

# Five Steps for Creating Your CareBrigade

*Partner in Your Own Healing by Creating a Team to Support Your At-Home Recovery*

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**CareBrigade** is a Patient and Family Engagement System, that empowers newly-diagnosed Patients facing cancer or any life threatening disease to interact as full partners with their doctors, asking questions, making informed treatment choices, and managing their emotional wellbeing, and resting in the support of a loving community of friends, family, colleagues, acquaintances, and neighbors, at every stage of the Patient's medical journey.

Your Friends and Family members chosen by you (even those living at a distance), discovers ways to contribute to you, emotionally, spiritually, medically, and practically, from early in the Diagnosis, through extended treatments and/or surgery, all the way to helping with your At-Home Recovery. The idea is to customize your CareBrigade to empower you to support yourself during your entire healing journey by mobilizing friends to fill whatever predictable "support gaps" are identified by you, the Patient. And YES, your CareBrigade can support your Caregiver too.

Your CareBrigade can be as small or as large as needed, made up of Roles rather than People—anywhere from 3 people each taking on several Roles, to 50 + people helping out with at-home tasks, during any long term treatments or surgery. If there are TOO MANY volunteers in one category (ex. meals) for a CarePartner and/or a caregiver to manage over an extended period of time, a Brigade Coordinator (ex. Daily Bread Brigade) can be appointed to manage them. Once established, the Patient, caregiver, or CarePartner can resurrect and use these CareBrigade teams again and again, whenever needed, using email, phone or text.

Your CareBrigade begins with one special person (your CarePartner) chosen by you. The CarePartner's Role is to be a compassionate companion to the Patient, accompanying you on your medical journey. A CarePartner listens compassionately, supports you (in the way you like to be supported), lets you vent and feel what you feel, stands in for you when you are too stressed, tired, or ill to manage people or tasks or details, and buffers you from needless worry, negative energy and people you don't care to see.

Different people can play different Roles at different times, or one person can play 2 or 3 Roles at the same time. In the beginning, before you choose a Scribe, Spiritual Advisor, and Medical Advocate, for example, your CarePartner might play any or all of those Roles for you, by going to early doctor's appointments or scary tests with you. This allows you to begin with as few as 3 People (one of them is you) and still have what you need to be both empowered and supported, until other friends and family can be invited to play.

## Step 1: Getting Started – Choose your Core Support team (5 key roles)

Choose and invite people who you love (or minimally like a lot) to become your Core Support team playing the Roles below. Persons asked to serve in any of these 5 Roles should be your favorite people and receive a personal invitation preferably from the Patient, explaining why they were chosen and what the Patient will need from them.

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**CarePartner:** Someone to stand in for, stand up for, or lead for you, the Patient, when you can't deal with people, choose not to, or when you are too ill or "zonked" to do so. This Role can sometimes be fulfilled from a distance.

- Review the "Choosing Your CarePartner" Form to learn what characteristics are recommended for a successful CarePartner and help you choose who might be yours. Download this Form at the Roles Page: under Patient or CarePartner.
- Share with your chosen person why you chose them. Ask them to review the entire Website. Download and print out the 5 Steps Booklet.

**Scribe:** Someone to accompany you, the Patient, to your doctors' visits, to take accurate notes, and to remind you what questions you want answered. Before each visit, the Scribe will help you brainstorm (and then record) your questions, so you won't forget. This Role needs someone who lives close to the Patient.

- Review the Scribe's Duties to learn what is required. Download both Scribe's Duties form and the Scribe Prep form at the Roles Page: under Scribe. Ask your chosen person to review the Website and download those Forms.

**Medical Advocate:** A doctor, nurse, home health aide, or other medically trained person, for you to consult with, when you need assistance translating medical terminology, navigating the online maze of medical research, searching for and finding second opinions, and/or new treatment options. This person (or your CarePartner, Spiritual Advocate, or Scribe) can be invited to support you when hospitalized or during treatments, interacting with the medical staff on your behalf, during times when you might be "out of it." This Role can sometimes be fulfilled from a distance.

- Review the Medical Advocate's Duties on the Roles Page: under Medical Advocate. This page includes links to some useful websites, Apps, and forms for both you and your Medical Advocate. Ask your chosen person to review the Website and/or share with him/her what this Role does and how you envision him/her fulfilling on it. Ex. Doing online medical research on your behalf, helping you understand difficult medical terminology, and/or consulting with you in making complex treatment decisions.

