FRANKLY SPEAKING ABOUT CANCER

Support from a Distance

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CANCER SUPPORT COMMUNITY

GILDA'S CLUB WORLDWIDE

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The Cancer Support Community and our partners *Caring from a Distance, Living Beyond Breast Cancer,* the *National Family Caregivers Association,* and the *Rosalynn Carter Institute for Caregiving* would like to dedicate this booklet to honor the vital energy and devotion of short- and long-distance caregivers in cities, towns, and neighborhoods nationwide.

Prologue

When a parent, sibling, relative or friend has been diagnosed with cancer, and they don't live with you, it is difficult to know how and when to get involved. You may not consider yourself to be a "caregiver" but you likely care a great deal and want to help.

The term "Long-Distance Caregiver" is often used for anyone who provides some form of physical, emotional, spiritual, financial or logistical support to a person with a serious illness, though they live at a distance from the person needing care.

If you find yourself in this position, this booklet is written to help you navigate the issues that arise from the point of diagnosis, through periods of treatment, to survivorship or the possibility of bereavement.

Cancer can be traumatic for everyone involved, and caregivers can play a vital role in providing comfort, hope and support.

Note: For the purpose of this publication, we will use the term "loved one" for the patient affected by cancer. This booklet is for long-distance caregivers. If you'd like specific information about caring for someone with breast cancer, you may also find ***Frankly Speaking About Cancer: When a Woman You Care About has Breast Cancer*** *helpful.*

1 *Who is a Long-Distance Caregiver?*

HELPFUL CONSIDERATIONS:

- ☐ It is not uncommon to feel shocked, fearful and angry after someone you love is diagnosed with cancer.
- ☐ There are many things you can do to help, even when you are not near: research, phone calls, listening, support with decision-making and finding helpful resources, to name a few.
- ☐ You will feel more control as you gather information and assess the situation.
- ☐ It helps to break down problems into manageable parts.
- ☐ Remember that cancer affects your loved one's body and life most directly — their opinions matter most. Please ask what you can do to help — don't assume.
- ☐ You are not alone — valuable resources and organizations are available.

ARE YOU A LONG-DISTANCE CAREGIVER?

A *caregiver* or *family caregiver* is anybody who provides unpaid help, or arranges for help, to a relative or friend because they have an illness or disability such as cancer. Help can be physical, emotional, spiritual, financial or logistical support. *Long-distance caregivers* are those who live a distance from their loved one with cancer.

Even if you live far away, you may find yourself in the position of overseeing your loved one's care (as the *primary caregiver*), or you may share caregiving duties with other siblings, hired support, friends, or a parent (as the *secondary caregiver*). Caregiving can continue for a lengthy period of time — and can include periods when care needs are intense, or periods when the care needs are minimal.

This responsibility can feel stressful or overwhelming, but with reliable information, practical guidance, and support, you will feel more control over the situation.

Many community agencies and services exist that can help you and your family handle a wide range of questions and challenges (see p. 38-40). Remind yourself that there is no right or wrong way to provide help. Your role will evolve along the way, so it's wise to take small steps.

"I live in the DC area and my parents live in Atlanta, Georgia. Both were diagnosed with cancer. It's been a huge challenge for me to visit and take care of business. I have a full time job, so it's a matter of juggling to manage my work, and manage time off, and manage to get plane tickets, and schedule doctor appointments along the way..."

– Tilda, caregiver

WHAT SUPPORT CAN A LONG-DISTANCE CAREGIVER PROVIDE?

Before jumping in, it helps to ask questions and listen. Assess the situation and determine what you can do versus what others can do — rather than assume or guess that you know what's best.

To assist a loved one with cancer, many things can be done from afar, such as: research and information gathering; coordinating and accessing services; assisting with decisions; and providing emotional support.

For example, what can you take responsibility for, or assist others with?

- Gathering cancer treatment and post-treatment information through contacts, internet research and phone calls.
- Using organizational skills to keep track of appointments, health insurance documents, and medical bills.
- Making arrangements with neighbors/friends to help with transportation, household chores or meals.
- Keeping family/friends updated.
- Making visits and offer respite to local caregivers.

These tasks are most helpful when discussed with your loved one and others who are also helping, and when done in a regular, coordinated manner. It also helps to keep written files that are accessible, so everyone involved can easily find important information and contacts.

Often family caregivers neglect to take care of themselves when they are consumed with helping someone else. Pace yourself and carve out time to manage your own needs and responsibilities.

Knowledge and confidence will grow over time. Sometimes you may have to step sideways or even backwards before you make progress. But bit by bit, you will sort out the challenges and identify workable solutions. What you and your loved one find supportive will be unique — the important things to remember are that you are not alone, and that you can help.

HOW IS LONG-DISTANCE CAREGIVING DIFFERENT?

For obvious reasons, it's difficult for a long-distance caregiver to be involved with day-to-day necessities. Unless it's absolutely necessary to provide direct support, long-distance caregivers may feel more able to gather information and assist with long range plans.

It is important periodically to evaluate the situation, determine what you can do to help, and adapt your actions as needs change. When you don't live nearby, you may feel that you're not doing enough or that what you're doing lacks value. Yet, the role you play from afar (and during your visits) can be very significant.

