

Creating a Support Network for Someone Who is Seriously Ill

by John Hain and Jennifer Allen

WHAT IS A SUPPORT NETWORK?

A support network is a logical extension of personal support. The main difference is that the challenges faced by the individual are too overwhelming for him/her to manage with limited help of a spouse, partner or friend. In this case, it becomes preferable to look outward to the greater community for expanded support. This can apply to situations such as a serious illness, recovery from an accident, major surgery, childbirth or after the loss of a loved one—any situation requiring an extended period of physical and/or emotional care. For the purposes of this article, we'll be applying this concept of help to the situation with a life-threatening illness.

APPEALING FOR HELP

One of the most difficult roadblocks to getting help is often asking for it. For someone struggling with a health crisis, this may not be a realistic possibility. The asking may need to be done by a family member or friend. *Who* to contact then becomes the question. It would be ideal if everyone had a list of people to contact for support in the event of a crisis. Unfortunately, few of us have composed such a list. Personal computers, e-mail, cell phones and written address books are good starting places. Contacting the wider community via e-mail is almost essential in today's e-world and can result in extraordinarily rapid response.

The closer one is to an overwhelming crisis, the more likely one will need others to help with clear thinking, decision-making and consideration of the wider range of possibilities for support. A good next step, therefore, is to gather a few support-minded people who can put together a list of contacts, review the challenges, help brainstorm problem areas and facilitate a course of action before the support network's first meeting. This group should include one or two committed individuals capable of being *coordinators* of the greater support network.

Working closely with the caregiver and patient, the *coordinator* makes a list of what specific types of help are needed and the scope of support desired by the various parties. For instance, there may be a caregiving spouse who needs to work or children who need to be cared for after school. Each family member needing support may require a separate sub-team created to provide his or her care. The list of needs will later prove critical to members of the support network who are seeking to identify ways they'd like to help.

ORGANIZING THE SUPPORT NETWORK

The coordinator, along with the few others initially planning the support, hold an initial meeting of prospective support network members. Potential members can be drawn from any available lists of friends, neighbors, community members (from church, school, sports and various organizations) and family. Personal contact by phone, when making the invitation to join the support network attend the initial gathering, will elicit a better response than e-mail alone, when possible.

The meeting has several purposes. One is to communicate the condition and situation faced by the patient, as well as the caregiver and any dependents. Another is to let people know how a network of support works, giving examples applicable to the situation. The third is to share the list of anticipated needs (including material items) and invite those interested in being a part of the network to and identify what they'd like to help with and how often. Contact information and availability are collected at this time, as well. The book, *Share the Care* (Capossella/Warnock, 1995) has very helpful, pre-made forms that can be copied for this meeting.

Helper's information can then be stored on a computer database program (such as an address book), which can then be searched and groups created to form various teams of support (such as meals, rides, body work, emotional support, children's help etc). Any large team may best be assigned a team captain who can relay specific instructions and requests for help to the other team members. Team captains are supplied with a roster of their team members and contact information. The coordinator should supply the patient and primary caregiver(s) with copies of the support network master list (including teams and team captains).

Each week, the coordinator communicates with the patient/caregiver, relaying updates in medical status and needs to network via email. Applicable teams respond to specific needs and the coordinator fills in the week's calendar with the services (based on availability of help and need of patient/caregiver). S/he then gives the calendar (in person or e-mail) to the patient/caregiver. It isn't always possible to meet all the needs listed. The goal is to match up as many as possible using skills/interests/availability of a large group of people. The saying "Many hands make light work," is a burnout-preventing concept. Organizing those many hands so they don't feel like "Too many cooks in the kitchen," is the key.

PREVENTING BURNOUT

One of the great advantages of a support network is that the patient/caregiver can choose to communicate with the support network members primarily through the coordinator, thereby preventing many unwanted phone calls and messages. Likewise, their peace and privacy can be maintained by limiting visits by appointment only—again arranged through the coordinator. Requests for specific forms of manageable communications, such as postal mail or e-mail, can be made to the network through the coordinator. In some instances, when the demands are not too overwhelming and if most of the members have email, periodic updates and system-wide requests from the person in crisis or his primary caregiver(s) can be made directly via e-mail, bypassing the coordinator. * There are currently website services for these kind of communications where one person can log (like blogging) medical status and others can check for updates and make comments. See www.caringbridge.org

As early as possible, all network members must be educated or reminded about the importance of exercising healthy boundaries and listening skills whenever relating to the patient/caregiver. Boundaries can take the form of saying "no" when needed, balancing their help with hearty doses of self-care and not unloading worries and grief onto the patient/caregiver. The last thing the patient/caregiver needs is to care-take the unaddressed emotions and needs of their support network. This can be tricky at times because helpers do have feelings about what is happening (anticipatory grief, resentment, stress, etc.). They may also have ideas about how things will go (getting better/dying) and what helps (latest treatments, positive attitudes, prayer, etc.). While the needs of the patient/caregiver are paramount to those participating in the network for the purposes of the network being helpful vs. counterproductive, it is imperative that helpers get outside support for themselves as needed to prevent overwhelm and burnout.

