



**The Transition Network's
Caring Collaborative
2011**

GUIDE TO CREATING A CARING COLLABORATIVE IN YOUR COMMUNITY

Supported by a grant from the New York State Health Foundation

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FORWARD

"The Caring Collaborative has created such a level of comfort. Staying in my home, in my own community as I get older is something I want to do, and this can really help."

The Transition Network (TTN) is a national non-profit organization that helps women over 50 explore their next steps by using the TTN community to support each other as they move forward. It is a groundbreaking organization for these women as they face new challenges in health, finances, family and friendship bonds, and second careers. Living and aging in community is a priority of TTN.

Founded in 2000, TTN now reaches 7,000 people in 44 states through its online newsletter, membership, and workshops. The basic building blocks of the organization – from its inception – are peer groups of about 10 women who help each other with, “what’s next,” and life’s transitions. Peer groups provide an intimate forum to discuss all sorts of interests and concerns, ranging from photography and travel to careers and retirement. As friendships form and trust develops, these peer groups have become a natural support network for women to turn to when they need help. See our website at www.thetransitionnetwork.org.

In 2009, TTN launched the Caring Collaborative, an innovative model of healthcare support built on human connections that exist within informal communities. Book clubs, church congregations, neighborhood associations and Rotary clubs are types of informal communities where people come together based on common interests, values, and/or geography. They are a rich repository of social and human capital, and with motivation and organization, can become a powerful resource for healthy aging through the mutual exchange of information, services and care.

The Caring Collaborative pilot was made possible by a grant awarded to The Transition Network (TTN) by the New York State Health Foundation in December 2007. More than two years of research and planning went into the design of TTN’s Caring Collaborative model. Members researched existing models for “aging in place”; conducted surveys and focus groups to assess what supportive care services were needed in the TTN community; and wrangled with the issue of asking for help – why it’s such a difficult thing to do.

Thanks to the grant funding and the commitment of more than 40 talented volunteers, TTN was able to develop, organize, and operate all the benefits of such a group under the Caring Collaborative umbrella. More than 200 members of the TTN New York City chapter joined the Caring Collaborative pilot. The group logged close to 1,400 hours of service and information exchanges in just one year, involving 538 events. Self-reported benefits of participation include:

- Relief from the stress of worrying, “who will take care of me?”
- Pleasure of being part of a community committed to helping one another
- Heightened sense of well-being and competence

The model has captured national attention and interest. The Institute for the Future featured the Caring Collaborative in a report about future trends, calling the Caring Collaborative a preview of what caregiver networks might look like. Gail Sheehy features the model as a “winning strategy” in her new book, *Passages in Caregiving*, and a host of community organizations across the country has expressed interest in the model.

This manual shows how to leverage the power of informal communities to provide health-focused support by and for members. It provides a roadmap based on TTN's experience, along with tips and tools developed along the way. While the Caring Collaborative was created by and for a middle-class community of women 50 and older, this manual takes care to show how the model can be replicated by all types of communities. The model can be scaled to fit the size and needs of your community, and requires a minimal financial investment because it runs largely on human capital. Whether you belong to a small book club, a medium-sized food co-op, or a large alumnae association, the Caring Collaborative model can work for you. This manual will show you how.

Guide to Creating a Caring Collaborative In Your Community is one component of the Caring Collaborative. In addition to this manual, TTN offers two other manuals: *Creating a Vertical Village in a High-Rise Building*, for creating a healthcare support network in apartment buildings or neighborhoods; and *What You Need To Know When You Go To The Hospital*, for understanding and influencing emergency room and hospital discharge practices. The Caring Collaborative is managed by a dedicated team of TTN members who are professionals in medicine, law, government, business, social work and journalism, and who have put together these manuals.

All of these manuals are available free of charge to organizations interested in offering a version of this program suited to their needs. The manuals are written in Word and use Word's standard Table of Contents. They can be modified and customized to community needs. We do ask that if you use these manuals, you respect our copyright and credit The Transition Network by keeping the copyright statement in the document. And, please let us know at www.thetransitionnetwork.org/ContactUs how use of these materials helped improve life for your community.

Table of Contents

THE CARING COLLABORATIVE MODEL	5
POWER OF INFORMAL COMMUNITIES	5
BUILDING BLOCKS FOR A CARING COLLABORATIVE.....	5
ADAPTING THE MODEL TO FIT YOUR NEEDS	6
GETTING STARTED	8
FIRST STEPS	8
FINANCIAL CONSIDERATIONS	8
<i>How to Fund a Caring Collaborative</i>	9
<i>Charging Membership Dues: A Lesson Learned</i>	9
GATHER INFORMATION	10
<i>Build Scenarios</i>	10
CUSTOMIZING THE MODEL	12
<i>Service Corps</i>	12
<i>Member Information Exchange (MIX)</i>	13
<i>Health & Wellness Resource Directory</i>	15
<i>Education Programs</i>	16
<i>Neighborhood Groups</i>	17
<i>Time Bank</i>	17
MEMBER RECRUITMENT	20
<i>Membership Guidelines</i>	20
<i>Orientation</i>	20
<i>Orientation Options</i>	22
<i>Member Agreement Form</i>	22
OTHER CONSIDERATIONS	23
<i>Who Can Join?</i>	23
<i>Liability Issues</i>	23
<i>Governance</i>	24
STRENGTHENING YOUR CARING COLLABORATIVE	25
PARTNERSHIPS	25
COMMUNICATIONS	25
PUBLIC POLICY	26
FREQUENTLY ASKED QUESTIONS	27
APPENDIX A: PLANNING FOR YOUR CARING COLLABORATIVE	29
PUTTING TOGETHER A FOCUS GROUP SESSION	29
CONDUCTING A FOCUS GROUP SESSION	29
FOCUS GROUP QUESTIONNAIRES	31
APPENDIX B: RESOURCES FOR ORGANIZING YOUR COMMUNITY	35
MEMBERSHIP SURVEYS	35
<i>Service Corps</i>	36
<i>Medical Information Exchange (MIX)</i>	37
APPENDIX C: HEALTH & WELLNESS RESOURCE DIRECTORY	40
APPENDIX D: WHAT MEMBERS SHOULD KNOW WHEN PROVIDING SERVICE	43
GUIDING PRINCIPLES FOR SERVICE CORPS MEMBERS.....	43
ACCOMPANYING MEMBERS TO MEDICAL APPOINTMENTS.....	43
SAMPLE MEMBERS AGREEMENT FORM.....	45

The Caring Collaborative Model

"So many times I see people being thanked for doing a favor and they say, 'Oh, it was nothing.' This assigns a palpable, tangible value to helping someone."

The Caring Collaborative provides a framework for mobilizing and organizing the goodwill that resides within communities, such as bringing a home-cooked meal to a neighbor who is sick, or accompanying a friend to an outpatient procedure. Members benefit from the healthcare experiences of others, for example, knowing what to expect during breast cancer treatment or how to optimize recovery following knee replacement surgery. And, it allows members to plan for that rainy day -- when an accidental fall or unexpected diagnosis can compromise their independence. There's tremendous comfort in knowing a network is in place where friends stand ready to lend a helping hand.

Power of Informal Communities

Research shows that social ties and connections can help people live longer, stave off memory loss and improve outcomes associated with chronic diseases. Moreover, many people report that they would prefer to turn to a network of peers or friends for help with illness and/or disability than family members. Perhaps the strongest argument for community support comes from older adults themselves, 89% of whom say they want to grow older at home in their community. Yet many communities lack the infrastructure and resources to accommodate changing needs that occur as part of the normal aging cycle.

TTN believes that informal communities are an untapped resource for many of the challenges confronting an aging society. In the next 20 years, there will be more people over age 65 than ever before. Yet, we are woefully unprepared to meet the health and social needs of a rapidly aging population. A dwindling supply of professional caregivers, weakened family ties and an increasingly fragmented healthcare system undermine availability, access to and quality of care. Largely ignored in discussions of potential solutions are informal caregivers - friends, neighbors, and members of religious and social groups – who have a vested interest in the health and wellbeing of the members of their communities.

These informal communities can play an important role in supporting healthcare if they can mobilize and organize the support of their members.

Building Blocks for a Caring Collaborative

The Caring Collaborative has three discrete, health-oriented service programs: a Service Corps, a Member Information Exchange (MIX), and a Health & Wellness Resource Directory. In addition, it sponsors a strong program for health education that is promoted through health seminars, a newsletter, and regular Neighborhood Group meetings where members discuss timely health topics. A Time bank records reciprocal member contributions.