"'Fear-Nots' became the name I called my friends from near and far who came to care for me when I was diagnosed with breast cancer. In some extraordinary way they managed to share their individual strengths with me. Some cooked, some helped in the morass of documents, others sat through chemo sessions or humored me. Without these close and distant caregivers, I would have been a single mother living alone, consumed by fear. Because of each of them, I am a survivor who knows first-hand the vital impact of long distance care. No one should face cancer without their 'Fear-Nots.'"

– Paris, cancer survivor

Most often, you will count on phone calls, emails or text messages to stay in touch. You and your loved one (or the primary caregiver) can establish a plan for how often and when you are updated.

Be aware that long-distance caregiving can take a toll on your personal life and can become costly both in terms of time and money. It is important to prioritize what you can and cannot do, and find balance between your personal responsibilities and being a caregiver. Long-distance caregivers must make hard choices such as using money to pay for needed medical supplies, depleting family vacation funds for repeated caregiving trips, etc. If you find that caregiving takes over, you will need to find help (see: www.cfad.org).

In a 2007 study, long-distance caregivers spent on average close to $9,000 per year compared to $4,600 per year on average for those who care for someone nearby. (Family Caregivers—What they Spend, What they Sacrifice. Report of Findings. Nov. 2007.)

RESEARCH AND INFORMATION GATHERING

Assess the situation with your loved one and his/her doctors

Before you can know what's needed and what you can do to help, you must understand the situation. Below are some suggestions — you and your loved one will determine how involved you can/should be:

- Learn about the cancer including its location, stage, treatment options and anticipated treatment side effects.
- Decide with your loved one and other caregivers who will be the "point person," the one person in addition to the patient who has the patient's permission to speak with the medical team and gather direct treatment information. Additional facts can be found through credible organizations like the **National Cancer Institute**.
- Try to identify the top medical centers and experts in your loved one's (or your) area for a second opinion or additional services, as needed.
- Create a "to do" list with your loved one of immediate versus long-term needs. Decide what your loved one can address independently, what you or someone else can address from a distance (via phone or internet) and what requires hands-on support with a visit.
- Recognize and respect the unique capabilities of your loved one, in addition to the roles played by others involved.
- Organize a care-plan featuring coordination and open communication among all participants (who is doing what, when?). This plan will help reduce family stress and bring needed relief.

Remember that each stage of care requires different levels of support, and everyone's roles will change along the way. Cancer is not the same as other major life events; it is ongoing and often unpredictable.

CREDIBLE RESOURCES

If you are informed, you will feel more confident about treatment and supportive care decisions and less anxious about the unknown. Don't be afraid to ask questions – no question is irrelevant.

National Cancer Institute
1-800-4CANCER (1-800-422-6237)
www.cancer.gov

ASCO's Cancer.net
www.cancer.net

Living Beyond Breast Cancer
1-888-753-LBBC (1-888-753-5222)
www.lbbc.org

See p. 38-40 for more resources

COORDINATING AND GAINING ACCESS TO SERVICES

Create a list of important contacts and information for emergencies

Work with your loved one to compile and maintain an up-to-date list of key phone numbers and email addresses. Your contact list could include phone numbers and/or emails for: doctors, pharmacists, case managers, health insurance providers, employers, community service contacts, friends, neighbors, family members, dog-walkers, etc.

This list can also include information about whom to call for ready access to medical records and important legal and financial papers. At the top of the list should be the names of those who hold the designated Powers Of Attorney (see p. 24).

- From afar, you can offer to make arrangements to access needed services (like second or third opinions, a support group, financial aid, or federal services). The organizations listed on pages 38-40 can help you identify appropriate services.

- Keep a notebook (with dates) to track decisions and people involved. Encourage your loved one to maintain a journal to track their experience.

- Fostering open communication among the people involved in providing care should be an ongoing goal. Though it can seem time consuming and frustrating, this ultimately reduces stress and anxiety and brings everyone involved closer together.

ASSISTING WITH DECISIONS

Don't rush

Take time to research and ask questions before making decisions.

Cancer treatment decisions are stressful, important and numerous. For example, with breast cancer, early decisions must be made about a lumpectomy (removing a part of the breast) versus a mastectomy (removing the entire breast); breast reconstruction; and/or having chemotherapy, radiation, or targeted therapy.

Every situation is unique, but you can prepare with some of these tips:

- You can offer to help weigh the pros and cons of each treatment option with your loved one — including elements like time, where treatment will be given and cost.

- You can help your loved one think through reasonable short- and long-term expectations.

- If your loved one needs help navigating insurance issues, you can offer to contact the insurance company to learn about what is covered and what isn't. Pose questions about coverage beyond standard treatment, such as for: wigs (if hair is lost with chemotherapy); transportation to/from clinics for treatment; in-home medical assistance following treatment; out-of network care; medications; etc. If you are assigned this role, arrange a multi-party phone call, so your loved one can give the insurance company permission to speak with you.

- If your loved one is having difficulty paying for care — see the Cancer Support Community's *Frankly Speaking About Cancer: Coping with the Cost of Care* materials: www.cancersupportcommunity.org.

- Utilize an oncology social worker at the cancer center or affiliated with the oncologist. They offer a wealth of information and can answer many logistical and financial questions.

Remember that this is about your loved one's body — and these are his or her decisions to make, not yours. Your loved one is the expert in this cancer experience, especially with respect to what s/he feels, what is important to him/her, and what s/he wants. Your role as a distance caregiver is to help frame important questions that will help with decisions about treatment and recovery, and to let your loved one know that you care.

