



Family Caregivers of British Columbia

Advocating for a Family Member

Dependent on the health and ability of the person you are caring for, it is likely that at some point in your role as a family caregiver, you will be advocating for that person. You may need to be present at appointments to ask questions, research and access services, resolve problem situations and ensure all care needs are respected and met.

The following are some tips for helping you to be an effective advocate:

Communicate with the care recipient: As much as possible keep them involved in decisions regarding their care. Focus on their wishes as you work to advocate on their behalf.

Develop an action plan: Set realistic goals and take one step at a time toward reaching them. When tasks seem overwhelming, having a plan that lays out each step makes everything seem more manageable. The worst time to try and figure out what is available and how to access it is during a crisis.

Prepare questions in advance: Health care professionals often have limited time to spend with you. Write down your questions in advance so that you don't forget them if you become stressed or upset. Rehearse what you want to say. Decide what information is most important and ask those questions first. Be concise and specific about the information that you need.

Keep a written record: Write down answers you receive to questions. You may need to refer to this information in the future. Also keep a log of contacts, phone numbers, names, dates, and information acquired all in one place, so you can easily retrieve them when needed. In addition, keep a written record of any pertinent details related to your family member's health condition and behavior.

Remain calm: Believe that the information you seek and what you have to say is important and that you and your family member have the right to know it. Becoming angry or shutting down will only get in the way of the communication.

Communicate clearly and directly: Prepare well in advance for any meetings so that you can be clear and concise. Ask for what you want and express your feelings. Avoid rambling and don't expect the other person to guess what it is you are trying to say.

Be persistent and follow-up: Finding the answers you need may take time, effort and several telephone calls or emails. Don't give up. Persistence produces results. Keep in mind that even though you are focused only on your family member, the healthcare professionals have many patients to take care of.

Right person: Determine who the key contact is so that you don't waste time struggling to find answers where they are not available.

Find an appropriate time: Good timing is essential and can make the difference between managing the problem and making it worse. Wait until you are less anxious, angry or upset before trying to deal with a situation. Arrange to meet and talk at a time when both parties can focus on problem-solving.

By Barbara Small, Program Development Coordinator

Family Caregiving and the Role of Advocate

Often family caregivers are unprepared for their caregiving role as an advocate. The extent of the advocacy role depends on the age, ability, and condition (including frailty) of the person being cared for. Advocacy, especially for elderly people and other vulnerable individuals, is necessary to ensure not only access to services, but to ensure the voice and needs of the individual are respected and heard.

What does it mean to be an effective advocate? The following definition of effective advocacy provided by J. Dale Monroe, Community Services Oxford Regional Centre, Woodstock, Ontario is most helpful because it is particular to dealing with human services and it implies dialogue and partnership - two cornerstones of effective advocacy:

“Effective advocacy is defined as a non-violent empowerment and support process, through which families with relatives who are chronically ill or have a disability can constructively express dissatisfaction and contribute to creative solutions to problems existing in human service systems.”

The following approach to effective advocacy is a combination of strategies provided by J. Dale Monroe, and what we have learned over the years at the Family Caregivers' Network Society in working with family caregivers.

If at all possible, plan ahead. This means being realistic about the future (near or distant) if you have elderly relatives in the family. Chances are they will require some kind of support or assistance. Be aware also that the nature of caregiving is insidious - it can creep up on you ever so gradually. Find out what health services are available and how to access them. Locate community agencies that support elderly people, or provide support and information for family caregivers. The absolute wrong time to try and figure out what is available and how to access it is when you are in a crisis situation.

The advocacy role varies depending on the situation. If the family member or friend is in a care facility the advocacy role needs to be considered in a different light than, let's say, advocating for services in the person's home. The care facility is now the person's home where dialogue and partnership are even more important as building relationships with the staff becomes the focus. The fear of recrimination by staff if you “complain”, although mostly unfounded, can also become a factor. The impulse is to not say anything and this can be just as destructive as being aggressive and obnoxious. The ability to constructively express dissatisfaction or a problem requires assertiveness. A key trait of an effective advocate is the ability to be assertive. J. Dale Monroe offers this definition: “Assertiveness can be defined as the direct, honest, comfortable and appropriate expression of feelings, opinions and beliefs, through which one stands up for her/his own rights without violating the rights of others.” Nothing exacerbates a situation more than when a person, in the process of exercising their own rights (or those of another), tramples on the rights of others, including the rights of those who are in the position of making decisions and providing a service.