Recognizing that not all communities have the same resources at hand, the model was designed as a "menu of options," so that communities can tailor a Caring Collaborative

to the financial and community resources that are available and the specific needs of potential members. The basic elements of the CC model are briefly described below. A more detailed discussion is provided in the next section, *Getting Started*.

- **Service Corps** is a group of volunteers who deliver helpful services to members when illness or injury leads to temporary disability (escorts to healthcare/dental providers, companionship, pet walking, meals, paperwork, etc.).
- **Member Information Exchange (MIX)** is a way for members to exchange information based on their experience relating to medical conditions or procedures. It offers a way to help members cope with illness or surgery, allay concerns and support the decision-making process.
- **Health & Wellness Resource Directory** suggests links to a wide variety of information on health-related topics and on sources for obtaining outside services, such as food delivery, legal counsel, and home care.
- **Education** programs help members gain the information they need to maximize their ability to stay healthy. Through Health Seminars, members learn coping strategies on such key issues as osteoporosis, prevention of falls, tools to stimulate memory, and sleep problems. The quarterly newsletter, *Caring Times*, reports on members helping members and recent news on the health front. On the CC website and in these programs the focus is on practical strategies for staying healthy and independent.
- **Neighborhood Groups** meet informally in members' homes, every month or so, to discuss health issues and to share information and local resources.
- **Time bank** is an optional database that powers the exchange of information and services, and documents transactions. Volunteers providing service receive credit to be applied when they need help. The Time bank is designed to overcome resistance to asking for help.

Adapting the Model to Fit your Needs

If your community is a book club, neighborhood association or service club, you might start with Service Corps since geographical proximity is a factor in a member's ability to deliver hands-on support. If your community is virtual or linked by common interests, -- such as an alumni association -- you might start with a Member Information Exchange since email and telephone communication can overcome the problems of distance. Or, maybe you just want to organize information about health services that are available in your community, with the Health & Wellness Directory being the best way for you to start.

A TTN chapter in San Francisco launched a small Caring Collaborative with just a volunteer Service Corps. Members wanted health-focused services that they could provide for each other as needed. The group felt a Time bank was unnecessary. They

plan to introduce a Member Information Exchange once the Service Corps is well off the ground.

Getting Started

“It was a really wonderful experience to know that so many nice people were there to help me. Facing impaired mobility when living alone creates a whole other set of anxieties separate from health issues and having my peer group there for me made a difference to my state of mind.”

First Steps

It doesn't take vast resources to start a Caring Collaborative. Like most new initiatives, you'll need one or two people with good leadership skills who can inspire and motivate others. This is perhaps the most important factor since leaders establish the vision and set the strategy for getting there. If you're reading this manual, perhaps, that leader is you – or someone else in the community who is enthusiastic, well liked, and respected.

Next, you'll need some people to help you – a planning committee. The planning committee can be large – 10 to 12 members, or small – 2 or 3 people – depending on the size of your community and aspirations. The committee should be comprised of people who see value in a Caring Collaborative and have the time and tenacity needed to get a new project off the ground. Below are some characteristics of an effective planning committee, which might be useful to keep in mind as you get started.

Characteristics of an effective planning committee:

- a. Share common vision
- b. Commit to clear objectives
- c. Promote open communication
- d. Actively participate
- e. Have clearly defined roles/responsibilities
- f. Trust, accept and support members
- g. Be resourceful and creative
- h. Value all opinions/contributions
- i. Check egos at the door

Financial Considerations

You also need to think about available resources because they will likely inform the scope of your project. While the Caring Collaborative is a low cost model, you will need some financial and human resources to develop and operate the model. For example, in the TTN Caring Collaborative model, fixed costs for operations include:

1. Annual subscription fee to on-line survey vendor - \$250
2. Software to develop and operate the health services time bank - \$200
3. Liability insurance - \$700
4. Training materials and meeting space - \$3,000
5. Part-time paid staff to coordinate the program and time bank – \$10,000 (10 to 15 hours per week at \$15 per hour)

It's important to note that these costs are for a fairly large Caring Collaborative based in New York City. Operational costs will vary. For example, not every Caring Collaborative needs to hire a part-time coordinator – many can rely on volunteers. Or, maybe there is staff within your organization that's being under-utilized. Similarly, you might not need time-banking software to get your program up and running. If you do, time-banking software is increasingly available with costs that range from \$200 to \$1,000 plus per year. You can find more details about customizing your program and costs in the following sections.

The point here is to start thinking about what you will need to create and sustain a Caring Collaborative. Then be creative. Remember that there are local and state grants available for community-based initiatives – especially relating to health – and you might find lots of in-kind support from your local institutions of higher education (community and four year colleges). And, you can always pursue sponsorship from local area businesses who might be interested in the purchasing power of your community members. Suggestions of possible funding sources are shown below.

How to Fund a Caring Collaborative

- a. Member fees
- b. Local, state, national grants
- c. Private funders
- d. Business sponsors
- e. Community fundraising events
- f. Contests
- g. Family members of those helped by your program
- h. Program partners

Charging Membership Dues: A Lesson Learned

Whether or not to charge a fee for your Caring Collaborative is major decision that should be made before you launch.

Once you offer anything for free, it's hard to change course. For example, when TTN first introduced the concept of a Caring Collaborative, members said they would be willing to pay \$100 to support this effort. Since the first year was a pilot project, membership was offered free. When \$50 membership dues were charged in year 2, many members balked at the fee. It was hard to recapture the members' original enthusiasm. The lesson here is to give careful consideration to the issue of membership dues, and if you do charge, try to integrate dues into the organization's annual membership campaign.

Gather Information

Once your planning committee is in place, the next step is to gather information about the types of services members need and are willing to provide to one another. There are many ways to do this – some are simple, and others are more sophisticated. If your community is small, your research might consist of discussions with members in person or by phone. If your community is larger, or you're taking a more formal approach to the development of a Caring Collaborative, you might start with a questionnaire and/or focus group.

Focus groups are a powerful way to test new ideas and concepts in your community. Typically, a focus group is comprised of six to eight people who respond to questions posed by a facilitator or moderator. Participants interact with and build off each other's ideas, making focus groups an excellent way to get a great deal of information in a short period of time.

Since TTN was working with a large membership group, its planning committee took a more formal approach to collecting information. Three focus groups were convened and a detailed questionnaire was distributed about the specific types of help members might need during periods of short-term illness and disability. The information collected was invaluable and guided the entire development process.

Whether you decide to talk informally with members or poll your group using other methods, the following scenarios and questions can be used to inspire thoughtful discussions:

Build Scenarios

Present the following situations to members:

1. *Suppose you fell and broke your leg. What is your emergency support system? What might you need? Who might help you manage until you were self-sufficient again?*
2. *Suppose you developed a life-threatening and/or long-term condition (i.e., open-heart surgery, cancer). How would you go about creating your support system? What might you need to think about? What would you need?*

Follow up with the following questions:

1. *What services do you think your members could provide in these different scenarios?*
2. *What kind of help would you be willing to contribute to a community support system?*

Take notes or record conversations so you can reference the feedback as you design the model.

Other steps to take include the following:

1. Look at the demographics of your group. What's the average age or age range? Where and with whom do they live? Are they working or retired? What's their overall health status? Do they drive or rely on public transportation? Are neighborhoods clustered or far apart?

2. What are the general concerns in your community about aging? About healthcare?
3. Are members ready and willing to make a commitment to help each other through short-term episodes of illness/disability?
4. Are members more formal with each other, or informal?
5. What types of resources are there in the community that might complement or compete with your service?
6. What type of resources do you have? Financial? Volunteers?

Customizing the Model

The information you gather will inform the design of your community Caring Collaborative and its size and scope of services. To help you get started, this section features more information about the core benefits – Service Corps, Member Information Exchange (MIX), Health & Wellness Resource Directory -- and the education programs, Neighborhood Groups, and the Time bank. These templates can help scale the model to fit your community.

If your community is a local book club, neighborhood association or Rotary club, you might start with a Service Corps since geographical proximity factors into one's ability to deliver hands-on support. If your community is virtual or linked by common interests – like an alumnae association – you might start with a Member Information Exchange since email and telephone communication can overcome the problems of distance. Or, maybe you just want to organize information about health services that are available in your community, and a Health & Wellness Directory is the best way for you to start.

