A Guide for Cancer Caregivers

by: Barbara Baroff Kavanagh, MSW, LCSW, a cancer caregiver
About Cancer CareGiversAz™

Our promise is to educate cancer caregivers to improve patient outcomes.

For over 10 years, the focus of the Cancer Caregiver Education Program ™ has been on the health and well-being of the caregivers, the patient and the family. A primary operating principle is to provide a wrap-a-round approach that offers meaningful support to all of those impacted by a cancer diagnosis.

Why Focus on Cancer Caregivers?

“Family caregivers have been ‘silent partners’ in health care delivery, functioning as de facto care coordinators. During care handoffs, family caregivers make important contributions to ensuring quality, safety, and adherence to patient preferences; their role needs to be formally recognized and supported.” (Source: Coleman & Williams, Journal of Hospital Medicine, Sept/Oct 2007)

CCEP ™ created by Arizona Myeloma Network (AzMN®)

“There are only four kinds of people in the world – those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers.”

Source: Rosalynn Carter Institute for Caregiving

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Introduction

"AN INDIVIDUAL DOESN’T GET CANCER... A FAMILY DOES."
-Jerry Tempest Williams

Statistic: There are 38,000 new cancer patients diagnosed each year in Arizona. And, for each cancer patient, there is at least one or more others who become ‘caregivers’. Calculate the figures nationally, and the numbers are staggering.

Cancer doesn’t just impact the patient; it impacts entire families. It affects a patient’s work colleagues, friends, and neighbors. It impacts routines, finances, and livelihoods. The person or persons who provide care to the cancer patient usually take it on out of necessity: their spouse, child, or parent needs care, so caregiving for them becomes a labor of love. But as selfless as this may appear, the act of caregiving is one with its own stresses, financial burdens, and disruptions of normalcy. Addressing caregiver needs is becoming recognized more and more by health care agencies, organizations and businesses as an area that needs direct attention.

Arizona Myeloma Network (AzMN®) is an organization that recognized the needs of caregivers at its inception in 2004, due in part through the organization’s founder, Barbara Kavanagh, serving as a caregiver for her husband, Jack, who was diagnosed with multiple myeloma in 1991. Multiple Myeloma cancer is a rare and complex ‘blood’/Bone Marrow disease. Barbara and Jack found it confusing and stressful trying to find information and resources for myeloma. They began providing free conferences and other educational programs and resources, and experts through conferences, workshops, blogs, newsletters, and their website. Cancer patients and their caregivers have been the organization’s labor of love. Now a 29-year cancer survivor, Jack and Barbara’s journey with his diagnosis and treatment, and her challenges of caregiving, inspired them to try and provide patients and caregivers ‘tools’ to face their day-to-day life with cancer.

Now, more than ever, cancer patients and caregivers are facing an even more dangerous battle as they are confronted with the COVID-19 pandemic. In addition to the usual concerns with possible infections or ‘catching’ something, cancer patients and caregivers need to be 10x more vigilant. They must also be mindful of dealing with doctors who are themselves overwhelmed with caring for their patients while also protecting themselves from this deadly virus.

This guide shares Barbara’s blogs that were published by AARP Colorado from June 2018 to January 2020. These blogs describe actual patient stories and shares tips for caregivers. Also included are a variety of resources for the cancer caregiver.

It is our desire that the items shared within this guide will assist caregivers in discovering strengths within themselves they may not have known they possess, so that they can better meet their caregiving challenges. And, that the information provided will help them navigate the cancer system. The ‘Good News’ is that there has been tremendous progress in not only myeloma research and treatment, but other cancers as well. And, there is HOPE, in spite of a cancer diagnosis.

COMING NOVEMBER 14-21, 2020:
The 2nd Annual Arizona Cancer Caregivers Awareness Week & Proclamation from the Governor
We welcome your own ‘caregiver’stories and messages.
You can visit our website: www.cancercaregiversaz.com

*This guide contains excerpts from Barbara’s book, Living with Cancer, A CareGivers Journey©, to be published in late 2020. Materials in part or whole cannot be reproduced without the permission of the author.
Arizona Myeloma Network, AzMN®

Our Mission is to promote collaboration, awareness, education and advocacy for improved treatment and quality of life, for multiple myeloma Patients, their families and ALL Cancer Caregivers with special consideration for the underserved.

Barbara Baroff Kavanagh, MSW, LCSW

Barbara B. Kavanagh is the Founder and CEO of Arizona Myeloma Network (AzMN). She is a published author and has served as faculty for several universities including Boston University, Boston College Graduate School of Social Work, and Arizona State University. She holds a master’s degree in Social Work from Boston University and a bachelor’s from Duke University.

AzMN is a 501(c)(3) nonprofit organization started in 2004 by Barbara and her husband, Jack, who is a 29 year survivor of multiple myeloma. In 2005, Barbara created the first Living with Myeloma Conferences and Research Roundtables® that now attract more than 350 attendees annually. All AzMN programs are free and open to patients, caregivers, healthcare professionals, researchers, and anyone interested in the treatments and advancements of care for myeloma and all cancer patients and caregivers.

During the past 12 years, she and her staff have developed and delivered over 75 cancer caregiver seminars throughout the State and have additional Cancer Caregiver Education Programs, CCEP®, scheduled through March, 2020*. The seminars provide caregivers of cancer patients and the patient’s team the practical knowledge, skills, and strategies necessary for effectively caring for their loved ones, as well as themselves. CCEP® is now available as a customized program for companies, healthcare organizations, and community groups who want to present the event for their staff, cancer patients, and caregivers. AzMN Celebrated the 2nd Annual Cancer CareGivers Week, November14-21 with a Proclamation from the Governor of Arizona. And, from Nov.21-December 21st held the 1st Annual Virtual Cancer Caregivers Walk/Race Event in Arizona.

On November 23rd, Barbara received Congressional Recognition from Congresswoman Lesko for her dedication to cancer patients and caregivers in Arizona. She was recently selected for an award as one of the Top 100 Healthcare Visionaries, 2021, by IFAH International. Conferences.

