SPOTLIGHT SERIES

FRANKLY
SPEAKING
ABOUT CANCER

Ten Tips for Caregivers

THIRD PRINTING

People who care about someone with
cancer become active *participants* in
enhancing wellness for themselves an
their *loved* nurturing their *relationshi*
through and cancer experience. Peop
who *care* about someone with cancer

CANCER SUPPORT
COMMUNITY
A Global Network of Education and Hope

Table of Contents

This book is dedicated to the millions of people who devote their time, energy, talent and love to care for someone with cancer. The Cancer Support Community is also grateful to the families who shared their inspirational stories for this publication, originally called "The Balancing Act," and to charitable contributions from the Breast Cancer Fund of the National Philanthropic Trust.

Prologue

Over the years, improvements with cancer treatment have enabled people diagnosed with cancer to live longer, fuller lives; and caregivers deeply share the challenges and joys associated with their loved one's cancer experience.

The National Cancer Institute estimates that we live among approximately 14.5 million cancer survivors, with more than 1.6 million new cases of cancer expected to be diagnosed in 2015.[1] For most of these people, someone will be caring for them throughout their experience.

A cancer caregiver is anyone who provides physical, emotional, financial, spiritual or logistical support to a loved one with cancer.

There is a growing need to address the long term well-being of cancer caregivers, and provide them with coping strategies that improve their capacity to support their loved one and avoid burnout.

- A national survey of 1,002 men and women conducted by the Cancer Support Community (CSC) in 2009 for the *CARE Campaign* revealed that many Americans who provide support to a loved one with cancer do not even recognize themselves to be a caregiver.
- Approximately ninety percent (90%) surveyed by CSC felt they were not very knowledgeable about cancer caregiving in general.
- Approximately eighty percent (80%) of cancer caregivers experience high levels of emotional distress.[2]

Taking care of someone with cancer can be, without question, a challenge. This booklet is designed to help cancer caregivers become more effective in their caregiving role, reduce their own distress, find hope, and know that help and support is available.

The Cancer Support Community believes that people who care about someone with cancer can actively enhance the health and wellness of their loved one and their relationships, without neglecting their own personal needs. CSC aims to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

[1] ACS, Cancer Facts and Figures 2015
[2] CSC survey, 2007 STAR Campaign

1

Get Connected

Find Support

Talk to others in your unique position.

One of the best ways to cope with the stress, uncertainty and even loneliness that may come with caregiving is to talk with fellow caregivers who share similar experiences.

This specific set of friends (new or old) can share effective ways to communicate about cancer, help you cope with your reactions to the disease, and help you learn about your new role as a caregiver.

So where are your fellow caregivers?
The Cancer Support Community offers caregiver support groups. To learn more visit *www.cancersupportcommunity.org.*

Many community resources are also available for support — for example, seek out a member of clergy with whom you can connect; an oncology social worker at the cancer center; or contact other support organizations such as the *Caregiver Action Network*, the *Family Caregivers Alliance* or *Caring from A Distance*. For a list of valuable support organizations for caregivers, see page 31.

Only you can determine which type of support system works best for your lifestyle, goals and schedule. It's easy to feel overcome by the responsibilities of caregiving — but you should remember that others are thinking about how to support YOU, too.

A C.A.R.E. Snapshot

DOTTIE LEVEN

A retired dietician and mother of four grown children, Dottie Leven is no stranger to caregiving. So when her husband Andy was diagnosed with prostate cancer in 2003, she was quick to take action.

As Andy's primary family caregiver, Dottie was there to drive him to doctor appointments, prepare healthy meals, run errands and "keep the household running in tip-top shape," as Andy recalls. One of Dottie's main objectives was to make sure that she and Andy were well-read on the latest discoveries in prostate cancer treatments and side effects. Remaining committed to being proactive helped their relationship strengthen. Dottie found that the resource library at the *Cancer Support Community San Francisco Bay Area* helped quench her thirst for information about Andy's cancer.

Soon after Andy's diagnosis, Dottie began attending the CSC's caregiver support groups. She attended a weekly professionally-led support group for caregivers, while Andy attended a group for patients at the same time.

It didn't take long for Dottie to realize the value in talking to other caregivers who shared similar experiences. In Dottie's words, "The single greatest thing I took away from the support group was peace of mind." Andy loved to see how these weekly support groups rejuvenated Dottie. "We were in this journey together and it was comforting to see that she was getting the support she needed. Our relationship grew stronger after my cancer diagnosis, because I was reminded every day how much my wife cared for me in new and inspiring ways." (2007)

Andy and Dottie cooking together. During Andy's treatment he would be Dottie's sous chef.

2 Read Up

Do Your Homework

Information is power.

Caregiving is easier when you understand what a person with cancer is experiencing. You wouldn't attempt to build a house without studying carpentry, or adopt a pet without knowing what it requires — the same is true with a cancer diagnosis. Read up! Find credible resources and learn about the specific diagnosis, treatment options and how to manage side effects. You'll feel more confident.

There is no way to completely grasp the ups and downs of cancer — and you shouldn't expect to — but being armed with knowledge will help you accommodate your loved one's needs and help you feel a greater sense of control by knowing what to expect.