For example, a TTN chapter in San Francisco launched a small Caring Collaborative with just a volunteer Service Corps. Members were interested in organizing health-focused services that they could provide for each other when needed. The group felt a time bank was not needed, and that a Member Information Exchange could be introduced once the Service Corps was well off the ground.

The guiding principle is to select the Caring Collaborative elements that are realistic and manageable for your community. Remember, keep it simple and go slow – you can always build over time.

Service Corps

A Service Corps is a group of members who have willingly agreed to deliver helpful services to others in the community when illness or disability strikes. It's comprised of four service categories – Home Tasks, Tasks in the Neighborhood, Medical Matters, and Escorting members to doctor appointments, and medical procedures. Services available within these categories include home and phone companionship, pet care and meal preparation. Accessing volunteer service requires planning – generally, 3 days notice. The Caring Collaborative is not designed to provide 24/7 emergency assistance.

The Service Corps creates a framework for organizing care that is routinely exchanged in your community – offering solace and friendship after the death of a spouse, coordinating escorts to physical therapy after a hip replacement, or caring for a pet during a hospital stay. Some of the tasks members may be willing to perform are listed on the accompanying chart.

Home Tasks

Bill Sorting	Home Cooked meal
Budgeting	Letter Writing
Companionship (home and phone)	Pet Care
Computer questions	Plant care
E-mails (related to health issues)	Reading
Food delivery	Sharing a Meal

Neighborhood Help

Mailing packages/letters	Shopping for gifts
Errands	Shopping for groceries
Obtaining/returning library books	

Medical Matters

- Taking notes at medical appointments
- Taking to/picking up from hospital
- Taking to and picking up from doctor's appointment
- Hospital visits

Escorts

- Personal care appointments
- Taking to social events, church/temple functions

These categories can be adopted for your Caring Collaborative or easily adapted to meet the needs of your community. For example, members of your community might want to help with household chores or respite care -- categories not featured in this list, but that can be easily added. You also should think about the capacity of your members. What is the ratio of healthy, independent members to those who are more frail? Are your members savvy healthcare consumers or would they need training to accompany members to a medical appointment?

Member Information Exchange (MIX)

"When I was diagnosed with breast cancer, I was confused and frightened. It was so reassuring to talk to someone who had already been there and could offer guidance about my next steps."

Decisions about medical treatments, such as, whether or not to have surgery for a chronic back condition, have a sizable impact on our lives. Making choices about medical tests, procedures, and treatments can be overwhelming, in part, because medical decisions are often complex. Personal connections are a lifeline for people who are sick, disabled, confronted with a scary medical diagnosis or just looking for a new healthcare provider. Hearing from a peer who has gone through what you are facing may reduce anxiety and promote healthy coping, even if it's just learning how to put on socks after back surgery, or how to manage with a leg in a cast. Personal

connections are also important for caregivers, who often need support and guidance in the functions they serve for others.

MIX facilitates the sharing of health information and resources within a community. This benefit provides a framework for organizing information members are willing to share about their own healthcare experiences. The goal is to support the individual decision making process in three key areas: Medical Conditions, Provider Selection, and Medical Products/Equipment that enhance comfort and mobility. MIX does not give medical advice or provide physician referrals – members are instructed to share only their individual experiences.

Since these key areas are so broad, organization is important when it comes to creating a MIX. In the Caring Collaborative, medical conditions and healthcare providers are organized according to disease and discipline, and each category features multiple listings. Members are then listed according to the information/experiences they are willing to share. Here’s an example of how it’s organized:

Medical Conditions

Cancer	Cardiovascular Diseases	Dental
Bladder	Arrhythmia (irregular heart beat)	Cosmetic dentistry
Brain tumor	Coronary Artery Disease	Dental implants
Breast	High cholesterol: lipid disorder	Gum disease (periodontal)
Colon	Heart attack	Tooth loss
Head, neck, throat	Heart failure	
Leukemia	Hypertension	
Lymphoma	Stroke	
Ovarian		
Pancreatic		
Prostate		
Skin (basal)		
Skin (Melanoma)		
Stomach		

When organizing information about medical conditions and healthcare providers, it pays to be specific. For example, there are many types of breast cancer and many ways to approach its treatment. Since you will be facilitating matches based on experience, it’s important to capture as much information as you can from members up front. This was

a key learning experience for the Caring Collaborative. It often took longer to facilitate a match because information about member experience was too general in some of the categories, like foot problems, back injuries/pain, and certain cancers.

You can use this organizational framework or adapt it to meet the needs of your community. Since the Caring Collaborative was developed for women, you will need to add categories for a mixed gender community.

Health & Wellness Resource Directory

When you're sick, injured or surprised by a new diagnosis, it's difficult to find information you need in a hurry. All sorts of questions may abound regarding the care you need; finding answers takes research skills and time you might not have.

The Health & Wellness Resource Directory was developed as part of the Caring Collaborative to help members cut through the clutter of health-related information and resources. It features information on an array of community-based programs that offer important services like Meals on Wheels, transportation, hospice, respite care – and much more. Information is organized by category, and a brief description of the program or service and important details like eligibility, costs and contact information is included.

In the CC model, the directory is web-based, with links to services. The directory complements other CC benefits, by providing additional information and links to services that volunteers may not be able to provide. For example, if a member asks a volunteer to perform a task she isn't allowed to provide or doesn't want to – like change a wound dressing or clean the bathroom – the directory offers alternative resources.

The directory is organized according to the following categories:

- **Diseases A-Z** identifies national non-profit organizations that deal with various diseases and conditions, along with some explanatory notes. Where available, phone and internet contact information for local chapters and support groups is provided. Resources are listed alphabetically by name of condition.
- **Home Food Services** describes ways members can obtain home food delivery on a short- or long-term basis. Websites and phone contacts are listed for restaurant and prepared food, and grocery delivery services, supermarket and grocery stores, not-for-profit agencies that deliver groceries or prepared meals. Service areas, delivery arrangements, and any registration requirements are included.
- **Short Term Nursing and Rehabilitation Care** offers tips and strategies for selecting a facility that best meets your needs, including what to look for in the physical environment, facility licensing, staff credentials, activities, atmosphere, and quality of services.
- **Products/Aids/Devices** includes information for seniors and those with temporary or permanent physical impairments.

- **Transportation Assistance** identifies services, which are available but often imbedded within other categories of services such as, senior centers, caregiver resources, or home care services. Many of the disease-based resources refer patients to Access-a-Ride although a few organizations provide their own transportation services. The section includes key eligibility criterion for senior citizen services, including age and income restrictions
- **Doctor Information, Recommendations and Ratings** provides links to websites featuring physician information, specialties, credentials, references, and ratings. It's designed to serve as a consolidated reference point for further research.

These categories were created by volunteers who met over a four-month period. Since the structure for a directory is in place, you can probably customize it to include local resources in less time.

Steps to Develop a Health & Wellness Directory

1. Convene a volunteer committee to research and describe relevant community-based resources.
2. Ask volunteers to select one or two categories to research and describe.
3. Define a meeting schedule and deadlines.
4. Decide whether you want to have a print or on-line directory. Engage design support as needed.
5. Review and update as needed, or at least once a year, to ensure accuracy of information

Education Programs

Caring Collaborative members, typically, are interested in staying informed and independent. The Caring Collaborative is an ideal platform for delivering important information on health-related issues. The CC education program includes health seminars, the *Caring Times* newsletter, and suggestions for discussion topics at neighborhood group meetings.

Creating an education program can be done fairly easily. Simply poll members about topics of interest and then contact your local hospital, medical groups or alternative care providers for speakers or people to interview. Most health practitioners (physicians, nurse educators, chiropractors) welcome an invitation to share their knowledge and may even be willing to donate resources – meeting space, handouts and coupons for discounted services.