She is currently working on her new book: "Living with Cancer, a CareGiver’s Journey®". This book features information from major cancer researchers and clinicians as well as sharing her own journey and those of the hundreds of patients and caregivers she has met and learned from over the past 29 years.

Barbara and Jack were also recognized in Tom Brokaw’s book A Lucky Life Interrupted: A Memoir of Hope. Her books on volunteerism and patient advocacy include The New Volunteerism, A Community Connection; The New Partnership: Human Services, Business and Industry; and Training Volunteers in the New Millennium: An International Connection They reflect a life dedicated to teaching and mentoring others to achieve their goals and transform their own lives and those they touch.

*During the current COVID-19 crisis, Barbara and Jack have continued to reach out virtually via the internet and phone to serve other cancer patients and caregivers like themselves. They know how difficult the isolation and fear are for everyone, but especially those with the added burden of cancer. They continue to publish their online newsletter, and also tv and radio interviews, updated information on ‘what’s happening’ with the research on the virus relating to cancer treatment and resources. And share their own message of hope and the inspiring stories of other cancer survivors.
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Dear Friends,

I am honored to be able to share my cancer caregiver journey with you. And, I am grateful to AARP Colorado for the opportunity to share what I have learned to help others.

It is a journey filled with love, faith, courage, and hope. I met wonderful people I might never have known if it wasn’t for the cancer diagnosis. I have overcome challenges I never dreamed of and lived and loved more fully than I ever imagined.

My journey began 27 years ago, on April 20, 1991, when my husband, Jack, was diagnosed with multiple myeloma. I selfishly confess: I would trade it all if Jack never had cancer, suffered so much, or given up so much of his life, and our life, to fight this disease.

During his annual company physical, Jack’s physician noticed something ‘wrong’ in his blood and referred him to an oncologist in Boston where we lived and worked. Jack didn’t want to worry me so he met with Dr. Ken Anderson at Dana Farber Cancer Institute alone. Lucky for us, Dr. Anderson was one of a few hematologists specializing in myeloma research and treatment at that time.

Jack called me after his appointment and said, “I just saw the doctor. How about meeting me after work to ‘talk’?” I knew this wasn’t good news. Over dinner, Jack explained that he had a rare bone marrow disease but they had ‘caught it early.’ I was frightened and numb! I couldn’t think. I kept asking myself: “What does this mean?” “Why Jack?” “Why us?” We learned all of this just a month before our wedding.

We had met through my consulting business. Both of us were divorced. We were so happy to have found each other and excited to start a new chapter in our lives. We knew very little about multiple myeloma and tried not to think about it as we prepared not only for our wedding, but a job transfer from his office in Cambridge, Massachusetts to Holland. We were moving to another country and we were going to be on our own!

On our wedding day, May 26, 1991, there were ‘3’ of us standing at the altar: the Bride, the Groom, and Cancer! Jack and I were so happy and in love but both of us were fearful of what the coming days, weeks, months, and years would bring. We told only our families and a few close friends about the diagnosis. We didn’t want Jack’s company to know. Thus the ‘secrets’ and the living with cancer journey began.

In next month’s post I will describe the challenges faced as I took on the hardest and most rewarding ‘job’ of my life: being a cancer caregiver! Let’s all come together to share, learn and build a true cancer caregiver community.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

www.azmyelomanetwork.org www.cancercaregiversaz.com
Cancer Caregiver Journey: Starting Our New Life

By Barbara Baroff Kavanagh, MSW, LCSW, July 2018

Dear Friends,

Starting our new life together in 1991 was scary and exciting. Jack and I were married and moving to Holland to advance his career with an international company. My joy was over-shadowed by the thoughts of how Jack’s myeloma diagnosis would impact our lives. Many questions crossed my mind: “How will I survive the guilt of leaving my business, elderly mother and two daughters behind?” “How will I cope with being a full-time cancer caregiver?” “Will we get the right medical care in Holland for Jack’s multiple myeloma?”

We learned quickly the importance of early detection, getting 2nd opinions and correct diagnosis. That is as true now and it was 27 years ago. From May 1991 to August 2003, when we retired to Arizona, Jack received cancer treatment in 5 countries, 3 US States and we moved 8 times. This made getting the right medical care tricky. (The numbers on the map (below) correlate to Jack’s job locations with #9 our return home.)

When Jack began treatment a month after we moved to Holland there was only one form of chemotherapy and one myeloma specialist located in the area. We were fortunate that our American doctor and international researcher knew the right doctor in Holland and the treatments worked. Though Jack had side effects, we learned what foods he could tolerate and how to manage the nausea and sleeplessness. We were optimistic, determined and hopeful.

I learned to help by encouraging him, making new friends, socializing with locals, and exploring our new ‘home’ together. For Jack, and many other cancer patients I know, having structure and balance in their lives really helps. Often that is the caregiver’s job!

Tips that saved us and may help you, too:

1. As cancer caregiver ‘Captain’, build a circle of care team: engage everyone - patient, doctors, family, friends, religious organizations, etc.
2. Educate yourself to communicate and advocate for your patient effectively and help make the right decisions together.
3. The patient’s role is to get better, take the meds/chemo, sleep, eat healthy or whatever is necessary to regain an acceptable quality of life.
4. Recognize everyone copes differently. Be gentle on yourself and the patient.
5. Give each other space and respect.
6. Remember, if you don’t take care of yourself first, who will take care of the patient?

Jack was the breadwinner and worked even on his bad days. Being productive distracted him from cancer. For me it was a respite from full-time cancer caregiving. I’d steal a few precious hours to take care of myself. Then launch into fighting with insurance companies, making appointments and handling hundreds of other details so that he wouldn’t have to! Unfortunately, not every full-time cancer caregiver can elect to stay home.