Consider learning about the stage of cancer, the possibility of relapse, recommended treatments and the side effects of cancer medications. The Cancer Support Community offers tips through a variety of education programs. Learn more at *www.cancersupportcommunity.org*

WHERE TO FIND CREDIBLE INFORMATION

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

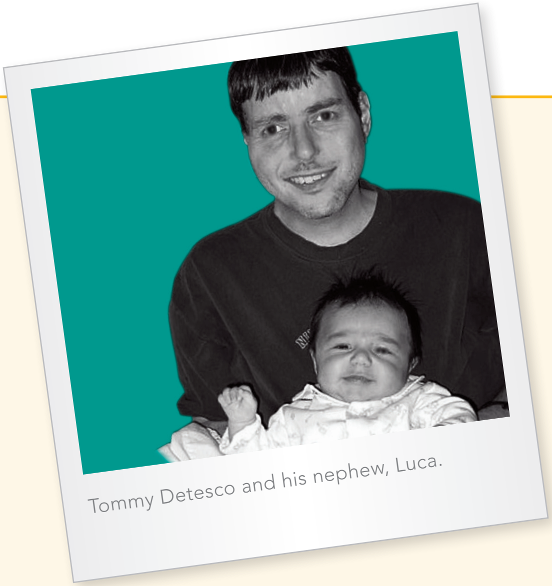
NCI is the Federal Agency responsible for providing cancer information, research, resources, and 24/7 telephone support.

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

CSC offers support to all people affected by cancer through in-person programs, online and over the phone.

CSC also provides information on many topics, including cancer treatments, side effects, ways to cope with the emotional impact of cancer and how to manage the costs of cancer care.

A C.A.R.E. Snapshot



Tommy Detesco and his nephew, Luca.

LUCILLE DETESCO

Tommy Detesco suffered from seizures beginning around age two and a half — sometimes more than one seizure each day, even with anti-convulsant medications. His mother, Lucille, felt that his epilepsy diagnosis was incorrect. After researching epilepsy, Lucille took Tommy to New York City for a second opinion and further evaluation at another hospital. Sure enough, that second evaluation led to the discovery of brain tumors, which Tommy would suffer from for the rest of his life.

Lucille's job as caregiver became much more involved over the years as Tommy's tumors became aggressive. Aside from her daily responsibilities to care for Tommy, Lucille was constantly researching what different hospitals were doing to treat brain tumors. She wanted to be sure that Tommy was getting the best care possible and enrolled him in several clinical trials. By understanding what Tommy was going through, Lucille and her family felt that they could help him live more comfortably — even though they knew, ultimately, they could not save him.

Jennifer Innocenzi, Tommy's sister, remembers how involved Lucille was in his daily life. "My mom did everything for Tommy — she became his eyes, ears and legs when Tommy lost his vision, hearing and ability to walk. She slept by him, took him for walks, fed him and bathed him — she didn't leave his side." Lucille remained proactive throughout Tommy's experience, providing him with things he needed to make the quality of his days better. Tommy died in August of 2007 at age 32.

> *"Tommy would start caring for me at times. He would tell me I looked beautiful, even on days when I felt really run down."*
>
> *— Lucille Detesco*

Caregivers Come in All Sizes

BRIAN & ADELE HEHER

CSC GREATER MIAMI - Brian Heher was only seven years old when his grandmother, Adele, was diagnosed with breast cancer. The bond between Brian and his grandmother grew stronger as they began to face cancer together. "El es increíble!" says Adele, reflecting on the support Brian has given her. He helped clean, file papers, prepare meals and was a consistent translator at medical appointments. Brian has been a very dedicated caregiver to his grandmother, even beyond her 82nd birthday! (2007)

3 *Embrace Your "New Normal"*

You can't do it all — at least not right now.

Patients and caregivers alike report feeling less control over their lives as they face the rollercoaster of emotions that cancer brings. Without fail, your responsibilities as a caregiver will create new routines in your life. After all, for the time being, you are taking on a new level of support in the patient's life in addition to maintaining your own needs.

There are ways that you can retain control over your daily routines to save you from becoming too stressed. It is important to maintain a balance between managing the needs of your loved one and the daily activities of your life.

Identify the parts of your life that you can still control — such as your own health and relationships. Stay as organized as possible so you can control your calendar and your time, while you aim to integrate new responsibilities with old ones.

You will have to be patient and accept that the familiar patterns of your life will change at different periods of time. Sometimes the laundry won't get done. Sometimes takeout will replace home cooking. It helps to **Prioritize!** Ask yourself: What is most important to do right now vs. later? What can other people help with? And try not to be hard on yourself — don't rush — you'll do the best you can.

"I think there are no sacrifices with caregiving — there are choices. I chose to be there for Jayne when she needed me. Being there for her was important to me, so I just did it. I found a way to fit my life around that."

— Julie Heckel, about her close friend, Jayne Collins, breast cancer survivor. Kirkland, WA

A C.A.R.E. Snapshot

SUSAN DUDLEY

During the winter of 2006, Susan Dudley was excited to settle into her new role as a grandmother. She never predicted that a little more than five months later she would be expanding her role to be a cancer caregiver to her daughter-in-law and grandson's young mother, Alisa Beattie.

Not long after her son was born, Alisa began noticing that her morning sickness wasn't going away. Her doctor suggested she get a battery of tests, including a colonoscopy. She was diagnosed with colorectal cancer at the age of 34.

Susan felt completely at a loss — her son Brent would soon become the sole breadwinner for the family as Alisa underwent treatment while raising her child. Struggling to balance family, work and cancer, her son had a hard time keeping Susan regularly informed — so she went directly to Alisa and asked how she could lighten the heavy load.