- The **Health Seminars** offer practical strategies for “healthy independence.” The focus is on “anticipatory guidance” that can delay frailty and disability – such as, learning to avoid accidents; watching for early signs of illness and disease; and how to ask for help when getting over an illness or accident. Offering the seminar in conjunction with a community health organization helps boost the credibility for the Caring Collaborative and provides a steady stream of topics and speakers.
- The quarterly newsletter **Caring Times** is chock full of articles on health topics, interviews with members pursuing healthy independence and examples of how people are benefiting from the Caring Collaborative. It not only educates members but also builds interest in and awareness of the overall program. The newsletter is e-based and written by volunteers, making it a high impact, low cost strategy. A *Caring Times* reader wrote:

“I was just about to sign up for a prescription drug plan which I thought led the pack. But I realized from reading the latest issue that another company would be \$200 cheaper for me. Thanks for the tip – you have already earned my \$50 membership dues.”
- **Discussion Topics** for neighborhood groups are addressed to the health concerns of members. Topics can be culled from member interests, community health offerings and time bank data. For example, you may see multiple requests for information on a similar topic – like osteoporosis or acupuncture. Members choose topics they want to discuss at their regularly scheduled, typically, bi-monthly, meetings.

Neighborhood Groups

If you’re creating a Caring Collaborative for a large community, you might consider organizing Service Corps volunteers by geographic area, i.e. by zip codes or neighborhoods. This is important for two reasons. First, proximity is important in the kind of help people are willing to provide for each other. Having your Service Corps volunteers “zoned” by district will enable local service and information exchanges. Second, your members may want a casual forum to meet and greet other Caring Collaborative volunteers. A familiar face makes it easier and more comfortable to ask for and give help. This casual meeting forum is also invaluable for sharing information important health topics, such as balance, insomnia and living wills.

The Caring Collaborative’s neighborhood groups foster local connections and friendships. Groups of 10 to 15 members meet every month or so to socialize, discuss important health issues and exchange information on successful health strategies. Membership in a group is optional; however, they are an enormously popular part of the Caring Collaborative model. More than half the members actively participate in a neighborhood group.

Time Bank

Time banking refers to a pattern of reciprocal service exchange where currency units are valued at an hour’s worth of someone’s time. Time banking offers a systematic way to organize and record the exchange of services that are often provided in communities, such as bringing a meal to a sick friend or taking a friend to the doctor. The concept

was introduced by Edgar Cahn, a social activist nearly 40 years ago, and has spread to over 37 nations and six continents.

Time banking was integrated into the CC model as a way to overcome reluctance to ask for help. Research showed that members are fiercely independent and that asking for help would be easier if there were a record of giving help. A transaction-based system – or time bank – provided a solution.

We evaluated several existing time banking programs to find one that would best meet its needs. Criteria included:

- Web-based to enable access from various remote locations
- Ability to customize service categories
- Closed access to maintain confidentiality
- Low cost to keep operating expenses to a minimum
- Simple – without a lot of bells and whistles

Fortunately, time banking programs are increasingly available and at many different price points. We chose a low cost (\$200 per year), off-the-shelf system to organize and facilitate exchanges within the Service Corps and MIX. The database allows for entry of demographic information, and the ability to customize categories of services and information to exchange, and the ability to make matches and run reports. It is password protected: access is restricted to select program staff.

A Time bank is optional. Not every community needs a computer and software to track exchanges. After all, the concept of time banking is based on the tradition of neighbor helping neighbor, and can be started with a logbook or simple spreadsheet.

If you decide to use time banking software to operate your Service Corps or MIX, you should do a bit of research to evaluate the different options. Generally, there are three to consider:

1. **Open Access:** This means members can access a web-based database to exchange information and services. Members enter information about the services they will provide into a shared database. When help is needed, a request goes out to members at large, and those who can help respond. This system is less than ideal for those concerned with privacy. While an open-access system reduces the need for a time bank coordinator, many time bank programs still have part-time volunteer(s) or staff to maintain the database and member records.

2. **Closed Access:** This means members do not have direct access to the time bank, and a coordinator facilitates the exchange of services. These systems are either password protected web-based programs, or software that you install on your computer or network. This system provides more control and protects the privacy of member information. It also requires a person or persons to coordinate requests and manage the database.

3. Open and Closed Access: A third option is a time bank program that features a mix of open and closed access. In this system, members can access certain parts of the database while other sections are password protected. For example, members could freely exchange practical help, but requests for health information (i.e., medical diagnoses) would go through a coordinator or volunteers appointed by their peers.

Practical questions to guide your research and decision-making process:

- Do you need software to get started?
- What type of computer hardware do you own or have access to?
- How computer savvy is your community?
- Do members have access to a computer?
- Should members have direct access to the time bank software?
- Is privacy in the database important to your community?
- What is your budget?

How the Time bank Works

When a member needs health information or services, she/he calls or emails the Caring Collaborative. The coordinator (staff or volunteer) takes down the pertinent details, such as type of help, where service is needed, date and time if it relates to a service. This information is entered into the time bank to find a match. The coordinator typically contacts three volunteers to fulfill the request. Once a match is confirmed, the volunteer contacts the member requesting help to schedule a time to talk about the details. Time given and received is recorded in the individuals' time bank records after the transaction is completed. It typically takes less than one hour for a coordinator to complete an entire time bank exchange, from start to finish over a period of a day or two.

Members can also arrange their own service requests through their neighborhood group. They can call or email a request to the group and make arrangements directly with friends and peers. Once the service is complete, information about the exchange is shared with the Caring Collaborative coordinator so it can be recorded in the time bank.

Most time banks allow you to test their software (at little or no charge) to see if their system meets your needs.

For more information, visit the following websites:

1. Time banks USA: <http://www.timebanks.org/>
2. Hour Exchange Portland (ME) <http://www.hourexchangeportland.org/>
3. Time banks UK: www.timebanking.org

Member Recruitment

Once you've established a structure for your Caring Collaborative, you're ready to recruit members. A simple and effective strategy is to send a letter or email to prospective members. Include a questionnaire asking about the types of services and information people want to receive and are willing to provide.

The CC developed a questionnaire using SurveyMonkey, inexpensive web-based software that enables anyone to create professional online surveys quickly and easily (<http://www.surveymonkey.com>). SurveyMonkey offers multiple formats and styles to choose from, and has an extensive "help" section to guide newcomers.

The on-line questionnaire is organized into four sections, allowing you to choose the questions that are relevant for your CC:

- Demographic information: name, address, contact information and notes
- Health services members want to receive and would be willing to deliver (based on Service Corps categories)
- Medical information members would be willing to exchange
- Limitations to participation in the program (i.e., pet allergies, driving, climbing stairs).

A letter or email from you or the planning committee should accompany the questionnaire, describing the new initiative, how it can help members, and why they should complete the survey and join your Caring Collaborative. Use language and examples that will resonate with your members. For example, *Have you ever felt stranded or in need of support when confronted with an unexpected medical diagnosis? Or wondered who would walk your dog while you're in the hospital? Worry no more because the Caring Collaborative is here!*

Use every opportunity to publicize the launch of the Caring Collaborative. Create flyers to distribute at live events, newsletter articles, website banners and links, and press releases. Also, be sure to leverage the enthusiasm and influence of your planning committee members – word of mouth is a powerful communications tool.

Membership Guidelines

At first glance, it might not seem important to have guidelines about participating in a Caring Collaborative. After all, helpful exchanges are likely taking place in your community already. However, some of the benefits within the Caring Collaborative model are unique, and members will need some guidance. For example, many of us like to share information about our healthcare experiences, but there's a fine line between sharing information and giving medical advice. And agreeing to take or pick up someone from a medical appointment requires planning and commitment. It's important, therefore, to articulate the roles and responsibilities of members who join.