It's ideal to form an *outer circle* of support when possible because of the unknowns inherent to a serious illness: how long it will go on and whether the person will die from it. This team is designated to offer emotional support via a non-judging, listening ear for the inner circles of the network; making themselves available by phone, e-mail or in person. Support network members are encouraged to process any distressing thoughts and feelings as they arise in order to be best carry out their support role. It's the same concept they tell you on airplanes: "Hold the oxygen mask to yourself first, so you're able to help others." Self-care is what keeps the helper/helpee relationship thriving, creating opportunities for connection and meaning. Martyrs only muddy the water.

Periodic gatherings may provide the network members an opportunity to congregate and celebrate each other and the journey of the patient/caregiver. Because there will be some network members with roles behind the scenes, this can provide a good opportunity to acknowledge their contributions. If the patient and/or caregiver are able to attend such a gathering, there can be great opportunities for intimate sharing of thoughts and feelings with the network members, who often become like extended family.

If death becomes probable from the illness (i.e. patient discontinues treatment, begins hospice palliative care and begins preparation for dying), it is an important time to hold a meeting for the support network to "shift gears" according to change of needs and focus of support. This can bring up many feelings for helpers. Some may be dealing with their own anticipatory grief and may need to get additional support from the outer circle, join a support group and/or step back from direct contact with the patient for a while. This may also be a time to shift roles. The coordinator and team captains may want assistance from alternates at this time, if they haven't already. Helpers on the periphery may be better skilled in simply "being" with the patient and those who helped with particular tasks (i.e. rides to treatment) may take a break or choose from the new list of needs applicable to the change.

If the patient does die, the support network can gather for members to share grief, debrief and honor the person who has died. If desired by caregiver, the network can look at ways to help with services (i.e. put together a memorial collage, help write obituary, assist caregiver in making arrangements, etc.). It may also be helpful to continue some level of support for caregiver, if s/he desires it.

The patient may also get better (i.e. remission). In this case, a similar meeting should be held to celebrate, debrief and shift into a slow weaning of support as indicated by changes.

In either case, the helpers often become close through the course of their support. Making time to gather for mutual sharing and reflection can create a meaningful closure for the network. Long lasting relationships may have taken hold out of such an intimate endeavor. Future networks can be formed when needed as each member takes their experience of a support network with them into other circles of their lives.

SNAGS AND REWARDS

The bad news first: there can be snags. The difficulty isn't always only in asking for help but receiving it. The parties needing help must adapt to the presence of support and learn how the system can best serve them. To some degree this will necessitate a period of trial and error to find out what works best before settling into a new routine. Since being generously supported is foreign to most of us, simply receiving an abundance of help can be challenging, and bring up various forms of resistance to the process. Because visits and services often need to be scheduled through the network coordinator, the patient/caregiver may experience a loss of spontaneity and freedom. In addition, having

people coming into their home, even if to help, can feel like a violation of privacy. Close friends, family members, and primary caregivers may also feel hurt, jealous, or angry as outsiders take over some of their roles or alter their usual (comfortable) patterns of relating to the patient/caregiver (i.e. having to communicate through a *coordinator* vs. calling up patient/caregiver directly).

Because of these pitfalls, direct, respectful, ongoing communication is necessary within the network. The best place to begin is with the rule of thumb that everyone is doing the best they can *and* there may be considerable room for improvement. Therefore, helpful observations, suggestions, and questions communicated directly and honestly (to coordinator or during gatherings) should be encouraged.

The potential rewards of participating in or being a recipient of such a network are multifold. We all know how good it feels to help, especially when we have so little control of our friend's the outcome (i.e. illness). When we choose to help in ways that honor our strengths and the overall balance of our lives, we are able to give without overwhelm, resentment or martyrdom. Helping allows us to maintain contact of sorts with the patient and caregiver, while it also connects us with a group of people joining forces in a difficult situation instead of looking the other way. In giving, we receive.

As recipients, it can be a huge relief to know we aren't alone in such hard times. When we are able to let others into our tightly knit world of patient/caregiver, delegate and surrender the idea of doing everything ourselves; we are vulnerable. In receiving, we give.

Though the road may be long, with steep hills and muddy ruts, the mutuality of a well-functioning support network can bring great meaning to the journey and the relationships formed along it.

A helpful book and website:

Share the Care by Cappy Capossela and Sheila Warnock (Fireside, 1995, 2005) www.sharethecare.org

Helpful website

The Compassionate Care Alliance: www.caringresources.org