Susan says she was thrilled to be there when Maddox called Alisa "mama" for the first time.

It wasn't long before Susan began commuting 90 minutes weekly from her home in Chattanooga, TN to the Beattie's house in Atlanta. "As soon as she would walk in the door on Mondays I would feel this weight lift from my shoulders and I knew everything was going to be okay," says Alisa, who welcomed her mother-in-law to move in during the week. In addition to this support, Alisa and her husband Brent attended support group meetings and special events at the *Cancer Support Community Atlanta.*

Throughout Alisa's treatments and surgeries, Susan wore the hat of nurse, grandmother, mother-in-law and wife. She was keenly aware of making sure to give her son's family their space. Susan maintained her own well-being with support from her husband, church and by staying physically active through tennis games set for each weekend. "It was a privilege to care for my son's young family. I feel blessed to have witnessed Alisa's grace as she battled this disease." (2007)

> *"Throughout my experience my mother-in-law has been there. From the mundane tasks of laundry and cooking to the profound responsibilities of providing a nurturing environment for my young son and lifting my spirits, Susan has been there."*
>
> *—Alisa*

ACTIVE PROBLEM SOLVING

REGAIN CONTROL WITH ACTIVE PROBLEM-SOLVING TECHNIQUES

1. Define the problem: break it down into smaller parts.
2. Decide what elements of the problem you can and can't control.
3. Gather advice and information to address the problem.
4. Make a plan and take action to deal with the problem.
5. If the problem cannot be solved, try to adopt a new perspective to make it an issue you can live with.
6. Acknowledge your feelings.
7. Find a support group, friend or counselor to help you when you need additional support.

4 *Take Breaks*

Taking time for yourself is not selfish.

Even if you're working hard to keep a normal atmosphere, you still need time to recharge your mind and body, and to avoid depression or burnout.

Once you come to the conclusion that you can only do the best you can (and you can't do it all), you will find that you can remain present for the person you are helping. The patient will benefit most from being with you when you have your own life nicely balanced.

Balance is about finding ways to take a break from caregiving to rejuvenate your spirit. For some, this is a 10 minute walk around the block or a phone call to a friend; for others it's making plans to take a short vacation. This can also include tapping into your spirituality, whether or not you participate in a religious tradition. Prayer, meditation and other spiritual practices are some techniques to ease distress; as are an exercise routine; music; and the mind-body techniques discussed in Tip 9.

Be sure to meet this need for renewed energy when you are serving as a caregiver. Even mini-breaks will do wonders for your stress levels. Every little bit of relaxation counts.

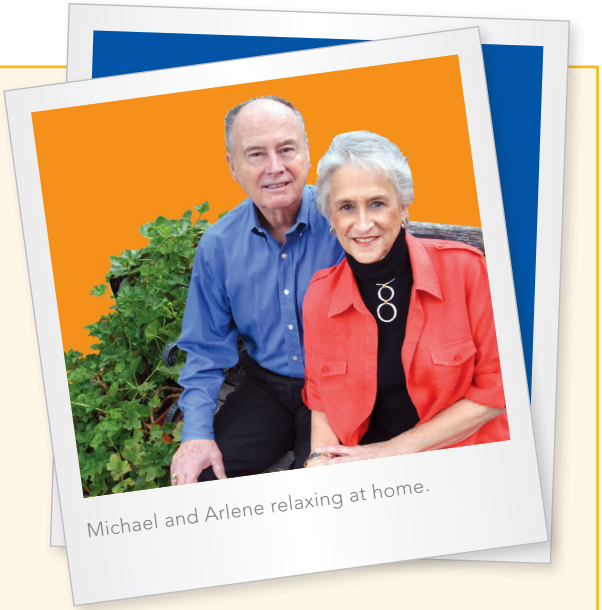
A C.A.R.E. Snapshot

MICHAEL & ARLENE WALACHY

Michael and Arlene Walachy have been through three cancer diagnoses. Arlene was first diagnosed with ovarian cancer in 1983 with a recurrence in 1993 and a diagnosis of breast cancer in 2005. Michael sat in many waiting rooms during several surgeries, chemotherapy sessions and checkups.

Michael has stood by his wife's side and, at the same time, found ways to reduce his own stress through difficult times. He set aside time for himself to do things he's passionate about, such as serving as a math tutor, donating blood to the Red Cross and volunteering with a Vietnam War Memorial exhibit.

During his wife's treatment, Michael maintained a job with an aerospace company. This was an especially difficult time to achieve a sense of "normalcy" and to give himself breaks, but he found a way. "I learned to rely on my family and friends. Talking to others about Arlene's cancer helped a great deal. I learned that not letting go of my fears created even more stress. Whenever I could fit it in, I would go for a run during my lunch hour. It helped to release some of my stress."



Michael and Arlene relaxing at home.

Spirituality played a big role in the coping process for Michael and Arlene. Arlene relieved stress by reading inspirational Bible passages at night. Michael sought advice from community clergy. He recalls, "They all helped me see a positive side of our problem. Prayers from our church community were comforting and helped put my mind at ease."

Arlene, after experiencing cancer three times, would dedicate time to help others seek understanding and community at the *Cancer Support Community Redondo Beach*. Being part of CSC not only helps others, but gives Arlene a sense of gratification as well. (2007)

Photo: Tom Underhill/Palos Verdes News – taken for an article about Michael's outstanding caregiving efforts.