Orientation

An Orientation program presents guidelines for participating in your Caring Collaborative. Information is presented during a two-hour meeting conducted by

volunteers, and features interactive vignettes to convey core values. Topics covered include the following:

1. **Logistics** – How do I join? Is it open to all members of the community?
2. **Accessing the Time bank:** How do I use the time bank? Who do I contact? How long does it take to make a match? Do I need time bank credits or points? Who initiates the exchange?
3. **Confidentiality** – Members participating in a Caring Collaborative have access to personal information about one another. This includes personal demographic information (age, phone number) as well as certain things that may be noticed during the course of a service exchange. For example, volunteers providing service in the home will be entrusted with all sorts of personal information, including the person's housekeeping capabilities and medication regimen. While most people would not intentionally divulge confidential information obtained during a health exchange, sometimes, it happens by accident. This section provides an interactive skit to illustrate how it might happen – i.e., “Oh no, Julie can't come to that meeting – she's having a biopsy that day,” or “Speaking of clutter, you should see Julie's apartment.”
4. **Setting Boundaries:** as a volunteer in a Caring Community, members should recognize how to protect their own time and space – how to be considerate yet assertive. Recipients of services need to appreciate the generosity of volunteers and their good intentions. For example, if a volunteer prepares a home-cooked meal, it's not appropriate to ask him/her to clean your floors or take out the garbage. Or, if a volunteer picks up groceries, he/she should be reimbursed for costs incurred. Similarly, volunteers should not perform any type of medical care, like changing a bandage or administering medication.
5. **Sharing information versus giving advice:** It's likely that most members of your Caring Collaborative will not have medical training, so giving advice is irresponsible and can be problematic. For example, a patient on certain medications may be at higher risk for bleeding than other people. Even casually suggesting that the person take an aspirin and go to bed could result in grave harm. This portion of the orientation program gives examples to illustrate the difference between giving advice and sharing information about your own experience.
6. **Accompanying members to medical appointments:** One of the most important functions within the Caring Collaborative is helping members navigate an increasingly complex medical system. In the model, volunteers take members to and from medical appointments, visit them in the hospital, and take notes when they're meeting with healthcare providers. This section offers useful strategies for success, such as how to prepare the medical office staff (i.e., Consent to share information) and set expectations between the volunteer and service recipient. A discussion of HIPPA (Health Insurance Portability and Accountability Act of 1996) is provided and a list of common follow-up questions for healthcare providers is reviewed.

Orientation Options

You will need to decide how best to develop and present your training or orientation materials. If your group is small, and you're building a Caring Collaborative slowly, you may only need a short discussion as part of a regularly scheduled meeting. Or, you may have a computer savvy group that prefers on-line learning methods. Some programs organize potluck dinners so members can get acquainted with each other and the benefits. Others schedule workshops or seminars.

Member Agreement Form

At the end of each Orientation, a Member Agreement form is distributed. By signing the form, members agree to respect the core values of the program discussed during the orientation and importantly, acknowledge that the CC and its members will not be held liable for claims relating to services or information exchanged by volunteers.

Other Considerations

This section describes the policies and procedures that can be used to help you develop your own guidelines. It also includes some general information about policies that govern other time bank programs. Since every community has its own mission and identity, policies and procedures will be different for each.

Remember that joining and participating in a Caring Collaborative should be easy. If your policies and procedures are onerous and/or complicated, people will not join. Simplicity should be your guiding principle.

Who Can Join?

Seems like a silly question, but who will be eligible to join your Caring Collaborative? Will it be open to all members or a subset? Will it be required or voluntary? Do you plan to charge a fee?

In the CC model, all members of The Transition Network are invited to join. Participation is voluntary, and joining is an easy, three-step process. Initially, membership was free because it was a pilot project. In the second year, \$50 membership dues were imposed to partially offset program expenses – software, liability insurance, and a part-time coordinator.

Many time bank programs have an application process and criteria for screening members before they join. These programs tend to involve childcare or driving. Background checks may require participants to submit a Criminal Offender Record Investigation (CORI), evidence of car/homeowners insurance, and personal references. The CC model did not include background checks, as participants are members of a peer group community where a level of trust has been established. In addition, the model does not include driving -- members rely on public transportation. If your program will involve drivers, check with other non-profit organizations in your area that provide transportation to see how it's handled. For example, some chapters of the American Cancer Society offer a Road -to -Recovery program where volunteer drivers donate their time and the use of their cars to take patients for treatment they need. They might be a resource for you – or check with your local Meals –on- Wheels.

Each time bank must establish criteria for screening and interviewing potential members. Again, the size, culture and values of your community will inform the types of policies and procedures you develop around the application process. Don't be overwhelmed by the idea of collecting all sorts of information about or from your members. You can always start small with simple friend-to-friend exchanges and build up from there.

Liability Issues

Many time banks obtain volunteer liability insurance to cover problems that may occur during a service exchange. This is another one of those decisions that each Caring Collaborative will have to make. Again, if you are an informal book club or knitting circle, liability insurance may be unnecessary. But, if you are part of a larger organization or institution, it may be required. Note that the parent organization usually

has liability insurance, and the program can be covered under the blanket policy. TTN has organizational liability insurance, and the program is covered under that policy. Pricing is not exorbitant and should be discussed with the parent organization

TTN purchased volunteer liability insurance. However, time banking is based on the principles of trust and reciprocity, which act as a deterrent to abuse or misuse. The Dane County Time bank in Wisconsin reports on its website that, “in the decades that Time banking has been around no claims have ever been filed against it. Time banking is based on trust and reciprocity.” (<http://www.danecountytimebank.org>) TTN members are also encouraged to remember the spirit in which the Caring Collaborative was developed – as a promise to help each other through life’s rough patches.

Governance

Policies and procedures will likely be set by those who have oversight for the development and operations of your Caring Collaborative. Again, this might be one or two people who confer over coffee, or a 10-15 person advisory board or steering committee. The Caring Collaborative model is governed and managed by volunteers. A 12-member Steering Committee has oversight for program development, policies and procedures, service delivery, communications, and education. This committee continues to operate and meets on a monthly basis.

It’s important that members feel they have a stake in their Caring Collaborative. Having a grassroots program – owned and operated by those who benefit – is important to a successful model.

Strengthening your Caring Collaborative

As you develop a Caring Collaborative, you'll likely identify ways to build and expand on the interest of members in your immediate community – and beyond. For example, the local hospital or area businesses may want to partner with you to reach out to your members and/or support your mission. Maybe your members will become more attuned to disease prevention or long-term care and want some direction or strategies. Or perhaps, as members reap the rewards of a stronger community, they will want to organize to advocate for new policies. Here are some guidelines for building the model up and out, based on CC's experience.

Partnerships

Developing partnerships can benefit your Caring Collaborative in many ways. They can raise your visibility, boost your credibility and stabilize your bottom line. Since all partnerships require a bit of give and take, you need to identify your “value proposition” – that which makes your program unique and of interest to others. Similarly, you have to define what you want to gain from program partners – funding, expertise, member discounts – and so forth.

CC developed a very effective partnership with a large homecare agency in its community. It had all the right “ingredients” for a successful partnership:

1. Something of value to contribute
2. Shared objectives: to improve community healthcare
3. Complementary skills and services
4. Willingness to invest resources – time, people and/or money
5. Willingness to share information
6. Formal status – recognized by advisory boards and/or powers that be
7. Trust and integrity
8. Understanding of and respect for differences

Benefits to CC include special member services, discounts, and education. The agency also adds credibility for the Caring Collaborative since they are nationally recognized experts in community healthcare. Benefits to the agency include access to an important and growing demographic group; insight into new grassroots models of community healthcare; and potentially, new customers.

Communications

Engaging members of the community in any new venture requires an effective communications strategy. People need to know that a new program is available, how they can join, what types of services are available, and how they can benefit. Word of mouth is very effective, but so too are websites and newsletters.

Websites can be an effective and cost-efficient way to communicate information about your Caring Collaborative. While there is typically an upfront cost to design the site, it allows you to reduce other program costs – mainly printing and mailing. In the CC model, all materials relating to the Caring Collaborative are posted on its website

(ttncaringcollaborative.org). Members link to the on-line survey to join, download the Member Agreement form, access the Health & Wellness Resource directory and read about how other people are using the program. Of course, having a website is contingent on member access to computers and comfort in using them. It's simply another option to consider.

Newsletters are another method of communication that can either be printed and mailed or sent via email. The quarterly newsletter, ***Caring Times***, raises awareness of the benefits and encourages utilization. Developed and designed by former journalists, the newsletter was a surprise hit with members and became an integral part of the Caring Collaborative. It features news about program events, neighborhood group meetings, health topics, and interviews with people who have used the services offered through the CC. You can tell the stories with names or, if privacy is needed, without names. The clear correlation between the newsletter's distribution cycle and utilization of the Caring Collaborative demonstrates its effectiveness.

Public Policy

Organizing and operating a Caring Collaborative strengthens communities and responds to the needs of a rapidly aging population by increasing the ranks of caregivers. It's a low-cost, high- impact program that local policy officials need to know about. Be sure to track the numbers of members helped by your Caring Collaborative and the types of information and services exchanged. Record anecdotal stories that illustrate its impact and share them. Enlist your members to understand the healthcare needs of their population and ask them to help champion needed changes in local, state and national health policies so that community Caring Collaboratives can obtain the political and financial support they deserve.

