GROUP HUDDLE**

Saturday, 15 September 2018, Johannesburg, South Africa

# The Huddle

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**Definition Huddle: verb (used without object),  
huddled, huddling.**

- 1. to gather or crowd together in a close mass.
- 2. to confer or consult; meet to discuss, exchange ideas, or make a decision.



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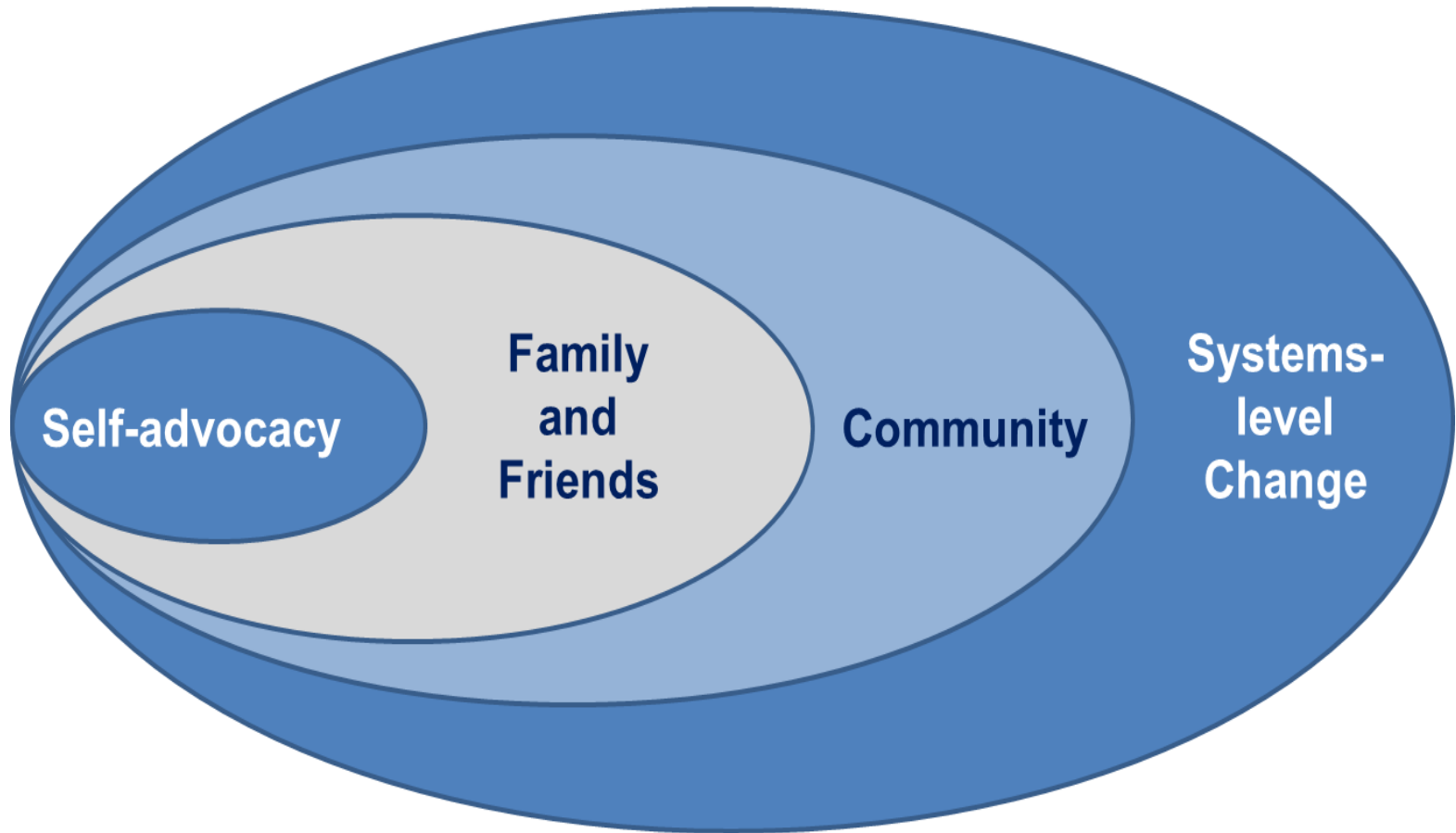
# **ADVOCACY 101**

**Lauren Pretorius, CEO, Campaigning for Cancer**

# What is advocacy?

- Endeavour to **influence decision-makers, to create change** through various forms of **persuasive communication**.
- A **systematic approach to changing policies, programs and systems** to reflect the needs of individuals and communities.
- It provides the patients an opportunity to become **involved in the decision-making processes** that ultimately affect their lives.