THERE ARE MANY WAYS TO RECHARGE

MINI-BREAKS:

- Rest your eyes
- Listen to music
- Go for a walk or stretch
- Watch a favorite TV show
- Meditate
- Write in your journal

PLANNED BREAKS:

- See a movie
- Meet friends for lunch
- Go for a run
- Schedule a tennis match or round of golf
- Get tickets for the theater or a baseball game
- Ask a close friend, neighbor, family member or professional respite organization to help with caregiving for your loved one so you can take a short vacation

“Respite care” is organized short-term help to enable a family caregiver to take a break from the daily routine and stress of caregiving. To find the right kind of respite care, you will have to assess your needs and learn about the respite services near you. *The Caregiver’s Library* offers checklists and questionnaires to assist you at *www.caregiverslibrary.org.*

> *“The thing that got us through Kim’s treatment was humor. We laughed at everything! We found humor where most would find sadness. It was our coping mechanism. It’s good to have something to laugh at, even though she was going through such tough times.”*
>
> *— Kathy Friess, about helping her friend Kim Shumway. Marysville, WA*

5 Remain Involved
with Community, Friends and Family

Strength comes from the support of others.

It's important to remember that you are still allowed to have a life of your own when you are caring for someone with cancer. If you can, continue to play an active role within your community of friends and family. Being with people who care about you will often give you strength and a positive attitude towards your "new normal."

Caregiving is stressful and can take up a great deal of personal time. A great way to reduce this stress is to remain involved with parts of your life that don't include caregiving. For some, this means maintaining a role in school, faith or community functions — for others, this means weekly visits with a best friend.

Your level of involvement may change over time, but you will appreciate having someone else to turn to while caring for a loved one.

SO, HOW'S SHE DOING…?

Often a cancer caregiver has the responsibility of giving a status report to well-wishers. You can feel bogged down by the amount of questions and "check-ins" from other loved ones.

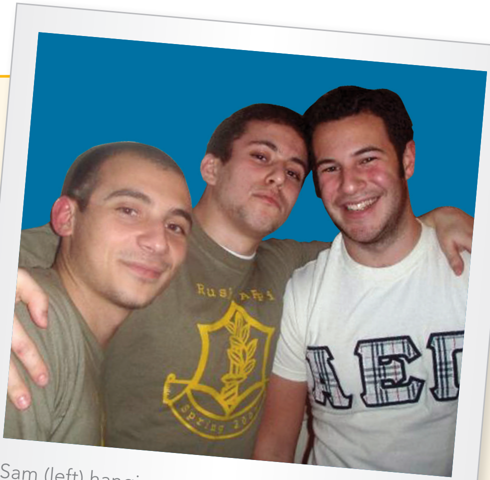
To make it easier, consider starting an email list or website to keep people updated with the information your loved one feels comfortable sharing. The Cancer Support Community offers many tips and resources for caregivers and patients to connect with others, through its interactive resource library, online discussion forums, personalized web pages and blogs. For more information, visit *www.cancersupportcommunity.org.*

A C.A.R.E. Snapshot

ALPHA EPSILON PI

Sam Kopolovich knows first-hand that caregivers come from all walks of life. When Sam was diagnosed with lymphoma in May 2007, he knew his close-knit family would be there for him, but what he didn't expect was that his entire fraternity would rally around him.

While undergoing intensive treatment over the summer at home in New Jersey, Sam says his Alpha Epsilon Pi brothers visited on a regular basis. When he returned to American University's campus in August, his brothers helped alleviate the stress associated with balancing rigorous academic demands with cancer treatment and recovery. One brother shaved his own head to support Sam, and others sent him a barrage of messages making sure he had everything he needed. Sam says he was especially touched when friends were willing to share low-key nights with him. "It's hard to go out when you are recovering from cancer and often your social life in college revolves around going out. My brothers were totally cool with just hanging out at my apartment and cooking. (2007)



Sam (left) hanging out with two fraternity brothers, Rafi Bortnick (middle) and Ben Kochman (right).

A C.A.R.E. Snapshot

ROBERT MILES

The Miles family has always been a fixture in their Athens, GA community. Felecia Miles was the secretary at Barnett Shoals Elementary School where her three sons were active in sports, clubs and academics. Robert Miles is director of life skills programs at the University of Georgia. The Miles family has always been known for their willingness to lend a hand, a shoulder or an ear to anyone in need.

In 2004, when Felecia was diagnosed with colorectal cancer, the Miles' school and church communities played an integral role in their transition to their "new normal" — adjusting to life with cancer. As Robert's responsibilities as a working parent, husband and caregiver were growing, he was comforted by the unending support of the Athens community. He credits the school faculty, parents and administration for rallying to make sure that his sons could remain athletes and scholars. "Principal Clark and several other faculty members at Barnett Shoals Elementary were so kind and helpful throughout our cancer journey. These people helped fund a trip to Tulsa, OK for Felecia to undergo further evaluation, and they made sure that our sons got to every scheduled sports event and activity when we were away."

The Miles Family, Easter 2008. From left to right: Caleb, Nathan, Felecia, Robert and Josh.

From meals to gift cards to prayer chains, Robert says his family was strengthened by the generosity of their "second family," their church community. A casserole wasn't just a casserole; it was a reminder that there were others looking out for his family. "The outpouring from our church family has been tremendous. The community strengthened me spiritually and their other means of support helped raise our three growing boys."(2007)

6 Make Plans

for the Future

No one knows what the future holds.