Frequently Asked Questions

1. **What does it cost to start and operate a Caring Collaborative?**

Costs to start a Caring Collaborative vary, depending on the size and scope of your program and resources available. Operating the program for a community of 500 or 1000 members will require more oversight and coordination than a program in a community with 50 members. Some organizations will have staff that can pitch in to manage a CC or a team of dedicated volunteers. Others may have to hire a part time coordinator. Based on CC's experience, the program costs approximately \$10,000 to \$15,000 a year to run, including a paid part-time coordinator, software, insurance and basic operating expenses (supplies, room rentals). With volunteers only, the program can be run for as little as \$2000. Depending on the size (book clubs) and the informality of the network, there may be no cost at all.

2. **How was the Caring Collaborative funded?**

Volunteers developed the model in 2007 following a year of research and development. It was a grassroots effort, with meetings and focus groups in member's apartments and countless hours of in-kind support provided by more than 70 volunteers. Once the model was developed, TTN secured funding (\$144,000 from the New York State Health Foundation) to test the model over a two-year period. By 2010, CC was a self-sustaining operation funded by membership dues and local fundraising efforts. Its operating budget is roughly \$10,000 with a paid, part-time coordinator. Remember, you don't need a lot of money to get started – a Caring Collaborative can run simply on the steam of volunteers with no out of pocket cost.

3. **How do I find funding to start a Caring Collaborative? Can I start a program without money?**

Yes. Be creative. First, determine what resources you have at hand. Maybe you lack financial capital, but have an untapped talent pool within your community that could be organized to jumpstart the program. Perhaps you have a group of dedicated volunteers, or staff that is underutilized who could help coordinate the program. Look around for area businesses that might want to sponsor your program, and community organizations that could partner with you. Check out funding that might be available from local government agencies. Remember that the CC model cuts across two major issues: health and aging. Be sure to look for funding in both categories, and pay attention to funding that may be available based on geography (urban/rural), socioeconomics, culture, and religion.

4. **What are common barriers to the success of a Caring Collaborative and how do you overcome them?**

There were few barriers to success. Our biggest challenge is the reluctance of members to ask for help. Our outreach and communications efforts, showcasing how members are using – and benefiting from -- the Service Corps and Member Information Exchange have been the most effective strategy to address this challenge.

5. **How does the Time bank work?**

When a CC member needs health information or services, she calls or emails the CC coordinator who takes down the pertinent details – type of help, date, time and place if it relates to a service. This information is entered into the time bank to find a match. The coordinator typically contacts three volunteers to fulfill the request. Once a match is confirmed, the volunteer contacts the member requesting help to schedule a time to talk about the details. Time given and received is recorded in the individuals' time bank records

after the transaction is completed. It typically takes less than one hour for a coordinator to complete an entire time bank exchange, from start to finish.

6. How successful is the time banking operation?

During the Caring Collaborative pilot, members exchanged close to 800 hours in the time bank. Close to 70% of the original members opted to pay membership dues for the second year. More importantly, members have come to recognize that caring and sharing have real value. A culture of care is taking root – which for us, is the biggest measure of success. As it develops, the time bank is less utilized and exchanges are more direct.

7. Can you give your time to someone else?

It depends on the policies you set up for your Caring Collaborative. Many time bank programs allow members to donate time among friends and within families. In the CC model, we did not count hours as credits or debits since our goal was to encourage members to ask for help.

8. How many people can join a Caring Collaborative?

It depends on your ambitions, infrastructure and capacity of your staff (volunteer or paid). More people will make for a robust Caring Collaborative, with a rich database and large pool of people to share services and information. But then again, a small Caring Collaborative can be very effective.

9. Is help available 24 hours a day?

The Caring Collaborative is not designed for emergency care, but many members have created “buddy systems” within the Neighborhood Groups. They exchange key contact and medical information with one another – to plan for the “what ifs” in life. Services and information available through the time bank generally require at least 3 days notice to coordinate individual requests.

10. How do I establish partnerships with formal healthcare organizations?

Look for organizations and agencies that share similar values and goals. Convene a meeting with people at organizations that have an interest in aging, and who might champion your effort. These may include your elected officials, faith-based and community leaders, health and homecare providers, area agencies on aging, assisted living communities, volunteer organizations, social service organizations, and local business owners. It’s important to leverage existing community resources and learn from people with different views, experiences, and skills. Effective partners will provide guidance, support and credibility, which is particularly important for program funding.

Appendix A: Planning for your Caring Collaborative

An essential element in establishing a Caring Collaborative is knowing what program pieces your potential members would like to see in the CC and what services they are willing to perform. An effective vehicle for gathering this information is the focus group, where those who may be interested in participating can express their views.

Putting Together a Focus Group Session

Logistics: Consider where you will hold your focus group, how many people you'll invite, and how long it will be. A focus group session is typically 1.5 hours; 8 to 10 members is ideal (no more than 12 per session). Since people are volunteering, find comfortable space and provide refreshments. Arrange chairs so that all participants can have eye contact.

Agenda: Should *briefly* describe the objectives and planned flow of discussion. Include a welcome, introductions, objectives, ground rules and general questions.

Facilitator: This role is critical; and should not be left to happenstance. Ask someone who is organized, articulate and congenial. He/she will need to set ground rules to move the session along while generating useful information from each participant. A timer, large print agenda and note cards are useful

Recruitment: Call, write or send e-mails to potential members asking them to participate. Include a description of your proposed initiative, why it's important, the time and date and proposed agenda. Send a reminder three days before the session to those who have confirmed.

Record the session or engage a good note-taker. Focus groups generate lots of discussion and ideas. Relying on your memory alone is not a good strategy.

Prepare a Summary: This will include observations, surprises and key findings. You could also reinforce participant's interest by sending them an e-mail thanking them for coming and stressing – with details – how productive the meeting was.

Conducting a Focus Group Session

The first step is to identify possible elements in the program that your potential members would value. Do members want to help each other through temporary medical incidents, and if so, how?

The next step is to develop scenarios that can help elicit clear responses.

Suppose you fell and broke a leg. What is your emergency support system? What might you need? Who might help you manage until you are self-sufficient again?

Suppose you develop a life-threatening or long-term condition (i.e., open-heart surgery, cancer). How would you go about creating your support system? What might you need to think about?

Follow-up questions include:

What services do you think a Caring Collaborative could provide in these scenarios?

What kind of help would you be willing to contribute to a support system?

The last few minutes of the focus group could be set aside to fill out a questionnaire about the specific types of help members might need during periods of short-term illness and disability. The categories include help with activities of daily living (ADLs), business and legal matters, communication and social needs, and medical assistance. The questionnaire also captures important demographic information, such as age, living situation, and existing health problems.

Focus Group Questionnaires

This questionnaire was used by CC organizers to learn the types of services and information of interest to members. It was handed out after the focus group session, and responses were unsigned.

1. What Would You Like to Do? ... What Would You Do For Members?

Imagine that you are having a medical emergency or you are in a period of life when you are not as high functioning as you usually are, and you need help. To get that help, you must turn to someone. But who? Your partner, your children, other relatives, friends, paid help?

Alternatively, if a member needs assistance, in which of the following areas would you be able and willing to help? Please check all answers that apply.

For Activities of Daily Living

If I needed help, I'd turn to:	CC	Partner	Other	Paid Help	I'd help a CC member
Shopping for and preparing food					
Ordering home delivered meals					
Serving food & cleaning up					
Cleaning the house + clothes					
Maintaining and repairing the house					
Paying bills					
Cleaning and organizing closets					
Sending and receiving mail					
Picking up the mail					
Being driven or taken somewhere					
Buying clothes, gifts, cards					
Answering e-mail					
Pet care					
Plant care					
Buying and fixing appliances					
Fixing computers					
Fixing cable/TV service					

For Business/Legal Matters

If I needed help, I'd turn to:	CC	Partner	Other	Paid Help	I'd help a CC member
Informal legal advice					
Insurance advice					
Accounting advice					
Investment advice					
Researching something					

For Communication and Social Needs

If I needed help, I'd turn to:	CC	Partner	Other	Paid Help	I'd help a CC member
Someone to spend time with					
Someone to chat with on the phone					
Phone buddy to check on me					
Someone to offer religious support					

For Activities; Medical Needs

If I needed help, I'd turn to:	CC	Partner	Other	Paid Help	I'd help a CC member
Locating health providers and specialists					
Getting a timely doctor's or dentist's appointment					
Going to a critical doctor's appointment to take notes, ask questions, recall important points					
Decide if a medical symptom is a serious problem					
Make sense of Internet medical information					
Make sense of competing diagnoses, treatments					
Filling out insurance forms					
Drawing up medical proxies, living wills, end of life decisions					
Peer counseling about a new illness with someone who has had experience					
Compile a list of doctors, massage therapists, home health aides, housekeepers					
Manage prescription drugs; sort out dosages, arrange pills to take as prescribed					
Choose and arrange for medical supplies or equipment					

2. Questions About You

Do not sign your name. We want to gather information about group demographics only.