"I was a caregiver for Judy O'Hara. I cared for her out of the love of my heart. I was never asked. I saw a need and wanted to meet that need — not only for Judy but also for Mike and Michelle as family members. I live two hours away, but I did it because I loved Judy and the O'Hara family."

– Marty, caregiver

EMOTIONAL SUPPORT

Listen — and seek help when you need it

You do not need to have the answers or fix all the problems. Sometimes just "being there" is important, whether over the phone or in person.

Cancer creates an emotional rollercoaster. You and your loved one will find yourselves worrying about big things (survival and mortality) and little things (meal planning). You will likely find it hard to focus on work, household responsibilities and other demands, yet those pressures continue.

At various points in this publication we comment on ways to manage the emotional distress that cancer can cause — for both you and your loved one. Some excellent resources include support groups (for both the person with cancer and/or caregivers), counseling, journaling, online bulletin boards, and relaxation techniques.

CANCER AND FAMILY CAREGIVER SUPPORT ORGANIZATIONS

It is often helpful to talk with others who have had a similar experience. Some valuable organizations include:

Cancer Support Community
1-888-793-9355
www.cancersupportcommunity.org

Living Beyond Breast Cancer
1-888-753-5222
www.lbbc.org

Caring from a Distance
www.cfad.org

National Family Caregivers Association
1-800-896-3650
www.nfcacares.org

2 *Relationships*

HELPFUL CONSIDERATIONS:

- ☐ Learning how to cope with the difficult emotions often associated with cancer is important. There are active and passive ways to cope. Active coping skills are best.
- ☐ It is helpful to be clear about your role in coordination with others. Relationships can be challenged, especially when many people are involved in caring for someone.
- ☐ When discussing sensitive issues around cancer, such as caring for a parent, finances, or even the fear of death... it helps to think in advance about what words to use and how.
- ☐ Be thoughtful of your own needs and feelings of guilt, sadness or anger — there are many ways to balance your support without neglecting your own physical, economic and emotional wellbeing.

CANCER IS STRESSFUL

Though each of us manages the challenges of cancer differently, cancer leads almost everyone to experience higher levels of stress. Living with cancer can affect family roles and relationships and pose unanticipated financial and career challenges.

Acknowledge when the emotional stressors of cancer negatively affect your life — or the life of your loved one or another caregiver. Reaching out to experienced individuals who understand what you're going through (with a support group, counselor, or other expert), will show you that you are not alone and that even severe depression or anxiety can be treated. It is important to identify what can be done to regain balance.

"It made me realize my own mortality. For so long we think we'll live forever — and then cancer strikes. When your parents get sick, you realize that it's really close; it really hits home."

- Tilda, caregiver

COPING SKILLS TO MANAGE EMOTIONAL DISTRESS

The ways that we deal with our emotions are often referred to as our "coping mechanisms." In general, it is useful to think about how you react in difficult situations. Many people find that an "active" coping style reduces stress and improves focus when trying to solve serious problems.

COPING MECHANISMS

ACTIVE COPING

- Define the problem
- Decide what elements of the problem you can control
- Look for advice and information to address the problem
- Make a plan and take action to deal with the problem
- If the problem cannot be solved, try to adopt a new perspective to make it an issue you can live with
- Acknowledge your feelings
- Find a support group or counselor
- Build a relaxing regimen into your schedule (Yoga, exercise, music)

PASSIVE COPING (AVOIDANCE)

- Deny that the problem exists
- Avoid any thoughts about the problem
- Withdraw from social experiences
- Wishful thinking
- Keep extra busy and ignore the problem
- Use drugs or alcohol to forget the problem
- Blame and criticize yourself for the problem
- Keep stress inside

TOOLS TO IMPROVE COMMUNICATION

Some people can express their feelings, concerns or questions with ease — while others tend to keep things private or lash out at others. When discussing sensitive issues, such as caring for a parent with cancer, finances, or even the fear of death... it helps to think about what words to use, when and how, so that conversations can be meaningful.

"Learn to read between the lines when talking with a loved one or family member about what they're dealing with...my mom is infamous for telling me on the phone that everything is 'fine' with dad; I've learned to pry a little deeper and almost always find that there's something troubling her..."

- Laura, caregiver

HELPFUL THINGS TO SAY WHEN SOMEONE YOU LOVE HAS CANCER:

1. **Acknowledge the situation.** Many people are afraid to talk about cancer after a loved one is diagnosed. You may fear that it's too personal or upsetting to talk about. Actually, silence may be more harmful. You can say something like: *"I hear you received some difficult news. I want you to know that I care about you."*

2. **Be specific in your offers of assistance.** People with cancer may find it difficult to ask for help, or they may be too overwhelmed to know how you can help from afar. They don't want to be a burden. Be specific: *"Can I order you dinner to be brought each Wednesday?" "Can I help you submit the recent pharmacy bills?"*, or *"Would you like something new to wear?"* Only make a suggestion if you can deliver.

3. **Listen.** Many people with cancer swing between hope and fear, optimism and despair. Sometimes simply letting your loved one 'vent' their frustrations is the most helpful thing you can do. Just quietly listen. You can say: *"I support you and wish you strength."*

4. **Guard their privacy.** Being treated for cancer means that physical privacy is lost with hospital visits, check-ups and constant calls from well-wishers. To help your loved one regain privacy and control, only discuss their situation (even with other family members) after gaining permission. Ask what information is okay to share and with whom. Let discretion guide your information sharing.