Often with cancer, it's important to focus on the present – and to make the most of each moment. However, planning for the future is also important; especially in terms of practical matters.

Planning for the future includes taking care of the financial and legal issues surrounding a cancer diagnosis. There are different roles you can take. Some caregivers help to gather paperwork and get questions answered around insurance, wills and powers of attorney documents. Other caregivers are not involved in this process, but offer other support when asked.

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. Ask your loved one if they need or want assistance with their legal and financial matters. Having these plans under control now will help everyone involved gain peace of mind for the future. For help to get started, see the Nitty Gritty Checklist on page 18.

> *"I intend to be here for several years, but at the same time I realize that to be in control I have to make all my final arrangements. My entire estate is laid out in my will, and my bank is named the administrator. I find that in doing this, at this time, I now have piece of mind with no anxiety."*
>
> *— George*

A C.A.R.E. Snapshot

LINDA CARLYLE & TIFFANY MCGUFFEE

Single mothers hold a lot of responsibility, especially when juggling a job and raising children. Donna Owenby was doing just that when she was diagnosed with cervical cancer in 1999. When doctors told her that she might not live to see her daughter graduate from high school, Donna knew that she needed to prepare for the future — not only for herself, but for her daughter, Tiffany (age 12 at the time).

Donna's sister Linda was there from day one as a primary caregiver and played a big role in planning for Donna and Tiffany's future. From paying bills to driving to medical appointments, she handled it all. When the family sat down to discuss the future, Donna remembers, "We didn't plan for failure — dying was not an option." This optimism has led her to celebrate more than five years of remission.

Linda understood the fears of not having an income; and often paid for gas, food and bills so Donna did not worry about falling behind financially. One year, Linda rallied with her coworkers to gather money to purchase Christmas gifts for Donna and Tiffany. After visiting with relatives that evening, the two of them returned home to a stocked house on Christmas Eve, full of gifts and food that Donna and Tiffany could not have bought on their own. (2007)

Tiffany, Donna, and Linda used "tongue-in-cheek" humor to help cope with stress.

NITTY-GRITTY CHECKLIST

☐ Review and become familiar with your loved one's health insurance policy.

☐ Always keep copies of medical records and bills and follow-up with insurance companies.

☐ Keep careful records of medical expenses such as receipts for supplies, prescriptions, basic expenses not automatically covered by insurance. Fill out claim forms as promptly as possible. Don't be afraid to ask for help (from the doctor's office, hospital ombudsman or a home care agency) with reimbursement.

☐ If your loved one's medical bills begin to accumulate faster than they can be paid, approach creditors to work out a payment schedule you or the patient can manage.

☐ Work with an experienced attorney to draft a will and advance directives, including definitions for a living will and powers of attorney.

☐ Consider keeping a journal of your loved one's visits to the doctor, tests, side effects and questions.

☐ 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.*

NOTES

7 Learn to Say "YES!"

Learn to have helpers.

Friends, neighbors, and family often want to chip in with caregiving and this can be quite helpful. Allow yourself to feel replenished by friends' gestures for help or other kindness.

Don't be afraid to delegate responsibilities to volunteers: ask one person to help feed pets and another to help with food shopping. Remember that most people say, *"Is there anything I can do?,"* because they want to help but don't know what you need. Show them your list. Allow others, who may also consider themselves caregivers for your loved one, to share in responsibilities. This will not only help lighten your load, but will also show the person with cancer how many people truly want to help.

ORGANIZE HELP

Create Your Own Webpage at www.cancersupportcommunity.org

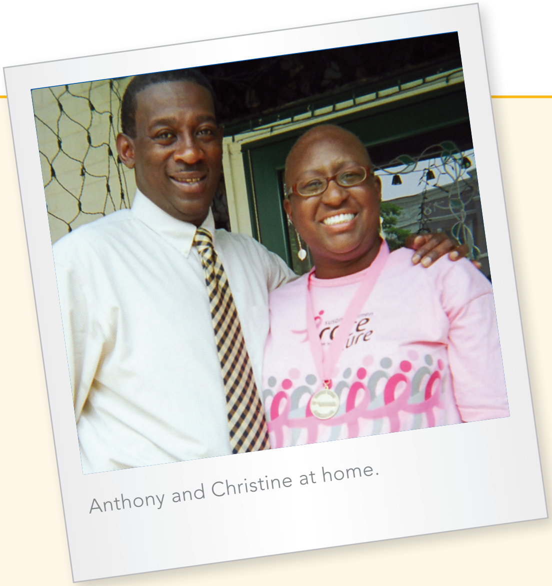
Offers a quick and seamless way to create free, personal websites for people with cancer who wish to connect with their friends and family easily via the web. It offers patient blogs, calendar functions and personalized webpages designed specifically for people affected by cancer.

Want to Help?

Here's How… Who/When

HERE'S HOW	HERE'S WHO/WHEN
Call, e-mail or blog updates to others in patient's "circle of care" (getting approval from your loved one first about what to share and with whom)	
Drive patient to medical appointments and treatment sessions	
Make phone calls to get answers to questions (pharmacy, insurance company, other)	
Go shopping	
Prepare dinner	
Provide childcare assistance, including driving kids to school or helping with homework	
Offer a fun activity (movie, walk, game…)	
Clean the house	
Take care of pets	
Ensure that bills are paid on time	
Do laundry	

A C.A.R.E. Snapshot



Anthony and Christine at home.