- 1) Age:
- 2) Occupation (present or past):
- 3) Are you ___ still working or ___ retired?
- 4) Do you live with ___ a partner or ___ alone?
- 5) If you live with someone, please check all that apply:
 - ___ Partner/spouse
 - ___ Son/daughter
 - ___ Sister/brother
 - ___ Parent
 - ___ Other relative
 - ___ Other
- 6) Type of Residence
 - ___ House ___ Apartment
 - ___ Concierge ___ Superintendent
 - ___ Building services available
- 7) Do you currently have any disabilities or serious health problems?
___ Yes ___ No Please describe:
- 8) Do you currently have a condition that is likely to be disabling at some point in the future, or a family medical history that concerns you? Please describe.

Appendix B: Resources for Organizing your Community

Membership Surveys

The survey is the building block for the database that will be used when connecting a volunteer with a member who needs help. This information should be kept on a confidential basis with the project coordinator.

Dear Member

Thank you for your interest in the Caring Collaborative. Completing the survey will let us know the tasks you're willing to perform and the medical information you are willing to share.

Name:

Address:

City/Town:

State:

ZIP/Postal Code:

Email Address:

Phone Number:

Cell phone:

Service Corps

Please put a check beside the SERVICES you would be willing to provide to CC members on a temporary basis when they are recovering from an illness or disability.

Home Tasks	√	Neighborhood Help	√
Companionship - home	<input type="checkbox"/>	Shopping for groceries	<input type="checkbox"/>
Companionship - telephone	<input type="checkbox"/>	Neighborhood errands (dry cleaner, pick up prescription)	<input type="checkbox"/>
Letter writing	<input type="checkbox"/>	Obtaining, returning library books	<input type="checkbox"/>
Reading	<input type="checkbox"/>	Shopping for gifts	<input type="checkbox"/>
Bill sorting/paying	<input type="checkbox"/>	Mailing letters, packages	<input type="checkbox"/>
Budgeting	<input type="checkbox"/>		
E-Mails	<input type="checkbox"/>	Medical Appointments	√
Computer questions (minor)	<input type="checkbox"/>	Taking/picking up from doctor's	<input type="checkbox"/>
Phones (programming, set up)	<input type="checkbox"/>	Taking notes at medical appointments	<input type="checkbox"/>
Plant care	<input type="checkbox"/>	Taking to/picking up from hospital	<input type="checkbox"/>
Pet Care (during illness/disability)	<input type="checkbox"/>	Accompanying	√
Food delivery	<input type="checkbox"/>	Taking to social events, church/temple	<input type="checkbox"/>
Home cooked meal	<input type="checkbox"/>	Personal care appointments	<input type="checkbox"/>
Share a meal	<input type="checkbox"/>	Hospital visits	<input type="checkbox"/>

Please indicate how far you are willing to travel to provide services to a fellow member.

- In my immediate zip code or building
- In my geographic neighborhood
- Distance is not a factor

Please indicate any barriers or limitations to providing a requested service.

- Allergies (please specify below)
- Pets
- Smoking
- Stairs
- Other (please specify)

Medical Information Exchange (MIX)

At one time or another, most of us have faced medical challenges, either through an unwelcome diagnosis or through the inherent barriers in our healthcare system. The Medical Information Exchange provides an opportunity to help others benefit from your experience.

Please check the specific medical conditions you may have had experience with, either personally or as a caretaker, and about which you are willing to share information. Please note, we recognize the confidential nature of information provided.

I have had experience with the following conditions (check all that apply.)

Cancer

Bladder	Brain tumor	Breast	Colon	Head, neck, throat
Leukemia	Lung	Lymphoma	Ovarian	Pancreatic
Prostate	Skin (basal, squamous, melanoma)	Stomach		

Cardiovascular Diseases

Arrhythmia (irregular heart beat)	Coronary Artery Disease	High cholesterol: lipid disorder	Heart attack	Heart failure
Hypertension	Stroke			

Dental

Cosmetic dentistry	Dental implants	Gum disease (periodontal)	Tooth loss	
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Ear/Nose/Throat

Balance	Deafness	Hearing loss	Tinnitus	Voice disorders
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Endocrine Diseases

Diabetes	Hyperthyroidism	Hypothyroidism	Metabolic disease	Obesity
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Gastrointestinal

Crohn's disease	Gastric/duodenal ulcer	GERD (reflux)	Ileitis/Colitis	Irritable Bowel Syndrome (IBS)
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Immunology

Allergies	Fibromyalgia	Lyme Disease	Lupus	
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Mental Health

Addiction (alcohol,	Anxiety disorders	Bereavement	Depression	Eating
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drugs, gambling)					Disorder
Phobias					

Neurological

ALS (Lou Gherig's disease)	Alzheimer's disease	Dementia	Migraine	Multiple Sclerosis
Parkinson's Disease	Peripheral neuropathy (numbness/tingling)	Tremors		

Ophthalmology

Blindness	Cataracts	Glaucoma	Macular degeneration	Vision impairment
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Orthopedics

Arthritis	Back injury/spine	Joint replacement (hip, knee)	Osteoporosis	Podiatry (foot problems)
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Plastic Surgery

Cosmetic	Reconstructive			
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Sexual/GYN/Health

Fibroids	GYN problems	HIV disease	Hysterectomy	Menopause
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Sleep Disorders

Insomnia	Sleep Apnea	Restless Legs Syndrome		
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Urological

Incontinence	Infections	Irritable Bladder	Kidney Stones	
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Miscellaneous

Chronic Kidney Disease	Gallbladder disease/stones	Pancreatic Disease		
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Healthcare Providers

I have had an outstanding experience with the following healthcare providers. Check all that apply and provide contact information for professionals in the given categories.

Acupuncturist	Anesthesiologist	Audiologist	Cardiologist	Chiropractor
Complementary Care	Critical care	Dentist	Dermatologist	Endocrinologist
Fitness Specialist	Gastroenterologist	Geriatrician	Geriatric Care Mgr	Gynecologist
Hematologist	Hospice	Home Health Aide	Hypertension Specialist	Immunologist
Internal Medicine	Lipid Disorders	Massage Therapist	Nephrologist	Neurologist
Nurse, Home Care	Nutritionist	Occupational Therapist	Oncologist	Ophthalmologist
Orthopedist (general)	Orthopedist (hands)	Orthopedist (hip/knee)	Otolaryngologist (ENT)	Pain Specialist
Physical Therapist	Plastic Surgeon	Psychiatrist	Psychologist	Pulmonologist
Radiologist	Rheumatologist	Skilled Nursing Facility	Specialist, Rehab Medicine	Speech Therapist
Surgeon, general	Surgeon, Specialist (describe)	Thyroid Specialist	Urologist	Other, please specify

Medical Devices and Supplies

Have you used any medical devices or supplies you would recommend? Please check all that apply, describe the device or item, and how to purchase it.

Adaptive technologies (i.e., sensors, lights)	Bath/shower aids (i.e., Grab bar, shower chair)	Bedroom comfort (i.e., Foam wedges, mattress)
Eating/drinking (i.e., good grip utensils, cups)	Foot/shoe products	Hearing (i.e., aids)
Low vision devices	Memory enhancement (i.e., interactive games, strategies)	Recreation
Walker/canes	Writing aids	Others:

Thank you for completing the Caring Collaborative Questionnaire. Please know that your privacy is of our utmost concern and all information collected is strictly confidential. Access to the database is restricted to members of the Caring Collaborative management team.

Appendix C: Health & Wellness Resource Directory

This Directory was developed to help members cut through the clutter of health-related information and resources. It features information on community-based programs that offer important services like meals on wheels, transportation, hospice, respite care. The information is organized by category; and includes brief descriptions of the programs or services; important details like eligibility, costs and contact information.

Here are the categories, along with examples of content.