Please contact me with your own cancer caregiver story and suggestions. Together we will build a healthy cancer caregiver community.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

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Dear Friends,

For cancer patients and their families, summer isn’t always an opportunity for vacations or for fun and relaxing. The kids may be home from school, but Mom and Dad still need to work and keep up the same routine of doctor’s visits or treatment. Finances can also be an issue. Many who are battling cancer don’t have the extra money or time to get away. Sometimes, simple and short getaways or ‘staycations’ can help. If you haven’t had a break, please try and do something special with friends and family before summer ends. Try a backyard barbecue, visiting a friend with a pool, or a drive to a cooler place just for a change of scenery before the fall schedule and routine starts again.

For the caregiver, summer isn’t time off. Caregiving is a full time, year round job. A lesson that I have learned is sometimes we need to give ourselves time off and time away. Even short mini-trips can help! Or, maybe you need a ‘no commitments’ time just for you: possibly a spa day, yoga retreat, a night out with friends, a movie or concert, or whatever ‘works’ for you. If you are a male caregiver, you might prefer to go to a ball game, fishing, to the gym or just have lunch with your buddies. The important thing for both men and women is to schedule some time just for you. Most important, don’t feel GUILTY. You deserve it!

Some important aspects to consider:

* There are religious, cultural, geographic, age and gender differences in the way people deal with cancer. What we all have in common is fear, confusion, sadness, anger, and an array of other emotions and practical concerns.

* The word cancer makes other people uncomfortable. They don’t know what to say to you, or they tell you about a friend or relative with cancer. It is not your responsibility to make them feel better. Accept their ‘I’m so sorry’ and either ‘move on’ or let them know some way that they can be helpful.

* You are a cancer caregiver not a cancer caretaker! You are ‘giving’ of yourself, not ‘taking’. There is no rule book or one right way to handle this process. We are each different and so is our patient.

* Delete ‘I should’ and ‘selfish’ from your vocabulary. There are too many shoulds in our lives. We need to try to balance what really needs to be done and what can wait, or what someone else can do. I recommend that you consider what is really important for you and the one you care for. ‘Selfish’, according to the dictionary, means ‘caring for self’, which is what we all need to do.

* Take time to say ‘I love you’ every day and share a moment to appreciate yourself and each other! And, my husband’s advice over the years is to have a laugh! He leaves a cartoon or joke on my computer every morning!

It would be great to hear from you. Email me, go to my website: www.azmyelomanetwork.org, and look me up on Facebook. Share your own advice, inspiration and caregiver journey. Together we can make a difference and be a true cancer caregiver community!

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

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Dear Friends,

This month I would like to talk to you about loneliness. Ironically, I think that I am lonelier than my husband, the cancer patient. He has ‘guy’ friends. They know he has cancer, but he never talks to them about it. He talks sports, politics, travel, and baseball. He has a dedicated exercise routine involving either swimming or walking every day. Last summer, he was desperately ill from two rare bacterial infections and was in excruciating pain and couldn’t walk. After extensive treatment and rehab, he got back into his routine. Meanwhile, I lost weight, had trouble sleeping, and even my hairdresser couldn’t cover all of the grey!

Everyone who called us during the three months that he was in ‘crisis’, started every conversation with: “How’s Jack?” I am fortunate to have two daughters and two grandchildren who called, sent notes, and flew from California to Arizona to visit me while he was ill. A few kind friends did call and one or two took me out to dinner, but, people are busy with their own lives while yours is on ‘hold’. Ironically, while the patient often has a very structured lifestyle while in serious care, the caregiver’s life becomes occupied with hospital visits, doctor interviews, hospital and medical costs, insurance claims and worry.

Most friends, family, co-workers, and the general public don’t like to talk about cancer or even think about cancer. It makes them feel sad and helpless. I have learned over the 27 years of living with a cancer patient that I have to help other people find ways to be in my life and also try to develop a life of my own.

Some suggestions I have undertaken for myself and learned from other cancer caregivers:

• Plan at least one fun activity of your own each week (or as often as you can). I get my hair done every week.
• Develop your own fitness/health routine: yoga, walking with a friend one or two mornings or evenings a week; make it an activity that gets you out of the house and away from your work or other caregiving responsibilities.
• Join a book or social club, take up golf, or attend a class (barbecuing basics, painting, etc.).
• Take up a new interest or activity with your patient so you are not talking cancer, work, or kids.
For me, it is dance lessons that Jack and I are taking.
• Watch a mindless TV show. My favorites are cooking, travel and bridal shows. They are fun and upbeat. Try to avoid too much news that might increase your stress.
• Sneak off for a matinee movie occasionally and buy a big bag of popcorn! The movies are cheaper and you can be alone and lose yourself in the movie.

What has helped me with the loneliness and isolation of cancer is that I like to teach, write, and help people. For me, helping others has always given me purpose and perspective. So, I started a 501c3 cancer charity, Arizona Myeloma Network® 14 years ago. We provide free cancer education and advocacy programs for cancer patients, families, and healthcare professionals. In 2007, we added our Cancer Caregivers Education Program (CCEP®) which offers topics available to all cancer patients and caregivers. It has been a huge responsibility and challenge, but incredibly rewarding. I have met many amazing people whose courage and humor are inspiring. I have also met wonderful doctors and researchers who are making amazing progress and giving us hope.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

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Cancer Caregiver Journey: Challenging Month
By Barbara Baroff Kavanagh, MSW, LCSW, October 2018

Dear Friends,

October has been a busy and challenging month. We held our 3rd and final Cancer Caregivers Conference for 2018. Nearly 100 attendees came from throughout Arizona, plus a few from Colorado and California. We brought together a faculty of cancer researchers, clinicians, social workers, nurses and cancer caregiver families. Our focus on young families with caregivers highlighted the special concerns of this population. Trying to take care of a spouse, while managing a job and children, is an incredible balancing act that many families are faced with every day. We explored various strategies and resources for the caregiver and the role of the caregiver in communicating with the treatment team.