ANTHONY WRIGHT

Having several caregivers can relieve stress for everyone — it lightens the load on the primary caregiver and can put survivors at ease knowing that there are so many people who want to help. Christine Hart-Wright could count on an extraordinary caregiving network, headed by her husband Anthony.

Anthony drove Christine to most of her doctor's appointments, served as her daily support and helped with physical and emotional difficulties. But he wasn't alone. Christine's many friends and co-workers chipped in with tasks of all sizes so Anthony could also focus on his own responsibilities and career. He couldn't always be there as he juggled work and caregiving and was always eager to accept offers to help.

Christine's friends were critical for her well-being — whether it was simply to sit with her, visit at the hospital or take on household chores like cleaning and walking the dog. One of her friends delivered three meals a day, six days a week to Christine. Friends were always there for her and no task was too large to conquer. (2007)

"Anthony would have done it all, but he always accepted offers to help. I think it made them feel better, too, knowing that they were contributing to our successful journey. The most important thing I've found is to have that support system."

— Christine

8 Stay Healthy

Take care of yourself so you can take care of others.

It's easy to lose sight of your own health when you're focused on helping someone else get better. But if your own health starts to slip, who will be your loved one's caregiver?

Just like your mother always told you: eat well, get enough sleep, and build exercise into your schedule. Tend to any physical ailments that arise. To be present for your loved one, you need to take care of yourself.

HELP YOUR LOVED ONE FIND WAYS TO EAT IF THEY LOSE THEIR APPETITE

- **5 or 6 small meals each day instead of 3 large meals helps with a loss of appetite.** Smaller amounts at one time keep your loved one from feeling too full.
- **Keep protein-rich snacks nearby.** Easy snacks such as peanut butter crackers, nuts, granola bars, or dried fruit can help maintain your loved one's energy.
- **Recommend liquids that add calories and other nutrients.** These include juice, soup, and milk and soy-based drinks with protein. But be careful not to encourage too much at mealtime, to save room for solid foods.
- **Bedtime snacks can help.** This will give extra calories but won't affect your loved one's appetite for the next meal.
- **Suggest soft, cool, or frozen foods.** These include yogurt, milkshakes, and popsicles.

VEGETABLE WRAPS WITH CHICKEN AND HUMMUS

Serves 4; 15-20 minutes to prepare

1 c. diced cooked chicken
(use a rotisserie chicken from the grocery store!)

½ c. chopped cucumber

½ c. raw sugar snap peas

½ c. red bell pepper

½ c. chopped arugula or fresh spinach

½ c. hummus

4 flour tortillas

4 lettuce leaves
(green leaf or butter lettuce works well)

190 calories per serving, 3g. fat, 20g. protein;
10g. dietary fiber; 355 mg. sodium

1. Combine the chicken, cucumber, bell pepper, peas, arugula and hummus in a bowl. (or use other vegetables based on your preference)
2. Lay each tortilla on a plate, cover each with a lettuce leaf. Divide the chicken and vegetable mixture among each, spreading the mixture flat. Leave a ½ inch border around the edge of each tortilla. Roll tightly – cut in half and serve! Preserves well in the refrigerator with plastic wrap.


Dottie and Andy Leven

A C.A.R.E. Snapshot

ANDREA ROSCHKE

Andrea Roschke has been a part of *Cancer Support Community Valley/ Ventura/Santa Barbara* for many years. She became involved as a volunteer, not expecting to have a personal tie to the facility when her husband Mark was diagnosed with a glioblastoma (brain tumor). She and her husband soon became regular participants in the monthly brain tumor support group which includes a breakout session for caregivers.

As a beneficiary of the organization's free support services, she decided to give back. She and a close friend began training for *Strides for Hope*, a charity marathon that raised money for CSC Valley/Ventura/Santa Barbara programs and services. With the help of family and friends and hard training, Andrea completed the marathon and raised more than $10,000 for CSC and in honor of her husband, Mark.

Her vigorous participation in *Strides for Hope* reflects her giving spirit and her proactive approach to taking care of her own health. "I think the best analogy to caregiving is to follow the same directions you get from a flight attendant in the case of an emergency: 'Put your own mask on before you put a loved one's mask on.' This is to ensure that you are strong and fully aware when you take care of those around you. I really take that to heart. It is important for me to remain healthy to best care for my family."

From left to right: Ryan, Andrea, Mark and Jason. Andrea is a caregiver to both her husband, Mark and her son Ryan who was diagnosed with a rare auto-immune disorder two years after Mark's diagnosis. Her oldest son Jason donated his kidney to Ryan in 2006.

In addition to exercise, she makes sure to visit her own healthcare team for regular check-ups, take vitamin supplements as recommended, and enjoy a monthly massage to relieve stress. "My general practitioner is an advocate for preventative health measures and has helped me develop a proactive health regimen." (2007)

9 Find New Ways to Control Stress

Find ways to relax.

Sometimes it's hard to build anti-stress activities into your life; however, it's important to make time for relaxation.

Believe it or not, you can reach the natural state in which you feel fully relaxed. Experiencing the "mind-body connection" lets you feel that a sense of peace is possible in any moment, regardless of the stress and crisis around you.