# Where does advocacy happen?



# What is grassroots advocacy?

- Involves people from the general public, as a fundamental political and economic group
- Real people bringing compelling personal experiences and pressure to decision-makers
- Demonstrates to decision-makers how the community supports your advocacy issue
- Collective strength will help your NGO to reach advocacy objectives and systems change

# What can advocacy change?

- Public policy
- Laws and regulations
- Resource allocation, use of funds
- Access to services and medication
- Health insurance and public benefits
- Reduce disparities among underserved
- Public opinion – gain support for disease related policies

# Methods of Advocacy

- There are three approaches to advocacy - FOR, WITH and BY those affected.
- **Direct advocacy** - efforts that affect change to programmes and practices that are aimed at *influencing decision-makers*.
- **Indirect advocacy** - efforts that *raise general awareness and involve building support among the general public* so that people will pressure decision-makers or a community to make changes to practices.
- **Patient-Centred advocacy** - efforts by *individual patients to advocate on behalf of themselves* and their right to access treatment, care and not be discriminated against.



# Two methods when advocating for patients

- **Lobbying and direct communications**  
involve influencing decision makers by means of direct and private interaction and communication. Lobbying, can be a powerful and cost effective method of advocacy.
- **Campaigning**  
speaking publically about an issue. The aim of such campaigning is to generate a response from the general public in order for an issue to become a “talking point” amongst the public so that policy makers take notice.