A single mother from the Navajo reservation spoke movingly about what it was like when her youngest child, Shakira, was diagnosed at age 10 with cancer and how it affected her entire family. Her 16-year old son, who had taken over the role of the head of household after his father died, was the only one who could drive their truck. He drove his mother and sister to treatment for three years, sometimes even missing school. Thankfully, Shakira is fully recovered and was able to drive herself and her family 350 miles from the Navajo Nation to be at our conference. We were able to celebrate with them the good news that Shakira, now 18, is a freshman at the University of New Mexico. She is the first in her family to attend college and is studying to become a nurse.

Anna is in her early 40’s and caring for her husband Tom, who requires 24/7 care. She depends heavily on her 14-year old son, Joe. He is the caregiver to his father when he comes home from school and on weekends so that his mother can do her shopping and other tasks to keep their household going. He spoke quietly about how much he loved his father and wanted to spend as much time as possible with his dad while he can. They watch baseball on TV and enjoy talking about sports and science, which is Joe’s interest. Our team of professionals offered specific ways that could help this young family. And, when the family left the conference, they had actual resources and financial information to ease the demands on both mother and son.

There were so many inspiring stories shared and a caring and skillful team of professionals were ready to help. Our attendees left with practical strategies and resources to help them be healthier and more effective caregivers. We closed our conference with the song “We are Family”, since we believe that we are ‘family’ to one another and can build a virtual community of cancer caregivers. Our strength is in supporting each other to do one of the most difficult and important jobs of our lives.

Some successful attributes of the cancer caregiver shared during the conference:
* Perceives, believes
* Thinks, analyzes, plans
* Celebrates their success
* Stays calm
*Counts their blessings
*Plays, sees the beauty
*Believes they will succeed

Few of us have all these attributes, but by focusing on achieving them we will become better caregivers and, most importantly, learn to take better care of ourselves.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

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Dear Friends,

This month, we will be celebrating Thanksgiving. Many of us will be busy cooking or making other arrangements for this special holiday. It is a time to appreciate our forefathers who founded this wonderful country.

For many of us who ‘live’ with cancer, it is an opportunity to be thankful for a loved one who is still battling and surviving cancer. For some it may be the first holiday season since a loved one was diagnosed with cancer. Your life changed forever – you became a cancer caregiver. Oncologists, hospitals, medicines and tests are now part of your changed life. You begin to count each holiday and wonder if there will be another one with your loved one.

Planning ahead becomes difficult. Should we buy that cruise 6 months ahead? Will he/she be able to drive for a vacation next year? Will I be able to take care of the house and housekeeping if the patient becomes incapacitated? There is no one answer. But, planning and being positive can help. Personally, my husband and I make our future plans as if he does not have cancer, but we always buy travel insurance for future trips!

For those of us who have cancer or a loved one with cancer in our family, Thanksgiving may not seem the time to be especially grateful. Try to focus on the remarkable work being undertaken by cancer researchers, pharmaceutical companies, counselors, support groups, and members of the medical community that are working so hard on your behalf! We are all very grateful to them for their efforts.

You may be far away from family and friends and don’t have the support or energy to enjoy the holiday. How can we create our own Thanks-giving? We each have to find our own way and not feel obligated to be cheerful if we aren’t. Or, think that as a caregiver, that we have to try and provide the Thanksgiving meal regardless of how we feel. Some of us feel better if we are keeping up a family tradition, and have friends and family to help us. But if you don’t feel up to it, make a reservation at a local restaurant, or order a ‘to-go’ meal from a restaurant. A lot of grocery chains have prepared dinners you can buy. And, there are also private caterers who can host the Thanksgiving gathering for you.

If you do have family or friends in the area, please remember to ask for help. I think you will be pleasantly surprised at the positive response. People feel better at this time of year if they know how they can help you. Make a list of what you need: driving to the doctor; picking up medicines; housekeeping help; shopping; mowing the lawn; shoveling snow; or even financial help. And, if friends or family are far away, there are other ways that they can help. Sometimes we don’t want to burden others or let people know that we are sad, lonely, or just plain tired! It may not be easy to ask for help, but I know from my own experience that often it is equally difficult for those who know and care about you to know what they can do. They truly will feel better knowing how to help, whether it is during a holiday or any other time.

I am thankful for all cancer caregivers, whether young or old, family, friends, neighbors, and for the organizations and resources that are available to assist us. This is also a good time for those receiving care to express their appreciation with a kind word, extra hug, and a loving smile!

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

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Cancer Caregiver Journey: Surviving the Holidays
By Barbara Baroff Kavanagh, MSW, LCSW, December 2018

Dear Friends,

‘Tis the season for parties and presents…but not for everyone. No sooner do you get through Thanksgiving, and you are hearing Christmas songs. There is no recovery time between holidays. Everywhere you turn there are things to buy online and in shops, elaborate decorations to put up and ads showing happy families sitting around their ‘picture-perfect’ dining room tables. It certainly doesn’t look like my home, and maybe not yours, either.

In the first year after hearing those terrible words “You have cancer”, patients and caregivers will often try too hard to keep up their usual traditions and commitments. This can put a great deal of stress on both. The patients feel guilty because they can’t help, or they are depressed and not in a holiday mood. Friends and family often feel awkward…they don’t know what to do or feel uncomfortable for being happy. Whether it is the first year or after several years, you will need to find your own sense of balance.

I have been blessed with 27 years of caregiving. I have learned so much from the many caregivers that I’ve met over the years, so here is a list of some of my favorite Tips for Surviving and Enjoying the Holidays:

- Say “No” whenever you or your patient is invited to a holiday event that would be too stressful physically and/or emotionally to attend.
- Say “Yes” when a friend or family member offers to do the Christmas dinner, extends help to you with your holiday shopping, or just gives you the day off from your usual responsibilities.
- Division of labor is another way to reduce holiday stress. Share the holiday get together planning and give everyone an assignment of what to bring or do.
- Plan ahead so that you don’t get overwhelmed. You can make a reservation at a restaurant or go to a hotel for the holidays…there is no ‘rule’ that you have to do what you have always done!
- Do something that you and your loved one can enjoy together or with your family…maybe just staying home, eating ‘take out’, watching your favorite movie, playing games, or staying in your pajamas all day.
- Remember to take care of your spiritual and physical self.
- Spiritual beliefs can bring renewed hope to those dealing with cancer. Cancer caregivers and patients may find it very calming to focus on that aspect of the holidays.