Relaxation exercises are designed to enhance your mind's capacity to affect bodily functions and responses. Research increasingly shows that stress-reduction techniques can improve quality of life. Examples include: tai-chi, yoga, meditation, imagery, deep breathing, prayer, and therapies that use creative outlets such as art, music or dance. The Cancer Support Community offers relaxation classes such as these, as do other community organizations.

One example of a relaxation technique that you can do at home or at any moment by yourself is imagery. The basic concept of imagery is: take a deep breath, think of something positive and your emotions will be led in that direction. You can evoke the positive feelings of relaxation and relieve stress when you focus on specific thoughts and images. For instance, when you recall a positive life event, you can experience the same good feelings you felt at that time.

A C.A.R.E. Snapshot

PATTY SILVER

In 2000, Pamela Bradshaw was diagnosed with a recurrence of inflammatory breast cancer. After a visit to the oncologist, her husband picked up a copy of the Cancer Support Community's brochure featuring the free professionally-led support groups, educational workshops, nutrition and exercise programs and stress reduction classes offered by *CSC East Tennessee*.

Something told her this would be the fresh approach to healing that she was looking for. She began participating in yoga classes and attending support group sessions and through these programs, met people she never would have crossed paths with if not for cancer — including Patty Silver.

Pamela first met Patty, a creative expression therapist, during a guest lecture Patty was conducting at CSC East Tennessee. The workshop introduced spiritual healing practices to help people living with cancer develop "adaptability in the face of catastrophe." Patty created an eight-week program that addressed survivorship and mortality by helping participants understand how the body can heal and reduce the stress of cancer with every breath. Pamela says, "I believe that the spiritually-based practices and insight I learned from Patty were an excellent complement to the knowledge, inspiration, and support I received from CSC East Tennessee." (2007)

Patty Silver and Pam Bradshaw.

PATTY SILVER'S MEDITATION TIPS (FOR BEGINNERS)

Pam Bradshaw leading a yoga class at the Cancer Support Community East Tennessee.

1. **Create a comforting and nurturing space.** Light a candle, play soft music, wear comfortable clothes and sit where your body will be at ease.
2. **Try to sit in the same place each time you meditate.** Intentional energy builds, making it easier to achieve a relaxed, meditative state of mind.
3. **Sit with your spine straight (but not rigid) and the front of your body open and receptive.** Sense the front of your body being as soft as cotton.
4. **Focus on the breath.** Slowly follow your breathing in and out. Just like the waves of the ocean rolling in and rolling out. Your breath will gently rock your body back and forth, relaxing and calming.
5. **If you find that the mind wanders, just bring your focus back to your breath.** Following the breath in and following the breath out…

PATTY & PAM'S FAVORITE RELAXING ALBUMS

Adagio for Meditation, Peter Davidson

Inside the Taj Mahal, Paul Horn

Angels of the Deep, Raphael

Rhythms of Peace, Nawang

The Essence, Deva Premal

Shamanic Dream, Anugama

Ocean's Dream, Dean Evenson

Chakra Suite, Steven Halpern

Life at the Beach, Gary Knox

Nocturn, Nature's Quest

10 Set Limits

Define what you can reasonably do and what you can't do to help.

It's OK to tell yourself that there are limits to your caregiving. Your help is still very valuable.

It's easy to get caught in the whirlwind of appointments, daily errands and medication doses for your loved one. Come to terms with feeling overwhelmed (it will happen!) and be firm when you can't do something to help.

One way to cope with this is to keep a journal (especially when you feel like you are hitting your limits). Writing in a journal can give you a place to vent frustrations, list priorities and problem solve without causing conflict. It will keep your feelings private, while helping you release your feelings of distress.

Another way is to keep a list handy with the phone numbers/contact information of people you can reach out to who can step in to help when you can't.

Caregivers Come in All Sizes

EMILY HOCHSTEDLER

When Emily Hochstedler was in fourth grade her mom was diagnosed with breast cancer. Her mom had help from friends, family, and fellow nurses, but at the end of the day it was just Emily and her mom. She was quick to take on small responsibilities she could handle. She attributes her mom's recovery to her house specialty of peanut butter and jelly sandwiches with tea. Her advice to other caregiving kids — "Don't give up – it can get better!"

ADDITIONAL CARE TIPS

- **Get the facts.** Learn as much as you can about the type of cancer your loved one has, including potential health issues and how to handle pain.
- **Make connections.** Your local hospital likely has an oncology social worker who can help you with caregiving and can connect you with a homecare course or workshop in your community. Many visiting nurse services also provide home training for caregivers. The more you know, the more secure you'll feel — so ask around.
- **Encourage your loved one to manage discomfort before it gets bad.** Try to manage pain as it starts, so medicine won't need to play "catch-up." Always have sufficient medication on hand to control nausea and other side effects of cancer treatment. Your loved one's doctor can determine a good medication schedule and provide tips.
- **Keep germs away.** People with cancer have impaired immune systems, and are more susceptible to illness. Play "germ police" for your loved one — advise sick visitors to stay home; keep and use alcohol-based hand sanitizer. Keeping the patient as healthy as possible during treatment is the best way to a speedy recovery.
- **Respect privacy.** Don't just barge in on your loved one — respect their need to be alone, be discrete about when to share information and with whom (always ask first), and respect their decisions. This is your loved one's body, and their life.
- **Take a step back.** Don't assume your loved one needs you for everything. Ask if he or she needs help before giving it. Chances are, you'll know when you are needed.
- **Fight boredom.** Cancer treatment and recovery often requires home rest or bed rest — but this doesn't mean you can't have fun! Help alleviate the doldrums with movies, books, or games. Sometimes even the smallest distractions can make someone's day better.
- **Honor quiet moments.** At times, it may seem like quiet is hard to come by. Soft music, aromatherapy (when tolerable) and warm baths offer much in the way of comfort — for both you and the patient.
- **Listen.** Listening and asking questions can be some of the greatest ways to take care of your loved one. Sometimes just letting them "vent" is very helpful. Other times, you can speak up when your loved one is too weak, or listen to the doctors' advice when they may not be able.