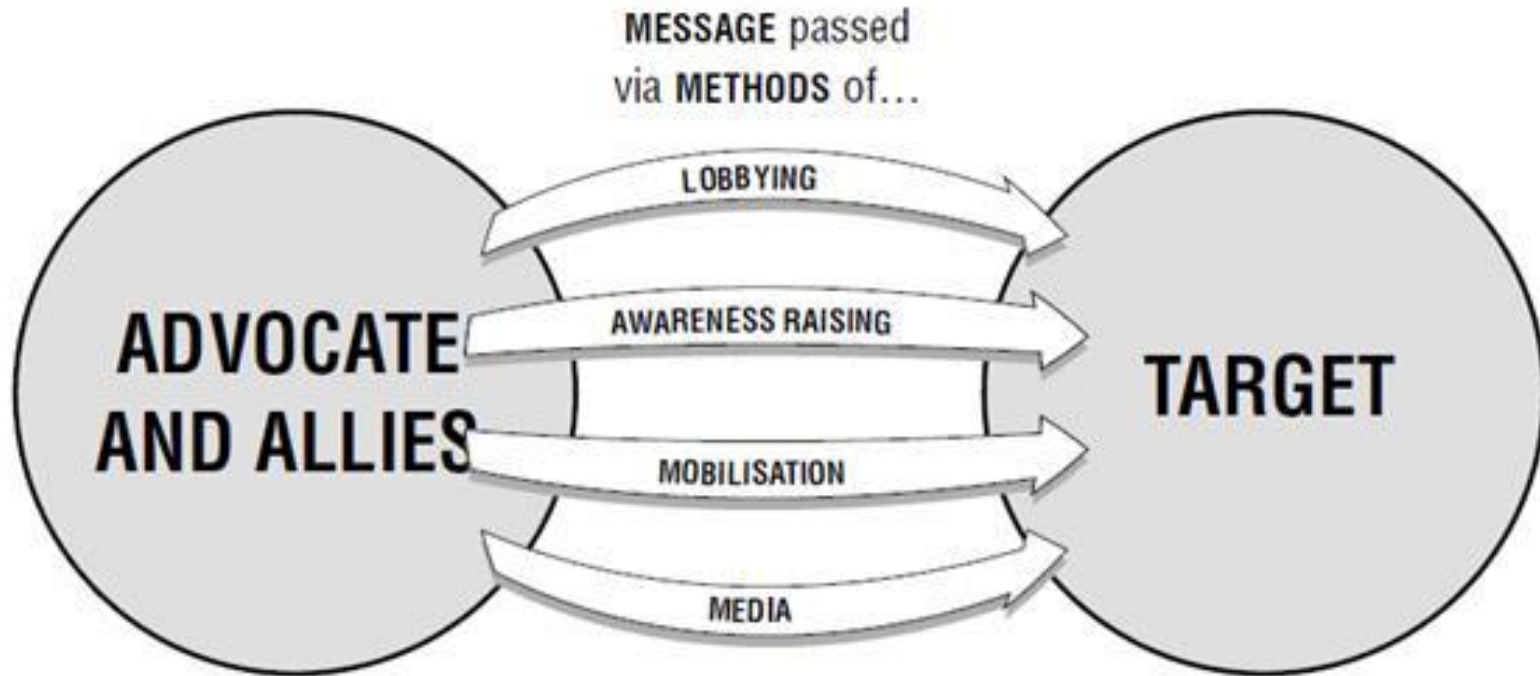
Possible  
advocate roles

ROLE	CHARACTERISTIC	
Represent	Speak <b>for</b> people	
Accompany	Speak <b>with</b> people	
Empower	Enable people to speak for themselves	
Mediate	Facilitate communication between people	
Model	Demonstrate the practice to people or policy makers	
Negotiate	Bargain for something	
Network	Build coalitions	

**Key**

- advocate
- targets / those in power
- those affected by a situation

# Advocacy methods



The overall objective is to change the particular policies or practices of the target for the benefit of the poor.

# Planning advocacy

**Stage 1**      **Defining the current  
state of the problem**

**Stage 2**      **Data and Research**

**Stage 3**      **Audiences**

**Stage 4**      **Developing messaging  
and persuasive  
arguments**

**Stage 5**      **Building Support**

**Stage 6**      **Monitoring and  
Evaluation**



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**QUESTIONS?**

Lauren Pretorius, CEO, Campaigning for Cancer

# Planning advocacy

- What are the key issues facing our community right now?
- Brainstorm issues
- Brainstorm solutions
- Prioritize issues
- Categorize issues
- Develop a list of advocacy issues
- Develop a problem statement
- Define who to speak to and what to say
- Build support for your plan



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# STEP 1: DEFINING THE CURRENT STATE OF THE PROBLEM

Group Exercise

# Group Exercise 1

- In smaller groups, brainstorm a list of problems that in your work with patients and loved ones are most prevalent
  - ▣ 10mins
- Report back to the group
  - ▣ 15mins



# Group Exercise 2

- In your smaller groups, to each problem you listed identify what the root cause of the problem is.
  - Ask yourself:
    - Why does the problem occur?
    - What are the main aspects of the problem?
    - What are the effects it causes?
  - 10mins
  
- Report back to the larger group
  - 15mins



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**BIO BREAK**

**Back by 5mins**



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# **STEP 2: FINDING SOLUTIONS – CHARITABLE ACCESS PROGRAMME**

Tanya Collin-Histed, European Gaucher Alliance



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**PROBLEM + SOLUTION =  
ADVOCACY ISSUES**

Lauren Pretorius, Head of Strategy, Prime Consulting

# Distinctions between problems and issues

- What is a “problem”?
- We all have “problems” – e.g., lack of affordable, quality health care is a problem; inadequate funding for research is a problem.
- **The problem is something that is wrong.**
- Advocates do not organize around problems, however, they organize around “issues” - the solution or partial solution to the problem.
- We have to have a clear demonstrative problem though to develop an issue.

# Distinctions between problems and issues

- A solution is a necessary aspect of successful advocacy.