5. **Respect and honor your loved one's dignity.** Dignity is the public recognition of self-worth. Cancer and its treatment can make people feel like they've lost dignity. You can remind your loved one that they are beloved and valued parents, daughters, sons, friends, etc. Never refer to them in the third person while they are in the room.

6. **Asking for help is OK.** If problems become too great to handle, there is help: *"I can call the nurse to see if she can find a visiting nurse or home care aide for you /us."* There are many cancer support organizations that are available and poised to help. See pages 38-40 for more information.

7. **Your loved one has control.** You may want to remind your loved one that they have control to make choices, connect with family and services, strive for a better quality of life and make the most of each moment.

EMOTIONAL BONDS MATTER

The relationship you have with the person diagnosed with cancer (friend, parent, sibling, grandparent, child) impacts the way you care for them and how you interact with others involved.

If you live at a distance, you might feel awkward or resented when visiting and "inserting" yourself into the routine or the dynamic of your loved one's local support network (assuming they have one). Various family members or caregivers often disagree as they figure out what to do, or who is doing what. It is important to be flexible and open-minded.

Strong emotions, fears and competing pressures are often involved when dealing with the demands of cancer and caregiving. Honest communication is critical while being aware of, and sensitive to, the feelings and interests of others involved. No one who cares likes to be left out.

Over time, routines will form as everyone involved finds their place and finds ways to feel useful and appreciated. Sometimes having a conversation with a neutral third party will help resolve differences.

Remember to think about yourself in the mix, so that you don't overlook your own needs (with your family, children, spouse, job...) as you strive to help your loved one.

"In our case, I think it deepened our relationship. I'd like to believe we always had pretty good communication skills — but we really appreciate each other even more now that it's over. It is part of the mixed blessing that goes along with cancer."

– Russ, caregiver

GUILT, SADNESS AND ANGER

Feelings such as guilt, sadness and anger often arise when there's a mismatch between what assistance you ideally want to provide (for instance, to drop everything and be with your loved one during treatment) versus the real demands of your life (health, employment, other family commitments, etc.).

You may feel guilty when you choose to address your own needs first. You may feel angry about the injustice of your loved one's illness. You may believe that your own needs are insignificant compared to those of your loved one. Or, you may even feel angry at your loved one for getting sick! These negative thoughts are common, and they can diminish your ability to cope with the cancer. The trick is not to let negative feelings determine your decisions.

TIPS TO MANAGE NEGATIVE EMOTIONS:

- **Recognize feelings such as guilt, resentment and anger.** Admit them. It will help you address the problem rather than ignore it or let anger grow.
- **Be compassionate with yourself.** There's no one way a caregiver should feel. Give yourself permission to separate your feelings from your actions.
- **Take positive action.** Needs are not bad or good; they just are. If you can't be there because you don't live close, find someone else to help or plan a future trip when you can be together.
- **Consider the positive impact of small gestures.** For example, if you can't call every day – send a quick email, text "hello," or drop a card or funny gift in the mail.
- **Reach out to your own support network for some coping ideas.** Call a family meeting and say, "Our lives have been a lot different since mom got sick. Let's figure out how we can help each other."
- **Take time on a regular basis to care for yourself.** Your batteries must be recharged so you can be a better caregiver over the long haul.

3 *Practical Considerations*

HELPFUL CONSIDERATIONS:

- ☐ Prioritize your time and budget: determine when it's most important to be onsite vs. when you can provide help from a distance.
- ☐ Use online resources to gather information, connect with others, and access support.
- ☐ If your loved one hasn't taken steps to designate who will act on his/her behalf in times of incapacity and doesn't have appropriate legal documents such as a living trust, will, living will, or power of attorney for healthcare — put those items on a "to do" list.
- ☐ Have a Plan B care plan available to use if Plan A no longer works.
- ☐ Put first things first — and don't expect to accomplish everything in one visit.

PROVIDING SPECIAL CARE WHEN VISITING

When you do visit your loved one (either on a regular basis or for special purposes), it is helpful to be prepared. Is the purpose of your visit to provide company, light housekeeping and emotional support; or does it coincide with important meetings such as those with a doctor, treatment team, or home health agency? Sometimes the main purpose of your visit is to give full attention to your loved one so the local family and friends caring for him/her can have a break (see respite care on p. 28). Regardless of the reason, your presence will be much anticipated, and you may find yourself juggling several challenges that you'll need to manage creatively.

It can help to coordinate visits by scheduling a "family meeting" with everyone involved in providing care, including your loved one. As always, the wishes of your loved one are most important.

It makes sense to agree how each person's efforts can complement one another; and ideally, to divide tasks according to each person's skills and limitations. If it's not possible to physically sit down to talk about these things in advance, a telephone conference or online group video call can be very effective.

Knowing when to plan a short or prolonged visit isn't always easy — but maintaining open and honest communication about when you can or cannot feasibly visit — and what you can or cannot accomplish while visiting — helps to reduce unrealistic expectations on all sides.

UTILIZING TECHNOLOGY TO ENHANCE SUPPORT

Using new age tools such as personal blogs, social networking sites, video communication (like Skype), email list serves, and webpages have transformed our ability to stay in touch in real-time, around the clock.

Smart phones and portable electronic equipment can allow you and your loved one to be easily connected. The support network can also use these tools to communicate with each other and stay updated on your loved one's progress.

