

GETTING A SHARE THE CARE™ (STC) GROUP GOING- WHERE TO BEGIN©:

1. Confirm that the caregiver and the person needing care agree to accept help.
2. Order two copies of the book *Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill* (links to purchase on www.sharethecare.org website)
3. Identify two people to organize the first STC meeting and give each a copy of the book. These can be neighbors, relatives, co-workers, acquaintances. One will serve as the Leader and the other, as the Coordinator. *Pay particular attention to Chapters 2-9 and see page 43 for desired qualifications.*

LOGISTICS FOR THE FIRST MEETING

These two people will work with the family caregiver and/or care recipient to figure out:

- **the care recipient's needs:** *see Chapter 5*
- **who to invite:** invite more than you think you will need as not all will be able to participate and invite them by phone and not by email *see Chapter 6*
- **best date for the meeting:** offer 2 dates and allow for 3 ½ hours. Select the date that most people can attend
- **where to hold the meeting:** it's important that the care recipient be at the meeting so find a place convenient for them. If their home is not an option, it is fine to hold it in someone else's home or consider a community center, office or faith institution.

PREPARATIONS FOR THE FIRST MEETING

After reviewing Chapters 2-9 the Leader and Coordinator will be able to run the meeting and:

- explain the STC systems to the group
- prepare needed forms for the meeting *download from STC website*
- Know which materials you will need to conduct suggested exercises

And it's always a good idea to bring food and beverages and/or ask others to contribute

WHAT HAPPENS AT THE FIRST MEETING

The Leader will take everyone through the exercises and the Coordinator will explain the forms, collect information and pair people into teams. The objective is for everyone to leave knowing the group is well organized, that everyone is informed of the situation (no hearsay) and feel a deep sense of purpose. The meeting flows as follows:

- **Introductions:** everyone introduces themselves and includes what they do for a living (this helps identify possible resources or needed skills)
- **Explain the situation:** the care recipient (or caregiver) shares details of the illness
- **STC systems:** Leader runs through the exercises and how the group will function *see Chapter 7*
- **Volunteer opportunities:** Coordinator describes all the ways the group can help
- **Forms:** group members fill out individual data forms and rate themselves on each job listed
- **Sign up:** individuals pick jobs they want to do and indicate the amount of time they can give. (No one is asked to do anything they don't feel comfortable doing)

FIRST WEEKS

The Coordinator will fill out the contact sheet *see page 91 for sample* and send to the entire team. Other matters that need immediate attention and that need to be shared with the team are:

- **emergency plan:** include telephone numbers and put on refrigerator as EMS knows to look there
- **money issues:** figure out how each person will be compensated for expenses incurred (**download from STC website:** important suggestions for organizing first weeks)
- **dietary restrictions:** list foods not allowed, allergies, etc. and preferred foods for the entire family
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SHARE THE CARE™
THE SEVEN PRINCIPLES© FOR GROUP CAREGIVERS

PRINCIPLE #1: SHARING RESPONSIBILITY IS THE KEY TO NOT “BURNING OUT”

- No one person has to be in charge all the time.
- No one person has to deal with every crisis.
- No one person has to be “on call” every single day.
- No one person has to make all the decisions, all the time.
- No one person has to try to run his own life plus the entire, complex life of his or her loved one.
- Let the others do their share. They want to. They need to.

PRINCIPLE #2: IT WON'T WORK UNLESS EVERYONE GAINS SOMETHING PERSONALLY

- Recognize the importance of personal rewards.
- The patient will feel too guilty unless you gain something too.

PRINCIPLE #3: KNOW YOUR LIMITS AND STICK TO THEM

- Whatever you can do to help is enough.
- If you can't or don't want to do something, don't. (Someone else is probably good at it, or loves to do it.)

PRINCIPLE #4: THERE'S NO ONE RIGHT WAY TO DO IT

- If there are ten members, there will be ten ways to do it.
- It's okay to disagree.
- Agree on basics, then follow the rules. You may learn some amazing things.

PRINCIPLE #5: ANYONE WHO WANTS TO HELP SHOULD BE ENCOURAGED

- A group needs eight, but ten is better.
- If main caregivers are “real” family, they must be willing to broaden the circle.
- “Free-floaters” (people who can help only occasionally) are very important.

PRINCIPLE #6: TRUST THE GROUP; SUPPORT EACH OTHER

- The group has power.
- Someone has the talent or the answer.
- Go on vacation. The others are there.
- Share your feelings; share the goal.
- Spend time together; acknowledge each other.