Each of us responds differently to this new life. Our goal is to find balance and make our own rules. A wise friend once told me: ’Just remember to breathe!’

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

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Dear Friends,

I hope that the holidays brought peace and joy and that 2019 is a healthy one for you and the one you care for. I also hope that you gave yourself a special holiday gift- the gift of doing something for yourself. Sometimes just having that time can refresh you and also allow your cancer patient to do something for you!

Do you feel obligated to make New Year’s resolutions? I used to. Among my resolutions were: I will lose 5 lbs; I will go to the gym 3x a week; I will clean my house more often; I will cook healthier meals; and I will go to more baseball games with my husband. I didn’t keep most of these resolutions or stopped after a few weeks or months and then felt bad about myself. Just what I needed - feeling bad about myself!

I finally realized that all I was doing was creating guilt and more stress about not accomplishing or following through on any or all of them. Instead, now I make 2 or 3 promises to myself and ask my husband, who I am caring for, to make 2 or 3 promises to himself. It is a way for each of us to take responsibility for ourselves. Another approach is to set realistic goals together. We keep it simple and do-able. That way, we can support one another and feel a sense of accomplishment.

In the year ahead, we can plan to take small steps together that will help us balance our own life better and at the same time help reduce our stress. The benefits will be that when we are less stressed, we also ease some of the guilt and stress of the one we are caring for. When we feel better, so do they! And, for those of you who have family living at home or nearby, include them in the promises and goals so that they, too, will be part of the caregiving circle.

A few suggestions for cancer caregivers to consider in 2019:

- List your realistic goals together, or as a family, and include them on your calendar so that everyone can participate and share in reaching them.
- Make time every day to offer thanks to your caregiver or patient and for spiritual support
- Ensure that every week you do something nice and/or healthy for both/all of you.
- Share a smile, a hug, and a loving moment with one another every day.

This year, we will continue to build a true cancer caregivers community!

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

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Dear Friends,

The New Year had just begun when I ‘missed’ two steps in my house and broke several toes on my left foot. I also hit my face and got myself a dark purple black eye. I know all of the statistics about the number of people who fall in their own homes and severely injure themselves. However, I was lucky. My husband, Jack, was home and got me to a doctor who prescribed a big, black boot, a cane, keeping my foot elevated, rest, and no driving! After four weeks, I graduated to a smaller boot and happily, for both of us, I now have more freedom and mobility.

This has been a real learning experience for both of us. My husband had to adjust his own schedule to take care of me. It was a role reversal for both of us. Jack is a 27-year cancer survivor and now he became the caregiver! In his new role (short term, thankfully), he had to learn to use the washer/dryer, oven, vacuum cleaner, and dishwasher. He now knows the location of all the various household cleaning products, powders, mops and brooms. Although he has always helped with the shopping, he became more efficient and cost conscious. He also learned the location of my hairdresser, manicurist and chiropractor!

The father of a young family with a wife in cancer treatment may suddenly have to learn the same kind of things my husband learned. In addition, he may have to make arrangements for child care, take the children to dance classes, sport practices, and attend games and recitals. Meanwhile, he must keep up the family’s spirits while maintaining a job.

Most men in this new cancer caregiver role remain kind and loving, but are uncomfortable and overwhelmed with these new responsibilities. Besides deep concern for their spouse, they fear for their wife and also have concerns about the effect it will have on their job. This is not a fear they can express to their sick wife, their children or other family members. After my own experience, I am now even more aware of the special challenges there are for men.

Men will often internalize these feelings which can adversely affect their own health. They also tend to become organizers in this situation: giving advice, scheduling, finding solutions, paying bills etc. In other words, they will apply common sense and practicality to deal effectively with the mechanics of the situation. This may lead them to neglect the emotional needs of their wife. She may need to receive occasional flowers, hear the words “I love you,” and just have special time alone with him. The woman patient may need to take the lead in the emotional side of the cancer caregiving dynamic. Don’t expect your husband to “know” your needs. Express them to him.

Valentine’s Day is a reminder to show our love and to be thankful for each other. Whether you are receiving care or giving care right now, it is very likely we will all be in one role or the other, or both, at some time in our life.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

www.azmyelomanetwork.org www.cancercaregiversaz.com
Dear Friends,

March is my time to celebrate the coming of spring and my birthday! I am so grateful to share my special day with my husband, children and grandchildren. It is also a celebration of 28 years that Jack has been a cancer survivor.

Cancer is an awful disease to face, but thankfully there have been an increasing number of resources available to patients and caregivers over the past 15 years. One of the potential resources available is the ability to seek a consultation with an expert in the field to partner with your current medical team.

There are so many types of cancer and each has very specific features and treatments. There are new drugs coming along almost every month and are as unique as each patient. What works for 1 person may not work for another. It can be very confusing and overwhelming for the patient and the caregiver. The relationship you have with your physician and health care team is vital – but often it can be enhanced by a consultation with another expert.

You are entitled to ask your general oncologist/hematologist for a referral to a specialist for a consultation or ‘2nd opinion’. It doesn’t mean that you don’t like or trust your current doctor, but no one knows everything and your priority has to be to make sure you get the best and latest information and care. A 2nd opinion/consultation can help the caregiver as well as the patient. There is a vast amount of information to take in about all the recent clinical trials and studies in oncology. Having a specialist review current treatment and explain the latest in the specific cancer of that patient can reduce anxiety in both of you.

Cancer should be a ‘team’ effort between you as the caregiver, the patient, and the cancer experts. There are side effects and consequences for every treatment and knowing what they are can help you make better decisions.

Reassurance can often be the best ‘result’ you can get from a Specialist consultation. Reassurance about the great care one is already receiving can give you greater peace of mind. Having an expert on the care team who is objective and also knowledgeable helps us make better choices and reduces our stress.