Before sharing information, however, your loved one MUST know what you are sharing, why and how. To ensure privacy, you can use passwords or other filtering mechanisms so messages stay confidential and are shared only with appropriate site visitors. Bottom line: your loved one must be okay with the information shared.

Valuable information sources can help you find answers to questions about cancer, treatment, recovery and how to improve your loved one's quality of life.

Make sure that you consider the source of web-based information so you can judge whether or not it is balanced, trustworthy and credible. We list several reliable organizations, discussion boards and online support groups throughout this booklet.

GET ORGANIZED

Some websites designed to help family caregivers and volunteers get organized:

My Lifeline
www.MyLifeline.org
Those with cancer can create their own personal webpage to communicate with family and friends. Pages include online calendar tools, scheduling timelines, and information about ways friends and family can offer support.

Survivorship A to Z
www.survivorshipatoz.org
Offers information about treatment options and how to pay for medical care.

Cancer Support Community
www.cancersupportcommunity.org
Provides information and free online support groups and discussion boards for people affected by cancer including caregivers.

MANAGING LEGAL, FINANCIAL AND EMPLOYMENT AFFAIRS FROM AFAR

A cancer diagnosis impacts many practical aspects of life: finances, insurance, legal matters and employment (if relevant). If you are the only caregiver, or if you are skilled in this area, you may be the one called upon to lend a hand with some of these practical matters.

If you have been asked to help with billing or insurance issues, be prepared to jump privacy hurdles to access information from your loved one's health insurance company or workplace human resources department. There may be requests for written (or oral) permission forms, or you may need to know personal details such as social security number, date of birth, address, phone and policy number. Every insurance company seems to have slightly different requirements, so it's important to ask.

Helpful Federal Benefits

There are federal laws which provide protections and benefits for people with cancer and their caregivers:

- **Americans with Disabilities Act (ADA)** — some with cancer can be considered disabled and receive reasonable accommodations to perform essential job functions. www.ada.gov.
- **Family and Medical Leave Act (FMLA)** — allows an ill person or family member caring for them to take up to 12 weeks off from work (without pay but with no loss of benefits). Time off can be taken a little at a time or all at once. (See www.dol.gov/whd/fmla/index.htm and talk with your Human Resources Department about your specific situation.)

Income is a typical concern for people affected by cancer. If your loved one is no longer able to work, s/he may be eligible to receive disability payments, either through Social Security Disability or a private policy. To learn more, s/he should check with the human resources department at work. For information about **Social Security Disability Insurance (SSDI)** call 1-800-772-1213 or visit www.socialsecurity.gov.

COPING WITH THE COST OF CARE

Comprehensive information about managing the financial burdens of cancer can be found in the free booklet entitled *Frankly Speaking About Cancer: Coping with the Cost of Care by the Cancer Support Community*, online at: www.cancersupportcommunity.org.

Establishing End-Of-Life Plans

All adults, regardless of their current health status, should have advanced directives including a signed living will and/or a power of attorney for healthcare. But, in fact, most Americans have NOT prepared these documents. Facing cancer reminds us to get our plans in order, and though these plans may not be needed for years to come, this could be a good time for both you and your loved one to prepare.

- A **living will** states the individual's preferences for medical treatment when faced with certain dire situations. Written health care instructions address personal choices such as the use of life support systems or feeding tubes and whether or when to perform invasive medical tests.

- A **durable power of attorney for healthcare** (also called a healthcare agent or healthcare proxy) assigns another person the authority to express an individual's preferences for medical decisions in the event that they cannot make decisions on their own.

- A **durable power of attorney for property**, a revocable living trust, or guardianship enables others to make financial decisions for an individual and for their beneficiaries, if they cannot do so themselves.

It is best to have a lawyer to create a legally binding will — but documents such as a living will and durable power of attorney for healthcare can be completed without a lawyer.

Make sure that only appropriate persons have ready access to important personal and financial documents. Everyone responsible should know where these documents (or safe deposit keys, for instance) are located. For example, if there is Power of Attorney paperwork, it belongs in the house and with the doctor, not in the safety-deposit box!

Establishing estate or end-of-life plans may seem intimidating or fatalistic — but, in fact, it's not. It will give you and your loved one peace of mind and relief to know there is a worst-case plan in place. That task is now off the "to do" list.

"I would tell someone whose parents or a loved one was just diagnosed with cancer that it's no longer a death sentence — I think people still have a very visceral reaction to the word 'cancer.' But you have to keep up the hope and the spirits that there will be a recovery, because it's always possible now."

– Annabella & her mother, Ellen

KEEPING YOUR OPTIONS OPEN — CREATING "PLAN B"

If your loved one is not receiving the help s/he hoped for, and there are more holes than patches in the quilt of care, it may be time to take a step back and reevaluate your loved one's expectations and the reality of the situation. You may need to call for help or secure a different type of support.

If you make a list of needs, you can clarify and brainstorm creative ways to address each issue by breaking problems into smaller parts and tapping into additional resources.

"We met in a support group. Just when I was thinking that I had to go to chemotherapy alone the next day since I couldn't find anybody to take me, Chris said: "I'll take you." And she did, and our friendship grew from there."