PRINCIPLE #7: KEEP YOUR OWN LIFE IN GOOD WORKING ORDER

- Take care of yourself, or you won't be able to take care of the patient.
- Exercise, rest, stay in “life.”
- Lighten the rest of your load.
- Don't forget about your own family and friends.
- Let your friends, your boss, and your own family know what you are doing.

SHARE THE CARE™ IMPORTANT SUGGESTIONS FOR ORGANIZING DURING THE FIRST WEEKS©

Be realistic. You will not be able to solve everything needed in the first weeks.

Prioritize. Handle the most important jobs first: medical issues (doctor appointments, getting prescriptions filled, making sure diet is being addressed, taking meds), food shopping and meals, support of children or elderly person in family, and home safety.

Deal with money issues up front. How will the group be reimbursed or get the funds to pay for groceries, and other expenses? Create a “slush fund jar” with patient’s available cash and ask members to put (initialed) receipts back in the jar—or find another way to track expenses. Is there a need to raise money if patient has very little?

Create “Critical Information Pages” as soon as possible. Make sure everyone gets a copy and post it on the refrigerator and in the Medical Folder. Make sure the group knows correct person(s) to call. (For example: If care recipient is with hospice, then hospice should be called rather than the EMS. Determine this as soon as possible with hospice.)

Find out diet restrictions and food preferences BEFORE people start preparing meals. Avoid making meals and treats the person/family cannot eat, or dislikes. Learn about any allergies (food or otherwise) in the family.

Continually think about others who might be able to help or join the group. Club friends, church/synagogue goers etc. Always be on the lookout for these folks, who can help in a pinch.

Research free services in the community that can supplement the efforts of the group especially if it is small. Contact the local Department of Health, or Department of Aging. Local Meals on Wheels. The ALS Association or American Cancer Society or other relevant organizations.

Start to create a plan for long-term issues such as: the patient and their family are scheduled to move in two months, or their son needs to visit prospective colleges in the fall, or the patient will eventually need a wheelchair, or the spouse needs to return to work.

Don’t promise more than you can deliver. Don’t feel guilty if you are not Superman or Superwoman. Everything the group can do will make a huge difference. As a caregiver you cannot afford to become ill or overwhelmed. Take good care of yourself.

Tell these people, as you come into contact with them, about the group and what you are doing: the doctor’s receptionist, pharmacist, mailman, or the building doorman. Be friendly—learn their names to help ensure that things move along smoothly. These people may go out of their way to help just when you need it the most.

Support your fellow caregivers and get to know them. A positive attitude can breed a warm sense of collaboration among the group members. Stop and chat with others when changing shifts or after doing a job together. Share experiences and feelings. You are building what might very well become some precious lasting friendships.

CREATE AN EMERGENCY PLAN
To be attached to Yellow Pages

The following information is **CRITICAL** and must be attached to the Yellow Pages. Every person in the group should carry their yellow pages with them at all times. A copy of the yellow pages should be kept near every telephone in the patient's home as well. And post a copy on the refrigerator door so that it is accessible to a visitor.

If care recipient is in hospice care you want to call them rather than the EMS especially if the patient has a DNR (do not resuscitate) order.

CRITICAL information that needs to be included:

- clear written driving directions to the home - for EMS personnel
- name/telephone number/directions to appropriate hospital ER
- hospice/palliative care numbers, faith community number, service that provides nurse's aides
- ambulette services, taxi service, car service (contact names at each)
- allergies (food or otherwise) or special condition needs

What to take to the ER

Picture ID, Medical Insurance Cards, Central Medical File (location in house)

Medical History Form, Medications List, Dosage Chart, **Advance/Medical Directives**,

Medications box, water, yellow pages

Have a "Just In Case" bag ready to take. It should include everything patient needs for their personal comfort. This needs to be determined up front with patient/family caregiver.

Who to call if going to ER

Medical Captain

Family, healthcare proxies

Captain(s) of week

What to do after EMS call

Ask for help

Remember to lock the house when leaving

Call phone tree

Other needs (kids, pets)

Other information:

- Dietary restrictions for making meals, allergies – whole family
- Foods patient AND family like or dislike
- Suggestions for outings: movie, park, library, café, lunch etc.
- Welcome gift ideas: music, toys, favorite flowers, audio book on CD etc.

PLUS – anything else that the family or group feels is important to include.