**Without presenting a solution we are merely voicing complaints, not affecting change.**

# Group Exercise 3

- In your groups, to each problem's root cause you listed identify a potential solution that will have a positive impact on all patients.
  - ▣ 10mins
- Report back to the group
  - ▣ 10mins
- **REMEMBER: Your solutions may be far-fetched or challenging to implement, and it will likely be the responsibility of decision makers to implement them.**
- **This is OK.**



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# **DEVELOPING A TAILORED ISSUE TREE**

**Group Exercise**



# Mobilizing our efforts

- Presenting our issues with potential solutions is a proactive way of addressing the issue, and even though we aren't the policy makers, our job is to help be a part of the solution by clearly identifying what we need as patients and advocates.
- How many of you came up with at least 5 issues and solutions? 7? 10?
- We can't possibly address all of these at once, so we need to narrow them down by prioritizing them.

# Group Exercise 4

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- Brainstorm with the larger group ways to prioritize the issues. (5 mins)

# How do we prioritize?

- Selecting an issue that has **broad appeal** not only to the people in the room, but also to others in the community.
- Select an issue that is **easy to explain and understand**
- Select an issue that can be **influenced in a realistic amount of time** (months vs. years)
- Select an issue for which there is a **clear idea of a policy change** in mind
- Selecting an issue for which there is **an identifiable decision-making body**,
- Selecting an issue that lends itself to a **clear “victory”** for patients

# Group Exercise 5

- Using the criteria we just established, narrow your list down to 3 issues.
- The group must reach a consensus.
- You have 15 minutes.



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# **STEP 3: THE ROLE OF DATA AND RESEARCH IN ADVOCACY**

Helen Malherbe, Genetic Alliance South Africa



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**REFRESHMENT BREAK**

**Back by 15:30**



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# **RESOURCING & SUSTAINING ADVOCACY**

Weronika Wojtowicz, Care Beyond Diagnosis



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# NARRATING PROBLEM STATEMENTS

Group exercise



# Group Exercise 6

- To adequately advocate for a solution you have to have all the facts about the issue and be able to present them to stakeholders in a credible and clear way.
- A way that demonstrates the gravity of the issue.
- In smaller groups of interested parties, evaluate your 3 chosen advocacy issues according to the following criteria:

# Checklist for Selecting an Advocacy Issue

- **Data:** Do you have access to qualitative and/or quantitative data demonstrating the extent of the problem/issue? Does the data demonstrate that the proposed solution will result in real improvements in cancer control?
- **Scope:** Does the issue affect many people? Do enough people feel affected to do something about it?
- **Understandable:** Is the issue easy to understand and explain? Are you able to frame the issue in such a way that people readily comprehend the issue and its solution?
- **Commitment:** Do people care enough about the issue to take action? A smaller number of people may feel so strongly that they are able to take on the work of getting petitions signed or raising resources for a campaign, etc.
- **Resources:** Will you be able to raise enough money to support work on this issue? Do people care enough to donate funds and resources?
- **Target:** Are you able to clearly identify the key decision-makers (individuals) to address this issue? Do you have their names and contact information?
- **Networks:** Do you have existing alliances with other NGOs or key individuals based on this issue?
- **Values:** Is the issue consistent with your mission statement and NGO values?
- **Addresses injustice:** Does the issue address stigma, historic imbalances or societal injustices or prejudices?
- **Feasibility:** Is the issue and its proposed solution feasible and/or winnable given the current political and social climate? Is there a good chance of success, even with opposition? Can the larger issue be broken down into smaller winnable issues?
- **Precedent:** Does the issue recognize national (or international) policies?
- **Future:** Does work on this issue provide the potential for:

# Group Exercise 7

- Report to the larger group
- As a group, which of your 3 chosen advocacy issue has the biggest chance of success in light of the criteria we used to evaluate it?

# Problem Statement

- **Policy problem:** Documented escalating rates of smoking (and exposure to second-hand smoke) have led to increased cases of lung cancer.
- **Question:** What could the Parliament and Justice System do to address escalating rates of smoking?
- **Policy solution:** Enact and enforce legislation that would ban smoking in specified public venues.
- **Advocacy issue:** In order to decrease the escalating rates of lung cancer due to smoking and exposure to second-hand smoke, legislators and the justice system must enact and enforce legislation to ban smoking in specified public areas.

# Group Exercise 7

- As a group, develop a statement that explains the reasons for your concern, what you suggest the solution is to the problem and how this problem can be solved.
- **USE THE FACTUAL AND EMOTIONAL HIGH GROUND**



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**THANK YOU**

End Day 1