- Chris & her caregiver, Sharon

THINGS A LOVED ONE MAY NEED HELP WITH & WHO CAN HELP:		
TYPE OF HELP NEEDED		WHO ELSE CAN HELP?
Home care needs (acute)	• Meals, grocery shopping • Daily support (bathing, dressing, laundry…) • Transportation	• Meals-on-wheels, neighbors, friends, spiritual organizations • A home-health aid, friends, other family members • Friends, neighbors, support organizations, the hospital social worker, spiritual organizations
Medical needs (acute)	• Making treatment decisions • Managing access to treatment • Managing anxiety and depression • Managing side-effects from treatment (what to expect)	• Medical team, second opinions, online research • Does the facility offer transportation services? Can neighbors/friends/family help? • The hospital's oncology social worker, a spiritual counselor, support organizations, telephone hotlines, support groups • Oncology nurse, oncology social workers (What prevention or preparation can be done?)
Practical support (long term)	• Coordinating follow-up medical care • Managing long-term side effects • Legal and financial support (paying bills, insurance issues, home maintenance, estate planning…)	• Medical team (doctors and nurses) – create a calendar, list what your loved one needs to know • Oncology social worker, family, close friends • Does her medical facility have payment programs? Can the hospital ombudsmen or the Patient Advocate Foundation identify sources of financial support? Is a lawyer needed?
Other	• Ongoing emotional support	• Support hotlines, support groups, connections with other cancer survivors, clergy, friends…

RESPITE

One vital role for a long-distance caregiver is to give a primary caregiver a break by taking short-term responsibility for the daily needs of their loved one when visiting (laundry, grocery shopping, bathing, other support), or to help find professional assistance like a home-nursing service.

Respite care is the provision of short-term, temporary relief to caregivers who provide intensive support in the patient's home. Respite also provides a positive experience for the person receiving care.

If you plan to visit, and your visit will involve respite care, it always helps to prepare by talking about care needs in advance with your loved one and their primary caregiver. This way everyone feels comfortable about the change in routine.

TAKE CARE OF YOURSELF

People who care for someone with a serious illness can forget to take care of themselves, or neglect their own needs. There are many ways to build-in time for your own care or for the respite care of a primary caregiver. Valuable information about how to access respite care for you or another caregiver can be found by contacting:

- Arch National Respite Organization
  www.archrespite.org/arch-membership
- National Family Caregivers Association
  1-800-896-3650
  www.nfcacares.org
- Family Caregiver Alliance
  1-800-445-8106
  www.caregiver.org

CARE TRANSITIONS

Inpatient hospital stays are sometimes a part of the cancer journey. It is critical to ensure a smooth transition between phases of cancer care such as from inpatient to outpatient treatment. There are many organizations listed in the resources section with information about care transitions. **Caring From a Distance** (www.cfad.org) has several particularly helpful publications available on their website.

Consider that even good transitions, such as the end of treatment or discharge from the hospital can be confusing. On one hand, your loved one will be relieved that treatment is over, but on the other hand they won't feel the protection of daily medical visits or the full-time attention that s/he once felt. People need to process their feelings during transitions, and caregivers should remember to respect and support the fact that it takes time for people to grasp this change in their lives.

4 Long-Distance Support at Diagnosis

HELPFUL CONSIDERATIONS:

- ☐ In almost all cases, your loved one has time to slow down and think about his/her goals and priorities for treatment. Don't panic. Take time to collect information.
- ☐ You don't have to jump on an airplane right away. Talk things through with your loved one and family to plan your upcoming visits.
- ☐ Don't discuss your loved one's cancer with anyone unless you ask first if it is okay.
- ☐ You can collect important phone numbers for your loved one to have handy, and familiarize yourself with local cancer support services.
- ☐ You can offer assistance with scheduling treatment appointments and second opinions and establish an online calendar to be shared with others.
- ☐ Think about your own obligations. Can you be away from your daily commitments to be with your loved one? Consider alternate possibilities: it may be easier for your loved one to stay with you during treatment or recovery.

USEFUL QUESTIONS TO ASK BEFORE MAKING TREATMENT DECISIONS

- How experienced is the doctor and medical team in treating your loved one's specific type of cancer? Is the doctor board certified in oncology?
- Does the medical team stay up-to-date on medical and side-effect treatments?
- Where will treatment be given? (In-patient? Outpatient? Location?)
- Do the recommended doctor and medical facility accept your loved one's insurance?
- Will your loved one have access to an oncology social worker or patient navigator to help with education and support, including tips on long-distance support?
- What other support services are available?
- How and when can your loved one (or a primary caregiver) contact the treatment team with ongoing questions? (Can you use email, phone or only office visits?) Who is the contact person? Who is the backup contact?
- Could you have the name of another oncologist for a second opinion?
- How are medical records transferred?
- Are clinical trials an option?

USEFUL QUESTIONS TO ASK THE DOCTOR ABOUT TREATMENT

- What is the goal of treatment?
- Why is the doctor recommending one treatment over another?
- What are the benefits and risks of each viable treatment option?
- How can your loved one and the family manage the side effects associated with each treatment option?
- How often will treatment be given and where? How long does each treatment last? How much time between treatments?
- If cost is a problem: are there ways to help our family with the costs of treatment?