Access to new clinical trials that aren’t available at your current treatment facility is another great benefit of a consultation. There are many exciting new drugs and having access to these may have a profound impact on your cancer patient’s quality of life and overall survivorship!

Spring is coming and getting a fresh perspective can help you and the one you care for.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

www.azmyelomanetwork.org  www.cancercaregiversaz.com
Dear Friends,

After the initial cancer diagnosis, most patients have a structured treatment plan with appointments and a time structure. As the caregiver, you are adjusting your life to help the patient with medications, getting to their doctor visits, and handling the everyday responsibilities of running the household, as well as trying to continue a job, business, or career of your own. You will try to balance his/her needs and your own. If you have children, you are also trying to maintain a normal family life and keep your own fears and concerns to yourself and not burden them.

Amanda was a busy wife and mother, enjoying her job as a hairdresser, active in her church and volunteering with a local women’s shelter. Her husband, Tom, an accountant, was active in Rotary and his son’s activities. Both in their late 40’s, they had worked hard to buy a small home and were planning their 1st real vacation to celebrate their 20th anniversary. Their son, Danny was 17 and busy with baseball practice, girls, and applying for college. Life was good! Just before their trip, Tom had a cough that wouldn’t go away. He finally went to the doctor. After a checkup followed by lab work, x-rays, the doctor made his diagnosis: it was lung cancer. For all of us who have heard those dreaded words: ‘You have Cancer’, you know that your life is changed forever. Amanda became a full time caregiver. Danny decided to put off college and help his mom take care of his dad.

Fortunately, Tom was diagnosed ‘early’ and correctly. He started his chemo treatment and was responding well. But, due to side effects of the treatment, he was not able to resume his work. He also required a lot of assistance as well as transport to weekly doctor’s appointments, physical therapy, etc. Amanda needed to continue working part time to help cover insurance and other expenses. This meant that Danny had to take over a lot of the caregiving for his dad.

When Amanda and Danny attended one of our Cancer Caregivers Seminars in the fall of 2018, our topic focused on how to achieve ‘balance’ in your life and not get caught up in ‘over‐care’. Both of them were so caught up in being available to Tom that they had given up most of their own interests, friends, and activities. The result was that the patient felt guilty and also resentful that he was made to feel useless and a burden. Other caregivers attending our program, as well as our professional faculty, shared advice and strategies for how Amanda and Danny could give Tom more control and independence as well as take ‘time’ for themselves.

Learning how to communicate with one another, planning activities they could do together (such as a movie night at home, board games, etc.), and pizza parties with friends helped. Danny got back to baseball practice and going out with friends. Mom and son came up with a schedule of ‘sharing the caring’. Danny had his time and his mom had her spa visits, and ‘girl’s night out’. It truly made a difference for the whole family.

As the patient’s needs change during treatment, the family also needs to change the way they are providing care and not ‘over‐care’, which can lead to depression for the patient and resentment for the caregivers. Enjoy your time together but make sure you also take care of yourself!

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

www.azmyelomanetwork.org www.cancercaregiversaz.com
Dear Friends,

It has been a busy few weeks for me as I embark on another Journey - writing my book: Living with Myeloma, a CareGivers Journey®. It has been a 28 year journey that has taken us to 5 countries and 3 states in the U.S. Over the years, my husband, Jack, and I have had to find oncologists wherever we lived and were fortunate that they were willing to communicate and collaborate with top myeloma specialists at Mayo and the Dana Farber Cancer Institute. Now, many years later, they have generously offered to contribute their own knowledge and expertise to my book. I plan to include information and resources specifically for cancer caregivers and families, who are such an important part of the cancer care team. I know that in spite of the writing and publishing challenges, I will find a way to complete the book and make it available to the many cancer patients and caregivers, families and friends, cancer researchers, and clinicians who are looking for help and hope.

I recently received a phone call from a myeloma patient who has attended our Living with Myeloma Conferences and caregiver programs over the past 14 years. Annie is an amazing woman in her mid 50’s, which is considered young for a myeloma diagnosis. It generally affects people over 60. What has always impressed me about Annie is her courage and faith. She has educated herself about her cancer and even reaches out to help others. And, she is her own caregiver. Annie moved to Arizona after her divorce and made a new life for herself. When she got her myeloma diagnosis, she built a caregiving network of friends, neighbors, colleagues, and her church. Through her stem cell transplant, long recovery, and subsequent treatments, she has remained strong and optimistic. And, she has become the caregiver for other cancer patients that she has met along the way.

She called me this week and told me that she was no longer in remission and was going to be in another clinical trial. I feel honored to be part of her caregiving network and offered information about 2nd opinions and an organization that helps match cancer patients with new clinical trials that are available for rare forms of cancer. I recommended that she turn again to her caregiving network and her faith.

Many of us have family who we can turn to (pictured is the England family), but as I have learned over the years, others are not always that fortunate. You may need to build your own caregiving network or be part of someone else’s. There are organizations and resources that can also help, and with the new treatments now available, you can use the internet to be part of your caregiving network.

Future blogs will inform about my book and our program plans for the fall.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

www.azmyelomanetwork.org www.cancercaregiversaz.com
Dear Friends,

For many families, the end of August signals the end of summer vacations, back to school and back to work until the Thanksgiving and Christmas holidays. Some of us may have taken one ‘more’ long weekend for Labor Day, but there is that sense already that we are saying ‘goodbye’ to vacations and a break in doctors’ visits, or that time at the beach or in the mountains, and we are now back to our cancer routine.

I want to dedicate this month’s blog to young families who are now living with cancer. Regardless of age or circumstance, being diagnosed with cancer is life changing for the patient and their caregiver. Either or both of you may be starting college, a career, a marriage, or ‘all of the above’. Cancer is not a respecter of age or situation.

