

## Setting up a Support Network for Someone with a Serious Illness

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### Issues that Get in the Way of Setting up a Support Network:

#### Clearing Roadblocks to *Receiving* Help

- **Block:** Patients and Caregivers don't want to burden others.  
**Clear it:** Help is mutual, it keeps people from feeling helpless and gives them meaning.
- **Block:** Fear of request for help being rejected.  
**Clear it:** Allowing for a "No" means you can trust a "Yes"
- **Block:** Fear of losing privacy, independence, and control  
**Clear it:** Affirm support as patient/caregiver led, respect communication protocol. INTERdependence is healthy and empowering .
- **Block:** Delegating and organizing help is overwhelming  
**Clear it:** Structure of a support network includes a buffer role = 1 person to tell needs & health update to weekly and *they* track it.

#### Clearing Roadblocks to *Giving* Help

- **Block:** Fear of illness and potential death of your friend.  
**Clear it:** Educate about anticipatory grief, illness, and remind that death is a part of living. When we face this reality, it frees us up to live more fully.
- **Block:** Plate is already too full.  
**Clear it:** If help is well matched to helper and his/her availability, helping can feel easy. Encourage boundaries.
- **Block:** Will over-extend out of guilt and become resentful.
- **Clear it:** Educate on use of Boundaries. A "no" to the coordinator is easier than a "no" to the patient.
- **Block:** Will over-extend believing others won't do enough.
- **Clear it:** Use boundaries and trust group. Allow people to do their part – no matter how small or large.

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## Ready? Help is on the Way:

### You Don't Have to Do It Alone

*Person with illness and caregivers:* Think outside the box for helpers. Family is great, but they may live at a distance and might be worn out. Try looking through email contacts or address books. Co-workers, churches, people from exercise classes, school, neighbors, old friends, even people from a distance— brainstorm a list without editing. Give them the *opportunity* to help.

*Helpers:* Many hands make light work. Let others do their part and stick to what works for you at the time. There are bound to be times where being part of a support network feels challenging – either logistically or emotionally AND there is also great potential in participation and belonging to a *group* that is helping.

### Identify Needs

*Person with illness and caregiver:* Again, think outside of the box—way outside. The more needs you can identify, the more likely it is there will be a well-matched helper. Not all needs will be filled. Having a big list provides more options for those helping. (i.e. - You may get someone who can walk your dog every Wednesday, but not a meal on Wednesday.) Lightening the load in any way possible helps the person who has the illness focus on their health and the caregiver to focus on their role and taking care of themselves.

*Helpers:* Be thinking about what you can offer: skills, talents, interests and time availability. At the initial meeting of the support network, you will have a chance to see what need you are best matched with. You can also offer something not on the list; it might be something the family didn't think of yet.

### Initial Meeting:

The person who is ill and/or caregiver may both be present at this meeting and share what the current medical status and anything about help that they want the group to know (i.e. “we are tired of talking about this and want visitors to talk about normal daily stuff”, or “no drop in visits please.”) They can also have the meeting facilitator do this. It is important for everyone who may be in the support network to be kept in the loop with information and it prevent misinformation going around. This meeting is an opportunity to “get on the same page” with medical information, issues that come up and how to deal with them, orient to the model of help (i.e. Share the Care), see where you best fit for helping (matching your interest/availability with needs), and meet the other people on your helping team.

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### How it Works in a Nutshell: (This might differ slightly with Lotsa )

- You fill out a paper with your contact info. and specifically what you'd like to help with and your availability.
- P&Cg communicate their needs and health updates to the Coordinator.
- Coordinator then communicates with group via email /website/phone to request help and provide updates. (Coordinator is the buffer/channel between P & Cg and the helpers. It is important to respect this person's role)
- Coordinator uses this information to fill P & Cg's "needs of the week" Thursday (confirming helpers) and returns a filled in schedule to them by Saturday.

### Helpers - Please Do:

- Respect P&Cg privacy: Follow protocol of communication through Coordinator unless P & Cg request other arrangements.
- Know your limits. Keep the help clean. Say "no" when you need to so your "yes" can be trusted.
- Others in group to do their part and value their contributions.
- Let your help be congruent with who you are: Choose to help in area that interests you, you have skills in, and you are comfortable with.
- Show up clean & clear: Have emotional support for yourself so you can be present with P & Cg when you are with them. No martyrs and no strings!
- Go with the flow: Be flexible and present. Change is the name of the game with illness. Release your agenda when you show up to help.
- Allow hope and grief. Both are natural responses to a serious illness. It is a challenge to allow for both simultaneously.

### Issues that can come up along the way

**Frustration:** When helpers think the person who is ill should/shouldn't do particular treatments and want to offer advice. This is frustrating for both parties. As helper, this is not your job, unless asked. Respect wishes of Pt/Cg

**Helpers' Resentment:** An indicator that one is helping too much, not matched with the right helping task, or has an agenda when helping. Re-evaluate help and clear any strings with help.

**Jealousy/Resentment:** When Pt/Cg idealizes non-ill helpers having "normal" lives and re: loss of privacy & control. Provide good listening without personalizing. Let the feeling cloud move through.

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**Guilt** - Helpers feel like they aren't doing enough or feel bad about having health. Reaffirm the importance of doing only amount of help that can be sustained so it remains mutual and encourage giving thanks for health. Remind them they didn't cause illness and don't have control of it.

**Talking About vs. With:** Avoid gossip. When possible communicate directly (exception: unload with co-helper vs Pt./Cg.) Know everyone is doing their best. You are a team with a common mission. If you talk about – make it kind.