5 Long-Distance Support During & After Treatment

HELPFUL CONSIDERATIONS

- ☐ If you cannot be present at all treatment or doctors' appointments, look at the overall treatment schedule to plan your visit(s).
- ☐ If your loved one is having surgery, discuss whether it's best for you to come when s/he's in the hospital or after s/he's discharged (the nurse might be helpful with answering this question).
- ☐ Consider a support group for your loved one, his/her primary caregiver, and yourself to help manage treatment side-effects and emotions. Online groups are available at www.cancersupportcommunity.org.
- ☐ Secure proper authorization to allow you or a local caregiver to gather copies of medical and treatment records (including operation reports and x-rays) for your loved one's personal files. This will help with follow-up care plans and future medical needs. Consider uploading these into a secure online Personal Health Record file.
- ☐ Understand that the recovery period can take a long time — possibly a year or more after treatment is complete. Your loved one may require support after treatment ends before s/he feels independent again.
- ☐ As always, open doors to communication with everyone involved in caring for your loved one.

QUESTIONS TO ASK DURING TREATMENT

- How will your loved one get to and from treatment appointments?
- Does s/he want someone to accompany him/her to treatment appointments?
- Are his/her daily needs covered (grocery shopping/preparing meals, laundry, household maintenance)?
- Are side-effects being managed? Pain?
- Is there a trusted confidant with whom your loved one can discuss his/her feelings (when ready)?
- Are there others who've gone through similar experiences whom your loved one can reach on a daily basis (via phone, online, or face-to-face support groups)?
- Is the primary caregiver up to the challenge? Is your help needed to make phone calls or to coordinate additional help?
- Is it okay to tell friends and family members how things are going? (And is it okay to share information via a group email or through a personal webpage, for example?)

QUESTIONS TO ASK FOLLOWING TREATMENT

- What types of support (emotional and physical) are available for your loved one now that treatment appointments are over?
- How long could the recovery process take before your loved one feels "normal" or energetic again? (Cancer treatment causes a great deal of fatigue.)
- How much support for daily activities is still needed?
- Does he/she want to celebrate the end of treatment? (Don't be surprised if your loved one doesn't want to celebrate...but it doesn't hurt to ask!)

6 Long-Distance Support for Advanced Disease

HELPFUL CONSIDERATIONS:

- ☐ Reach out! Family and friends, support groups, social workers and counselors who work with people affected by cancer are poised to help.
- ☐ Enjoying life is about how you and your loved one live with advanced disease. It IS still possible to enjoy each other's company, focus on the things that really matter, and enjoy happy times.
- ☐ End-of-life care plans should be in place. Make sure that all family members are on the same page. Be sure the doctor is aware of your loved one's preferences.
- ☐ Ask if your loved one is reporting pain and other symptoms to the doctor. Is his/her response helpful? And timely?
- ☐ When planning visits, contact airlines to ask they not raise your price on last-minute tickets. If you explain the situation, they may give you a regular rate.
- ☐ If homebound, is there a schedule of visitors? Do they know not to stay too long?

QUESTIONS TO ASK WHEN CANCER IS ADVANCED

- What kind of support does your loved one want right now? Who does he/she want to see in the near future?
- Are there items on your loved one's "wish list" that you can help fulfill?
- Is your loved one comfortable?
- How can he/she access palliative or hospice care when needed?

AVAILABLE SUPPORT

Those affected by advanced stages of cancer can and often do live full lives with their disease under control and managed by medication. Talk over how your loved one wants to be helped or not helped, and what type of visit schedule to implement.

With advanced disease, you may find yourself confronting thoughts or discussions around death. The idea of losing a loved one is one of the most difficult experiences in life. Reach out to find comfort.

Hospice is helpful to consider when facing advanced disease and end-of-life decisions. Your loved one's doctor, nurse, or the medical center's oncology social worker will be able to connect you with hospice services directly. Sometimes people with advanced cancer choose to relocate to be closer to family at this stage of the journey. You can prepare by calling a few different hospice programs (in-home or residential) to learn more about the service group that you feel most comfortable using.

Palliative care is a service to treat pain and other symptoms with the goal of achieving comfort, managing symptoms, and improving a patient's quality of life. Some hospitals and hospice programs have palliative care services. Many people prefer to have palliative care at home.

Hospice care is a coordinated program with a team of professionals to provide symptom management and support to patients and their loved ones when the cancer no longer responds to cure-oriented treatment. The hospice plan is aimed at relieving pain and other symptoms and it involves care provided by doctors, nurses, social workers, chaplains and volunteers — coordinated as a hospice team.

Respite care is short-term care that helps family caregivers take a break from the daily routine and stress of caregiving.

Support organizations and oncology social workers (accessible through most cancer centers) can address the many questions and challenges that arise.

7 Resources

"So long as we are human, at some point, some way, each of us will find ourselves being caretakers. At some point, some way, each of us will watch someone we care about become a sliver of who they once were. As caretakers, we may rise to the job, or we may become burnt out. We just have to do our best, take care of ourselves and be prepared to accept the unknown."

– Adam, caregiver

American Cancer Society (ACS)
1-800-ACS-2345
www.cancer.org
ACS provides information about cancer and its treatment, how to talk with others about cancer (including children), and how to manage medical costs among other topics. Publication worth note: *Dealing with a Cancer Diagnosis in the Family*.

ASCO's Cancer.net
www.cancer.net
Cancer.net provided by the American Society of Clinical Oncology provides oncologist-approved information about cancer. Information specific to caregiving can be found at www.cancer.net/patient/coping/caregiving.

AssistGuide Information Services (AGIS)
www.agis.com
AGIS offers advice on what to expect, how to get started, and where to turn for help when a loved one faces illness.