I was reminded of the special challenges that young people face when I read the blog of a woman I will call Martha. She had played on her college’s tennis team, never had a serious illness, ate healthy, and, after graduation, began her career as a teacher in her own hometown. She married her college sweetheart who had started his own law practice. They were able to save up enough money to buy their 1st home and welcomed their 1st child, a little boy, when she was 29 years old, and a daughter on her 32nd birthday. Life seemed perfect.

Martha always scheduled her routine annual mammogram during her birthday month, September. After one such exam, during the September when she turned 35, her family doctor asked her and her husband to come to his office. He told them Martha had breast cancer. The doctor said it was treatable and they had caught it early. But, once you hear the word cancer, everything else is a blur and you wonder if you will live to see your children grow up and your spouse worries how he will take care of his wife, children, and his job. Most important will she be ‘all right’? And will she be there for the children’s graduations and weddings?

Fast forward: this blog is being written as Martha celebrates her 55th birthday. Her son is studying to be a doctor and is engaged. Her daughter is attending college and wants to be a teacher like her mother. Twenty years after diagnosis, Martha and her husband are celebrating the highlights of their life together and all the other highlights in their children’s lives. Her blog included thanks to her doctors, family and friends who were with her every step of the way during her cancer journey. There were many rough times during her treatment. She prepared photo albums and journals just in case she ‘didn’t make it’. These serve as a great reminder of what the family went through. Her family can now share these memories and their years of caregiving that inspired her to keep fighting and that gave them all hope.

My summer has been busy, but exciting, as I work on my book, now re-titled Living with Cancer, a CareGivers Journey®. Over the years, our conferences have primarily focused on myeloma, but have also expanded to address other forms of cancer. I appreciate the feedback of colleagues, cancer patients, cancer caregivers, and my family, who felt that the title and contents of the book needed to reflect this and be inclusive of all cancers, not only myeloma. With this new emphasis, more cancer patients, caregivers, and those serving cancer patients in the medical community will be able to access the resources and expert advice this publication will provide.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™
www.azmyelomanetwork.org  www.cancercaregiversaz.com
Dear Friends,

November is National Caregivers Month. It is recognition of the millions of caregivers who are providing much-needed services for a loved one. We are proud to have received a Proclamation from the Governor of Arizona for the week of November 16th-23rd, 2019, to be celebrated as Cancer Caregivers Awareness Week. Arizona Myeloma Network (AzMN®) and our Cancer Caregivers Education Programs™ (CCEP®) have worked tirelessly over the past 15 years to raise more awareness of the needs of cancer patients and their caregivers and families.

AARP-initiated legislation is beginning to address some of these issues by requiring hospitals and other treatment facilities to provide training, education, and resources to the caregiver/family before the patient leaves the facility and goes home. The CARE Act (Caregiver Advise, Record, and Enable), has been enacted in 40 States and US territories. The goal is to reduce re-hospitalizations and also reduce stress for the caregiver and the family.

I know that most of you are only too aware of the challenges you face and the effect of cancer on not only the patient and caregiver, but the entire family and circle of friends, employers, and colleagues. Once you get on the ‘carousel of care’, it can feel like you are going around and around and up and down. In dealing with cancer, our roles and responsibilities can change in an instant; but, certainly as the disease progresses or even when it is ‘stable’ or in remission, there are often secondary health issues, drug side effects, or other related problems.

A valuable lesson to be learned is to realize when to ask for help, whether it is from the medical team or from neighbors, family and friends. Recently, one of the guest authors for my book, Living with Cancer, A CareGivers Journey©, talked about her experience of being a long-distance caregiver to her sister-in-law. She had some wonderful advice to offer for long-distance caregivers:

- If you can’t ‘be there’ in person: phone calls, ‘Facetime’, loving and positive notes, special gifts, or photos of happier times are welcome opportunities to connect.
- Contribute to the caregiving needs financially, or by organizing the patient’s local caregiving circle of friends, neighbors, church, school, etc. If applicable, provide special treats or trips for the patient’s children.
- Remember to also consider the spouse, who is often the primary caregiver for the rest of the family and give them a call, too.
- If possible, when you can visit in person, try and meet the medical team so that you are prepared to plan for both short- and long-term needs.
- Most of all, even though it is often depressing and scary to talk to a loved one with cancer, it often is helpful to them. Sharing the fear, pain, and practical issues can be a relief for the patient and the family.

During this time of thanksgiving, remember to thank a caregiver in your own life or thank yourself with some ‘time off’ by enjoying a fun and relaxing activity. We are all thankful to the amazing researchers, doctors, and the new advances in treatment. We can also be thankful for the privilege of caring for the one we love.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

www.azmyelomanetwork.org   www.cancercaregiversaz.com
Dear Friends,

Looking back on 2019, you may be thinking that you are grateful that you made it through another year! Living with cancer as a caregiver is often a series of small victories. And, sometimes the best news is that your loved one is ‘maintaining’, or has shown ‘no change’. Over the past 28 years of doctor appointments with my husband Jack, there was always anxiety. It was generally even more stressful at the holidays. You want to be happy and plan fun activities, but you also have to be prepared in case you have to cancel plans.

That is what happened to Elissa. She had just gone through her 2nd transplant. She had been diagnosed with multiple myeloma 5 years ago and had her 1st transplant. She was able to leave the hospital a week after that and seemed to be doing well. It was short-lived. During a routine follow up visit, about 6 weeks after her 2nd transplant, she was diagnosed with a rare form of leukemia. Her best chance at combating this new cancer was for a 3rd transplant, which would require 100 days of treatment and home isolation. Part of this time would be spent in the hospital and then daily visits to the hospital along with 24-hour home care. We were able to help her arrange a schedule of family and friends, both local and others, flying in for a week or a few days at a time. Elissa’s courage and positive spirit were amazing and 2020 looks very hopeful for her.

The new decade promises new treatments and more choices for all cancer patients and their devoted caregivers. We can look back on 15 years since Jack and I ‘founded’ the Arizona Myeloma Network® and shortly after, the Cancer Caregivers Education Program™ (CCEP®). From the 1st Living with Myeloma Conference with 60 attendees, including staff and faculty, we grew to attendees to our conferences numbering over 300. These attendees included patients, families, healthcare professionals, and cancer resource providers. We provided up-to-date information about clinical trials, the latest research and treatment options and quality resources. And, we learned about the importance of collaboration of all of these experts on behalf of cancer patients and families.