“Get the big picture” refers to the importance of understanding how the system works. Whether it’s understanding how to access services; the rules and regulations of the care facility your family member is now living in, or who is in charge on a hospital unit, it pays to become familiar with the “lay of the land”. This can save you valuable time and prevent unnecessary stress and frustration.

Timing your advocacy efforts carefully can make the difference between managing the problem or exacerbating it. Being aware of your feelings and checking yourself emotionally before approaching someone with a problem is a good idea. Because we are trying to act normal in an abnormal situation - emotions can run high where you run the risk of making mountains out of molehills. For instance, at the onset of a hospital admission, and if the individual is not already receiving home care services, you will need to identify the person who does the discharge planning to ensure there are appropriate supports for them when they are sent home. If the individual is already receiving home care services, their case manager or social worker needs to be contacted regarding their stay in hospital so planning for additional service on discharge, if necessary, can be arranged.

In facility care situations, find out what the procedure and process is for raising concerns, and who you speak with and when. For example, if you are concerned that your mother’s toileting regime is not sufficient and she is wetting herself, don’t attempt to address the issue at the time you go in to help her with her lunch. Meal times are very busy times in a care facility and you probably won’t be successful, not to mention running the risk of agitating the staff. Arrange to meet and talk with the appropriate person at a time when a discussion can occur where both parties will be able to listen to each other.

In the case of a serious or continuous problem, don’t go it alone. There is strength, power and support in numbers. Whenever possible, families should work with established groups or individuals in trying to secure a resolution, for example, a family council in a facility if they have one, an appropriate agency or consumer advocacy group (like the Family Caregivers’ Network), or an individual such as your local political representative. Be willing to compromise, as politics is the art of compromise. Results are the goal - revenge and ego-driven self-interest can do more harm than good.

Finally, don’t forget to express appreciation and show support for those who were helpful in solving the problem or concern. Successful resolution of a concern or problem in partnership with others strengthens relationships that, in the long run, benefit everyone. Expressions of appreciation when things are going well or when someone has been particularly helpful can motivate those who provide service to want to provide you with the support you need - because you can’t do it alone.

By Lorna Hillman

Eight Rules for Improving Advocacy Effectiveness

1. Never use cannon where a peashooter will do.

When family members are overly negative, aggressive or obnoxious, they risk being avoided and labelled "sick" and often alienate potential supporters and problem solvers.

2. "Get the big picture".

In order for the system to respond to their particular needs, it is first helpful for family members first to be able to visualize the wider context in which problems exist and the various factors influencing the decision-making process.

3. Time your advocacy strategies carefully.

Family members sometimes fail to recognize that proper timing is essential in order to have their concerns heard and addressed properly.

4. Use the "cards you've been dealt".

Too often, families fail to use the "cards they've been dealt" to turn their particular situation to their advantage. For instance, most families of people with disabilities possess inherent cohesion, skills and resources that can greatly facilitate the advocacy process.

5. Don't "go it alone".

In terms of effective family advocacy, "going it alone" is usually unproductive or even destructive. There is strength, power and support in numbers: whenever necessary, families should work closely with established groups (e.g. professional organizations, agencies and consumer groups) and influence individuals in trying to secure what they need.

6. Be willing to compromise.

Politics is the art of compromise, and families today must advocate in a very political world. In the end, results - not revenge or egotistical, self-interest - should be the family's overriding goal.

7. Humanize the concern.

In order for the family members to be successful advocates, they should try to humanize the presentation of their concerns in such a way that decision makers feel the uniqueness, the validity and the urgency of the request.

8. Express appreciation and show support to helpful problem solvers.

Sometimes family members who have had their concerns successfully addressed fail to even thank or otherwise support helpful professionals, managers and decision makers.

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By J. Dale Munroe, Community Services Oxford Regional Centre