Disease/condition resources

This section lists national non-profit organizations that deal with diseases and conditions (heart disease or Alzheimer's), along with explanatory notes.

Arthritis	<p>Arthritis Foundation New York Chapter 122 East 42nd Street 18th Floor New York, NY 10168-1898 (212)984-8700 For Medical Information & Assistance (212)984-8730 E-mail: info.ny@arthritis.org</p>	<p>Arthritis Foundation website: http://www.arthritis.org/</p> <p>Improve the quality of life for people with arthritis throughout the five boroughs and Westchester, Rockland, Orange, Sullivan, Dutchess, Ulster, and Putnam counties;</p> <p>Support research into the cause, treatment, and prevention of arthritis. Foster professional education and present educational opportunities to the public to learn more about arthritis and its various forms.</p>
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Home Food Services

This section lists ways members can obtain home food delivery on a short-term or long-term basis, including websites and phone contacts for a restaurant delivery service, a prepared food and grocery delivery service, supermarket chains, grocery stores, not-for-profit agencies, and other services that deliver groceries or prepared meals. Indicate service areas, delivery arrangements, and any registration requirements. Services can be coded by type. G = Grocery, M = Meals, R = Restaurant, A = Agency.

G	<p>Fairway www.fairwaymarket.com</p> <p>Select items can be ordered online. Not very clear on their website.</p>	<p>Delivery available for in-store purchases, with fees ranging from \$4.00 to \$7.00, depending on location. Now, some internet orders taken, but only on select items. Not very clear on website.</p> <p>Upper West Side -- 2127 Broadway Harlem – 2328 12th Avenue Redhook, Bklyn – 480-500 Van Brunt Street</p>
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Short Term Nursing and Rehabilitation Care

This section offers tips and strategies for selecting a sub-acute facility. It's difficult to recommend specific facilities, but you can include suggestions about what to look for in the physical environment, facility licensing, staff credentials, activities, atmosphere, and quality of services.

- LOOK beyond fancy entryways and offices, curtains and carpeting;
- LISTEN for laughter, chatter, people engaging with one another;
- SMELL the halls, room, bathrooms and other public places;
- TASTE the food being served for lunch or dinner;
- FEEL the ambiance as you walk through the center.

Products/Aids/Devices

This section includes local, regional and national websites that offer helpful products/aids/devices for older adults as well as local retail stores. For example, CC included a link to the national site for Living Better with Arthritis (<http://www.aidsforarthritis.com>) and listings of local suppliers:

	<p>Falk Drug and Surgical Supplies 259 East 72nd Street NY, NY 10021 212-744-8080 www.Falksurgicallsupplies.com</p>	
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Transportation Assistance

Transportation services available for older adults are often imbedded within other categories of services such as senior centers, caregiver resources, or home care services. It may take a bit of detective work to uncover transportation resources in your community, but your members will thank you. Be sure to include the name of the agency or service provider, a brief description and key contact information. For example:

	<p>MTA Transportation and Travel assistance – www.mta.info/mta/ada/stations</p>	<p>MTA site lists services for hard of hearing/mobility impaired individuals/visually impaired, and subway elevator locations</p>
	<p>NYC Dept for the Aging – www.nyc.gov/egovt/services/service_result.cfm</p>	<p>Provides transportation services through its ten Senior Service Centers: Transportation services are for medical appointments, week-end shopping trips, attendance at religious services. Eligibility is aged-based: 60 and over. There are no income limitations.</p>
	<p>New York Foundation for Senior Citizens– Project C.A.R.T : 212-956-0855; nyfscinc@aol.com.</p>	<p>Community Arranged Transportation Program. Free transportation for frail/elderly. For seniors 60 and over. No income limitation.</p>

Doctor Information: Recommendations and Ratings

This section includes links to websites that feature physician information, specialties, credentials, references, and ratings. Your members will appreciate a consolidated reference point for further research.

Sample listings can include:

	drscore.com	A site on which patients rate their physicians – free, easy to use – has links to patient advocacy groups, books and other media, articles, patient resources, and prescription savings.
	healthgrades.com	Provides information on disciplinary actions, board certification, education/training, patient opinions – you can research physicians (i.e., find a physician, compare physicians), hospitals (ratings, comprehensive reports), and nursing homes (locate/compare) – some information is free; there is a charge for more extensive information – you need patience; we found this site very slow.
	insiderpages.com	Lists over 9,000 doctors and more than 300 doctor referral services in Manhattan (you can specify other locations) – some are rated by stars, but it is not clear who did the ratings – all this is a little overwhelming and confusing, but it seems to be free and possibly useful.

Appendix D: What Members Should Know When Providing Service

Guiding Principles for Service Corps Members

The CC holds orientation sessions with new members to ensure that the principles for providing service are fully explained, both to those requesting help and to those providing a service. After a welcome, the typical agenda includes:

- Description of the elements of the program (Service Corps, Medical Information Exchange and Health & Wellness Directory);
- Discussion of ways to establish boundaries;
- The importance of confidentiality;
- Delineation between sharing medical experience and giving advice;
- Some “Don’ts” When Offering Help;

Setting Boundaries

It’s crucial that we learn to protect our time and space -- how to be considerate yet assertive on behalf of our own needs. It’s important, as recipients of services, that we recognize the generosity of volunteers and the time they are giving. Don’t ask for information or services that are beyond the capacity or the desire of your helpers. Both the volunteer and the person receiving help should be specific about the time commitment. “I would like to help you in the early afternoon, but I must be home by 4:00.” Always being upfront about your needs and desires will save anguish at a later date when a member seems overly needy.

Confidentiality

Confidentiality is critical. Participants must not discuss the medical or personal situations of members they assist. While we expect no one deliberately to disclose confidential or private information, our concern is with disclosure that happens by accident. “Julie can’t come to the meeting: she has a doctor’s appointment,” or, “You should see Julie’s collection of ceramic cows.”

Share Your Medical Experience but Don’t Offer Advice

Most of us have no medical training, so giving medical advice is irresponsible. For those with medical training, there’s not enough background to provide solid advice. If a member has a bad outcome, it may trigger the temptation to blame someone, anyone. You. And offering advice could make you feel guilty about the unfortunate outcome.

When talking about a medical condition you have experienced, the mantra is, “I’m only an expert about my own situation.” Your role is to relate the details of your own experience not educate or guide a member with knowledge you acquired along the way. Even a casual suggestion to take an aspirin can be dangerous; it could result in internal bleeding. So, don’t ask for or give medical advice. We also caution against relating horror stories that can only add to the member’s anxiety.

Accompanying Members to Medical Appointments

This is one of our most valuable functions. In addition to taking members to and from medical appointments, volunteers often accompany members who are meeting with their healthcare providers when they are discussing medical diagnoses and treatments. When this situation occurs, it’s important that the member seeking help clearly enunciates what she would like the volunteer to do, such as take notes, and, perhaps,

ask questions and seek clarification when needed. The role of the help is determined by the desires of the member seeking medical care, and it should be determined in advance. Perhaps, a list of questions could be put together to prepare for the meeting.

- What are the risks?
- What are the alternatives?
- How long is the recuperation?
- If pain is expected, how will it be managed?
- If side effects, how can they be reduced?
- What can I expect in the first 24 hours after the procedure?

Sample Members Agreement form

The Transition Network Caring Collaborative

Member Agreement

I understand that personal and medical information obtained in the course of my TTN Caring Collaborative activities is strictly confidential. It applies whether I am a provider or a recipient of either information or services. I agree to protect the privacy of all Caring Collaborative members with whom I engage as either a provider or a recipient.

I understand that my role, in sharing my medical experiences and lending support to a patient, does not extend to providing medical advice. I am aware that the most apparently benign medical recommendation can have unforeseen, grave, consequences. I agree not to give medical advice concerning procedures, medications or any other aspect of medical treatment.

I understand that the Caring Collaborative cannot guarantee the performance of any Caring Collaborative member, nor be responsible for injury to any person, or loss or damage to any property, which occurs while participating in the Caring Collaborative program. I agree to hold TTN, its employees and its members harmless for any claims or liability occurring while engaged in Caring Collaborative activities.

I understand that the breach of this Agreement is grounds to consider discontinuation of my membership in the Caring Collaborative.

This Agreement shall remain in effect, even if I am no longer a member of the Caring Collaborative or of TTN.

Date: _____

Signature: _____

Printed name: _____

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