Caring Connections
1-800-658-8898
www.caringinfo.org
Caring Connections offers comprehensive information provided by the National Hospice and Palliative Care Organization to improve end-of-life care planning.

CancerCare
1-800-813-4673
www.cancercare.org
CancerCare provides free education and a one-on-one counseling hotline for all types of cancer. CancerCare Assist specifically helps with financial issues.

Cancer Legal Resources Center (CLRC)
www.cancerlegalresourcecenter.org
CLRC provides free and confidential information about cancer-related legal issues to survivors and their families, friends, employers, and others in need.

Cancer Support Community (CSC)
1-800-793-9355
www.cancersupportcommunity.org
CSC provides support, education, and hope at no cost to anyone affected by cancer. CSC offers online and face-to-face support groups, one-on-one counseling, workshops and other services at over 100 locations worldwide and online.

CarePages
www.carepages.com
CarePages provides free patient blogs that connect friends and family during a health challenge.

CaringBridge
www.caringbridge.org
CaringBridge provides free, personalized webpages that support and connect loved ones during critical illness, treatment and recovery.

Caring from a Distance
www.cfad.org
CFAD is an organization created specifically to support long-distance caregivers.

Family Caregiver Alliance (FCA)
1-800-445-8106
www.caregiver.org
FCA addresses the needs of families and friends providing long-term care at home (primarily for issues of aging) through information, education, services, research and advocacy.

LIVE**STRONG**
www.livestrong.org
LIVE**STRONG** looks at the experiences of the cancer community, finds problems and develops solutions. This website offers many ways to connect with others and to learn about comprehensive cancer support.

Living Beyond Breast Cancer (LBBC)
1-888-753-LBBC
www.lbbc.org
LBBC provides education and support including a Survivors' Helpline staffed by trained peer counselors who are also breast cancer survivors.

Lotsa Helping Hands
www.rci.lotsahelpinghands.com
Lotsa Helping Hands offers online calendar tools and other information to help caregivers and volunteers schedule time to help loved ones and support family needs.

Mautner Project
1-866-628-8637
www.mautnerproject.org
The Mautner Project is a national health organization dedicated to lesbian health.

Men Against Breast Cancer (MABC)
1-866-547-6222
www.menagainstbreastcancer.org
MABC targets support services for men; educating and empowering men to be effective caregivers when breast cancer strikes a female loved one.

MyLifeline.org
www.mylifeline.org
My Lifeline offers a quick and seamless way to create free, personal websites for people with cancer who wish to connect with their friends and family easily via the web.

National Alliance for Caregiving (NAC)
www.caregiving.org
The NAC is a coalition of organizations focused on issues of caregiving with publications and resources to help.

National Cancer Institute (NCI)

1-800-4CANCER (422-6237)

www.cancer.gov

NCI is the highly credible federal agency responsible for providing cancer information, research, resources, and 24/7 telephone support. Two publications worth note: *When Someone in Your Family Has Cancer;* and *When Your Parent Has Cancer: A Guide for Teens.*

National Family Caregivers Association (NFCA)

1-800-896-3650

www.nfcacares.org

NFCA reaches across boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and wellbeing.

Nueva Vida

1-202-223-9100

www.nueva-vida.org

Nueva Vida is a support network for Latinas affected by cancer.

Partnership for Prescription Assistance (PPARx)

www.pparx.org

PPARx has established funds or can identify resources to assist qualifying patients with out of pocket treatment costs for a variety of illnesses or for medicines they need.

Patient Advocate Foundation (PAF)

1-800-532-5274

www.patientadvocate.org

PAF offers assistance to people coping with illness with specific insurance, employment, and/or creditor issues in debt crisis matters. PAF's Co-Pay Relief program provides co-pay assistance for prescriptions for qualifying patients (www.copays.org).

Rosalynn Carter Institute for Caregiving

229-928-1234

www.rosalynncarter.org

The Rosalynn Carter Institute for Caregiving establishes local, state and national partnerships committed to building quality long-term, home and community-based services.

Sisters Network, Inc.

1-866-781-1808

www.sistersnetworkinc.org

Sisters Network is a national African-American breast cancer survivorship organization.

Strength for Caring

www.strengthforcaring.com

Strength for Caring is a comprehensive website providing caregivers with a broad range of expert content and information including online "chat" services, daily inspiration, and support.

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GRAPHIC DESIGN

Gott Group

The Cancer Support Community ensures that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

THE CANCER SUPPORT COMMUNITY (CSC)

The Cancer Support Community is likely the largest psychosocial support organization in the world with a mission to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

CARING FROM A DISTANCE (CFAD)

CFAD aims to help caregivers organize and identify public and private service providers to help your loved one. We offer a range of communication tools to help coordinate and implement a feasible caregiving plan.

LIVING BEYOND BREAST CANCER (LBBC)

LBBC's mission is to empower all women affected by breast cancer to live as long as possible with the best quality of life.

NATIONAL FAMILY CAREGIVER'S ASSOCIATION (NFCA)

NFCA reaches across boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and wellbeing.

ROSALYNN CARTER INSTITUTE FOR CAREGIVING

The Rosalynn Carter Institute for Caregiving establishes local, state and national partnerships committed to building quality long-term, home and community-based services.

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People who care about someone with c
become active *participants* in enhanci
wellness for themselves and their *loved*
turing their *relationships* through and
cancer experience *people* who *care* ab
with cancer can become *active* particip