**Communicator:** A good friend or relative, who is a good writer, someone with whom you already share medical updates, and whom you trust to respect your wishes as to how much to share. The Patient always gets to say... what is shared, and with whom. This Role can often be fulfilled from a distance.

- Review the Communicator's Duties on the Roles Page. Ask your chosen Communicator to check out Communicator duties, as well as the useful tools and forms, on the Web site. Check out links to CaringBridge.com and CarePages.org,

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sites that will enable you to update folks yourself, and lets them send well wishes back.

- **Spiritual Advisor:** Someone who will support you emotionally/spiritually, according to your personal spiritual and/or religious preferences, in the face of any fear, anxiety, or worry. This Role may be played by any compassionate friend (sometimes by the CarePartner) whose presence, sensitivity, and listening skills brings comfort and ease to most anything you do together. Although this Role can be done from a distance, feel free to invite another Spiritual Advisor who lives close by to accompany you to any medical procedure in which you would appreciate emotional support.
  - Use the Spiritual Self-Care Practices checklist (and other Self-Care Web links provided) to try out some Complimentary and Alternative medicine practices used along side traditional medicine, to promote healing and relaxation. (Find forms on Roles Page: under Spiritual Advisor).
- **Scheduler:** The Scheduler, a “tech-savvy” friend sets up a group email address book, using names from the Patient’s email address book, and sends a Request Letter and the Wish list to everyone in that group. The Scheduler (with a cc.to CarePartner) also accepts all replies. All volunteers, including their contact info, the tasks they say they will do, and any restrictions they share are compiled in an Excel spread sheet, simple enough to be used by a Patient living alone, to reach volunteers directly, by phone or text, as needed, for emergency errands, household helpers, baby sitters, etc. Much of this Role can be done from a distance.
  - The Scheduler could also set up and train a CarePartner, caregiver, or other tech savvy volunteer (try older teens) to set up and use an online tool like Lotsa Helping Hands, Take Them a Meal, or another online calendar application.

## Step 2: Develop a timeline and identify tasks where you will need help

Once your Treatment Plan has been decided, you will know the predicted timelines for treatment/recovery and the specific restrictions (ex. no driving, no lifting) you will face. Work with your CarePartner to identify any specific tasks you can predict that you will need help with and for how long, and customize your own Wish List to match.

## Step 3: Identify your list of potential helpers; send them a request to be part of your CareBrigade; compile a list of responses

Working with your CarePartner, look through your email address book and identify your list of potential helpers. Look for folks whom either have said, or are likely to say “Let me know what I can do to help.” Using the sample Request letter, work with your CarePartner to draft your Request (to be sent from your CarePartner rather than you- you don’t want to receive all those

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replies), include the predicted timelines you will likely need help. This Letter, emailed with your Wish List, reminds volunteers to only to do what they are good at or like to do, and asks them to share their restriction (ex. no weekends, no blood, driving only, etc.) Replies are emailed back to the CarePartner, not the Patient.

The CarePartner then works with the Scheduler to compile a list of volunteer responses, formatted in a way that you, the Patient, your CarePartner, and/or the Scheduler can use it to schedule the support you need throughout your chemo/radiation treatments and/or any surgical at-home recovery period.

### Step 4: Oversee the implementation of the CareBrigade throughout the treatment and recovery period

Once the At-Home Recovery CareBrigades are up and running smoothly, the CarePartner oversees their functioning, making sure there are no gaps in needed care, and addressing any Patient-stressing issues that arise. During the life of the CareBrigade, the CarePartner monitors any changes in the Patient's condition or treatment plan, and customizes the CareBrigade appropriately.

Volunteers, needing to cancel, etc. communicate only through the CarePartner, caregiver, or Scheduler. The CarePartner buffers you from dealing with too many people or any "negative" person you choose not to interact with, when you are not up to it.

If it becomes necessary to extend your CareBrigade's commitment for any reason, an email thanking the current volunteers for their contributions to date, with an updated Wish list request (and timelines) is sent to all the current volunteers, plus the ones who couldn't help the first time because of schedule conflicts (vacations, work commitments, etc.) and any new friends you have made. Ask group one to continue their service and the others to step up if it now works for them to help. Be sure your Communicator thanks and raves (on your behalf) about the people who have been so generous to date, and graciously forgives those that can't continue.

### Step 5: Complete the CareBrigade with Thank You letters and a celebration for the Team and Patient

At the completion of your entire medical journey, the Communicator (or you) must send a Thank You letter to all volunteers. If you choose, and are up to it, a potluck thank you celebration would be a fun way to thank everyone who volunteered (they love to meet each other) and to celebrate your recovery.