

The need for patient group advocacy

Steps to creating an effective advocacy plan

By Ryan Clarke



The ability to effectively advocate is a fundamental requirement in the not-for-profit health sector as organizations like the Canadian Lymphedema Framework and the seven different provincial lymphedema associations seek to represent the interests of their membership, whether it be with key decision-makers in government or other stakeholders that have an impact on their issues. This article will review the importance of patient group advocacy, as well as outline the essential elements needed to engage in advocacy.

We begin with a definition of the word itself. According to the Canadian Oxford Dictionary, advocacy is *verbal support or argument for a cause, policy*. I typically describe it as telling your story to someone, through various means, with the express purpose of compelling that person to do (or not do) something. It is a process that almost always takes time to realize tangible results and the way it is done is very personal according to your own style and comfort level.

So why is advocacy important? Well, quite simply, the squeaky wheel gets the grease. Health officials in government react to those credible patient groups who can most effectively bring their issues to the forefront of the public agenda. The truth is if

you don't engage, some other organization will and you will miss the opportunity. It's also important because governments will do what they want (or they'll do nothing) unless groups intervene in the process. So from the outset, it should be clear; choose not to advocate for what you think is important, and I guarantee the result—nothing will happen. But take a chance and engage, and you just might be successful.

Patient groups need to ensure coordinated engagement in health issues at both the national and provincial levels, as well. Although health care is primarily the responsibility of the provinces, an organization like the Canadian Lymphedema Framework has a critical role to play in representing the unified voice of patients, emphasizing equity and consistency in the provision of health care services.

There are three steps to create the foundation of an effective advocacy plan and as you will see, each step requires focus to ensure you don't lose sight of your objective.

1 Key messages. The first thing you need to do if you are going to advocate to anyone about anything, is determine what you need to say, either in writing or orally. These are your key messages. I recommend

three key messages that explain the salient points of your issue in easy to understand language. Each of those key messages should consist of 25 words or less and be written in a clear, compelling, concise (focused) and consistent manner. They represent the essence of what you want a decision-maker to remember and respond to around the issue presented to them.

To ensure even greater focus, I suggest patient groups craft their three key messages to answer the following questions:

- i. What is the problem, challenge or issue? Or what are we here to talk about?
- ii. What is the impact of the problem? Or why is this problem important?
- iii. What would it look like if we solved the problem? Or what's in it for the decision-maker?

Lastly, make sure that the language you use in your key messages is focused on how you want the recipient to perceive your issue. Use subjective language, not just facts, to frame the problem in such a way that people will be drawn in by the words you've chosen.

2 Advocacy tools. Once you've decided what you want to say, you need to determine the means or vehicles through which you should deliver your three key messages. These advocacy tools represent the core of any effective advocacy plan. Anything a patient group uses to communicate with



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members, supporters or people outside the organization is a potential tool. Examples include texts, emails, in person meetings, websites, newsletters, petitions, postcards, news releases and, of course, social media.

Using your advocacy tools, you need to create what is known as a layering effect, to layer each tool on top of the next in a very focused manner in an attempt to elevate the noise level around your issue. You don't want to just randomly start trying everything you can think of to get

your key messages in front of decision-makers. Instead, determine which advocacy tools you are able to use or need to develop, and then

begin to link them together in a way that focuses on systemic layer building.

It's also important to give some thought to developing advocacy tools specifically for grassroots action. Social media and various e-advocacy programs

are good examples of ways in which members or supporters can become engaged at the local level with their elected representatives, for example. It's an important component you'll likely want to build in to the various advocacy tools at your disposal.

3 One 'ask'. This is the goal of any advocacy plan, to be able to ask a decision-maker for the one thing you need them to do, not a list of what you want from them.

It is particularly at this stage that most organizations engaged in advocacy fail to be focused enough in articulating what exactly they need. Instead, they

present a wish list of all of the things they want from the person to whom they are advocating. It may sound contrary to what most of us believe, but in advocacy, the less you ask for and the more specific you are, the more likely you are to succeed.



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Your 'ask' also needs to be tangible, something that can be measured, and this is where you cannot be too focused. For example, if your 'ask' is to have a piece of legislation amended to include the word *shall* instead of *may*, making an action required instead of optional, this is both significant and very specific. That's the level of precision that every 'ask' should seek to encompass. Both the Canadian Lymphedema Framework and the various provincial lymphedema associations have a strong commitment to advocacy. I am confident that they will continue to invest the time and effort to build their respective advocacy capacities to best serve their members. **LP**



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