**Group Conflict:** There are many ways to do things. Respect the basic structure of the group and Pt/Cg wishes. Have a group meeting so all ideas/concerns can be heard and be sure to re-affirm mission of group. Keep conflict separate from Pt/Cg.

**The big "D" word:** Sometimes the person who is ill and/or the caregiver and/or group members can be out of sync with acceptance of death as a possible, likely, or inevitable outcome. Keep health status updates accurate and address death at initial meeting to break taboo. Introduce as a fact of life that a serious illness brings attention to. It is an opportunity (for all) to take care of the "business" of being mortal (ie advanced directives). This frees one up to live. Normalize anticipatory grief and need to hold both hope and grief. Respect the person who is ill's process with this. Get support outside circle as needed.

### **Helping Kids Who Have a Seriously Ill Loved One**

- Listen, reassure and answer questions honestly.
- Keep routine as much as possible & discuss changes.
- Invite their help with caring for person who's sick.
- Allow child's lead on contact/visiting with person who is sick.
- Find ways they can help.
- Create support network that includes support for kids.\*
- Encourage outlets for sharing and expression.
- Let school, church, coach (etc.) know what's happening.
- Get support for yourself, so you can best support your kids.

### **Additional Points for Kids whose Friend's Parent is Seriously Ill**

- Tell your kids what is happening with their friend's family.
- Encourage your kids to continue playdates/contact with friend.
- Encourage your kids to express their care with homemade cards.
- Reassure them that you are healthy (they will fear it could be you).

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- This may give you opportunity to reassure kids “if it happened to you”
- Remind them there is a community that helps and they would be cared for.
- Be honest with not knowing (outcome). Normalize uncertainty.
- Encourage physical activity/play and creative expression. Fun is important.
- Let them see and participate in help, it is a good life experience to give/receive help.
- Realize that it is most often adults who are uncomfortable with being around illness & discussing death. Kids are often simply curious until adults teach them otherwise.

### *“What should we tell the children? We don’t want to frighten them.”*

I’ve heard this concern voiced numerous times over the years in my work with families who are dealing with a loved one’s serious illness. The simple answer is: the truth.

With a serious illness, the truth can also be the most difficult answer. Not only because we want to protect our children from imagining the worst-case scenario, but because we adults (doctors included) don’t always know how the illness is going to play out. When children ask big questions there often isn’t a concrete “yes” or “no” response. If you really don’t know, say so. Add your hope and plans to the answer. It could sound something like this:

(In this case child is around six and Mom is recently diagnosed with advanced cancer)

**Parent:** “I went to the doctors this week and found out I have a sickness called cancer. It’s when something that doesn’t belong in my body is growing inside.”

**Child:** “Will it go away?”

**Parent:** “I’m don’t know. The doctors are going to give me medicine to help me try to make it leave or at least keep it from hurting me.”

**Child:** “Will you die?”

**Parent:** “I don’t know if I will die from this illness. Usually people live to be old and that is what I’m hoping to do.” Child: “What if you don’t. Who will take care of me?”

**Parent:** “If I died, your Mom would take care of you. Uncle Charles and Aunt Karen would help her.”

Believe it or not, this conversation would probably end here if the child is younger. There may be emotions (older children), behavior (younger children) and similar questions (both) to follow as the child digests the news. The important point is the child has begun adjusting to what is actually happening (and not what they’ve imagined for better or worse) and the parent has established trust through honest communication and reassurance from the beginning. This will serve their relationship no matter where the illness ends.

Contrary to this type of conversation, and what seems to be our first instinct, is to protect and reassure our children through vague white lies. We might want to

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tell them (and we might really believe it ourselves) everything is going to be “fine.” Or we may not tell them anything, thinking we’re sparing them difficult feelings. The problem here is that children pick up all sorts of cues from us. Their ears are much bigger than they look and their imaginations ten-fold. Usually, they already know something is wrong and have already worried about the parent becoming disabled, not being able to care for them and dying. Not talking about it gives them nowhere to go.

### ***Talk, reassure and then listen.***

Once the “elephant in the room” is identified, give the child/teen some time to adjust, ask questions and share feelings/concerns. Younger children will often bounce off to play and we may wrongly assume they don’t understand. Though they may not comprehend the implications of illness and the finality of death, they do understand something has changed. Their emotional adjustment often shows up unrelated to hearing the news. For instance, a toddler may cling to a parent and be more anxious upon separation. A school-aged child may return to bed-wetting or may have melt downs over seemingly insignificant issues. This age group is prone to “magical thinking” meaning they did something to cause the illness.

### **Resources:**

[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com) This is a great platform to organize and keep a support network up and running efficiently. It takes some initial data entry but then leaves much of the coordinating to the helpers to sign up directly online. [Private groups help one family.](#) [Public community groups](#) help many families and anyone in need can request help from them. As a helper in a public group you may not know the person you are helping. The only missing piece here is contact with your network. This is where the “initial meeting” and occasional follow up meetings are key.

***Share the Care*** book is the “bible” of support networks. The website has the forms available for download and one can access resources, others’ experience and share theirs. [www.sharethecare.org](http://www.sharethecare.org)

<http://www.caringbridge.org> is a [website](#) that allows someone to communicate with others, via social networking, about their own or a loved-one’s medical status. It is blog-like and can be empowering to the patient and/or caregiver to write about their experience and receive communications from others. This isn’t for setting up support logistics but more for keeping abreast of medical and emotional conditions. It is a way to stay connected and be supportive from a distance as well.

Please visit my website for specific book lists for adults and kids, more resources, articles, etc. [www.jenniferallenbooks.com](http://www.jenniferallenbooks.com)