Adapted from: Thiboldeaux, K., Golant, M., *The Total Cancer Wellness Guide: Reclaiming Your Life After Diagnosis*, BenBella, (2007)

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 1-888-793-9355 or visit *www.cancersupportcommunity.org*

CANCER SUPPORT HELPLINE®

CANCER SUPPORT
HELPLINE
888-793-9355

Whether you are newly diagnosed with cancer, a long-time cancer survivor, or caring for someone with cancer, CSC's toll-free Cancer Support Helpline (1-888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Monday-Friday from 9 am-9 pm ET.

CANCER EXPERIENCE REGISTRY®: CAREGIVERS

CANCER EXPERIENCE
REGISTRY

The Registry is a community of people impacted by cancer where caregivers are experts. Help us gain insights about the social and emotional needs of patients, families and caregivers throughout the cancer journey. Together, this collective voice of caregivers will advance research, care and policy toward the benefit of caregivers and the patients they assist. Connect with others; Advocate as active members of a community; Learn from experts; Share your unique story. Your experience is powerful! Join now at *www.CancerExperienceRegistry.org* to share, connect and learn.

FRANKLY
SPEAKING
ABOUT CANCER

FRANKLY SPEAKING ABOUT CANCER®

CSC's landmark cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online and in-person programs.

AFFILIATE NETWORK SERVICES

Almost 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

THE LIVING ROOM, ONLINE

"The Living Room" offers much of the same programming available at each CSC affiliate, online. You will find web-based support groups, discussion boards and social networking, a "build your own website" service, and educational materials for patients and caregivers.

National Resources

INFORMATION AND SUPPORT FOR CAREGIVERS

Caregiver Action Network (CAN)
202-454-3970
www.caregiveraction.org
CAN serves a broad spectrum of family caregivers and is a non-profit organization providing education, peer support, and resources to family caregivers across the country.

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

Family Caregiver Alliance (FCA)
National Center on Caregiving
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.

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.

Rosalynn Carter Institute for Caregiving
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.

INFORMATION AND SUPPORT FOR FINANCIAL, LEGAL AND OTHER CONCERNS

Cancer Legal Resource Center
866-843-2572
www.disabilityrightslegalcenter.org
The CLRC is a national, joint program of the Disability Rights Legal Center and Loyola Law School Los Angeles. The CLRC provides free and confidential information and resources on cancer-related legal issues to cancer patients, survivors, caregivers, health care professionals and others coping with cancer.

Health Insurance Marketplace
800-318-2596
www.healthcare.gov
If you don't have health insurance coverage through a job, Medicare, Medicaid, the Children's Health Insurance Program (CHIP), or another source, the Marketplace helps you find and enroll in a plan that fits your budget and meets your needs.

National Patient Travel Center (NPTC)
800-296-1217
www.patienttravel.org
The NPTC works with patients and significant others to try to assure that no one is denied access to distant specialized medical evaluation, diagnosis or treatment if they cannot afford long-distance medical air transportation. Using donated frequent flier miles and other options, NPTC works to arrange low-cost air tickets for people traveling a distance for treatment or a second opinion.

Patient Advocate Foundation (PAF)
800-532-5274
www.patientadvocate.org
PAF is a national nonprofit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability relative to their diagnosis of life-threatening or debilitating diseases. Among resources offered are the Underinsured, Uninsured, and Financial Resource Directories, which help individuals and families locate valuable resources and seek alternative coverage options or methods for better reimbursement.

United Way
211
www.unitedway.org
The United Way is an excellent source of information about local charities and programs that may be able to provide financial and resource support.

c.a.r.e.
cancer advocate
resources & education

THE CANCER SUPPORT COMMUNITY
CARE ACTIVE CONCEPT:

People who care about someone with cancer can become active participants in enhancing health and wellness for themselves and their loved ones, and nurturing their relationships through and beyond the cancer experience.

Being **CARE Active** is more than just coping with cancer and the stress it brings. It is about actively recognizing your ability to care effectively for your loved one and, at the same time, it is about your ability to address your own physical and emotional needs.

THE CANCER SUPPORT COMMUNITY

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC) is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. CSC achieves its mission through three areas: direct service delivery, research and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C. and across the nation. For more information, please call the toll-free Cancer Support Helpline at 888-793-9355, or visit *www.CancerSupportCommunity.org*. So that no one faces cancer alone®

WWW.CANCERSUPPORTCOMMUNITY.ORG 888.793.9355

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cancer advocate
resources & education

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People who care about someone with cancer become active *participants* in enhancing wellness for themselves an their *loved* nurturing their *relationshi* through and cancer experience. Peop who *care* about someone with cancer

CANCER SUPPORT
COMMUNITY
A Global Network of Education and Hope