The Proclamation by Governor Ducey of Arizona, recognizing November 16th-23rd, 2019 as Cancer Caregivers Awareness Week, is an initiative we hope will become an annual event and perhaps a National one, as well, to provide greater awareness, education and advocacy for cancer caregivers. We are hopeful that in the next decade, we will finally achieve the greatest goal: a cure for all cancers!

My own personal goal for 2020 is to bring much-needed information and resources together in my book, Living with Cancer, a CareGivers Journey©. I am blessed and awed by over 15 cancer researchers, clinicians, other healthcare and cancer professionals, volunteers, cancer patients and caregivers who are contributing their ideas, knowledge, and advice in order to provide a practical guide and inspiration for all who ‘are’, or will be ‘living with’ cancer or are caring for those afflicted with this disease.

We welcome your caregiver story and have a survey on our website that you can use to provide your details (https://azmyelomanetwork.org/cancer-caregivers-survey/). It is an opportunity to learn what has helped you on your caregiver journey and get ideas for how we can improve services and programs.

Warm regards,

Barbara Kavanagh, MSW, Founder and CEO of AzMN® and Cancer CaregiversAz™

www.azmyelomanetwork.org  www.cancercaregiversaz.com
A Caregiver’s Bill of Rights

I have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- To seek help from others even though my loved ones may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that does not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt, and/or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved ones, for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.

- To __________________________________________
  __________________________________________
  __________________________________________
  __________________________________________

(Add your own statement of rights to this list. Read the list to yourself every day.)

The healthiest way to care for others is to care for yourself.
## Finding Balance for the Caregiver

### 16 Stress Reducing Strategies

| 1. Make all choices from a solid base of integrity | 9. Nest |
| 2. Be clear about today’s reality | 10. Make comfort food |
| 3. Talk honestly to family and friends | 11. Enjoy life today |
| 4. Expect and prepare for tough talks | 12. Journal for yourself |
| 5. Learn the medical lingo | 13. Keep a vision for the future |
| 6. During treatment, pain or pain medication might do some talking | 14. Give |
| 7. Control what you can control | 15. Take good care of yourself |
| a. Get help with housework |  
| b. Get help with yard work |  
| c. Prepare meals in advance & freeze them |  
| d. Keep bills & insurance paperwork organized so there are fewer financial surprises |  
| e. Do 3 things every evening before you go to bed |  

By: Lisa Bailey  
Today’s Caregiver  
See article for full strategy descriptions
How Well Do You Take Care of Yourself?

Rate each item below from 1 (almost always) to 5 (never), according to how much of the time each statement applies to you.

1=Almost Always  2=Frequently  3=Occasionally  4=Rarely  5=Never

Rating

1. I exercise on a regular basis.
2. I make and keep preventive and necessary medical and dental appointments.
3. I have a job or regular volunteer activity that is gratifying.
4. I am free of tobacco use.
5. I am free of alcohol or drug use.
6. I get an adequate amount of sleep each day.
7. I have a hobby or recreational activity that I enjoy and spend time doing.
8. I eat at least two or three balanced meals a day.
9. I have at least one person in whom I can confide (tell all my problems, discuss my successes, etc.)
10. I have an easy time sleeping at night.
11. I have personal goals and am taking steps to achieve them.
12. I take time to do things that are important to me (e.g. go to church, spend time alone, garden, read).

Add the numbers written on each line to get your interpretation.  

Total Score: ______

Interpretation:

A total score of 12 to 24: You are doing an excellent job of taking care of yourself.
A total score of 25 to 36: You have some room for improvement.
A total score of 37 to 48: You are doing a poor job of taking care of yourself and are at a moderately high risk for personal health problems.
A total score of 49 to 60: You are at an extremely high risk for personal health problems.

Basic Guidelines for Navigating the System

1. Do your homework. Prepare before attempting to navigate the system.
   - Gather important information about the person you are caring for (health status, insurance coverage, family financial problems and strengths, personal information).
   - Prepare in advance for meetings or conferences with professionals or specialists.
   - Learn all you can about resources or services in your area, including types of service available, admissions criteria, and service philosophy.
   - Talk with others about their experiences with agencies and individuals in the system.

2. Prepare for the worst, but maintain as positive an attitude as possible.
   - Expect delays, wrong information, unhelpful people, and frustration.
   - Keep things in perspective and try not to be overly concerned with minor details.
   - Try not to be overly critical of others in the system.

3. Evaluate the potential services for the person you are caring for before committing to them.
   - Is the service really needed?
   - Could it be provided in a more effective way?
   - What are the potential benefits and risks?
   - Is it cost-effective? (Worth the cost?)

4. Whenever possible, involve the person(s) you are caring for in decisions about the most appropriate services and keep them informed of your successes and frustrations.

5. Keep your own records of contacts and experiences with agencies, organizations, and individuals.
   - Write down and save information and accounts of your experiences.
     * Include dates, times, names of persons you talked with, what was said, etc.
   - Keep copies of everything: letters to and from service providers, insurance forms, etc.

6. Use guides, forms, and lists that others have developed to help you locate, discuss, and evaluate resources.
   - Telephone question checklists
   - Service evaluation checklists
   - Questions to ask service providers

7. Never give up seeking the best for the person(s) you are helping or stop looking out for their best interests.
   - Work through appropriate channels within the system when possible.
   - If concerns are not addressed within the system, apply pressure on the system, but consider the seriousness of your situation, the likelihood of success, and possible repercussions.
Learn to Laugh!  Humor...

- Eases tension
- Conveys good will
- Defuses negative emotions
- Relieves stress and sadness
- Helps reassert control
- Increases flexibility in problem solving
- Perks up the immune system
- Releases natural painkillers in the body

Put some humor in your day:

- Read funny books
- Go to funny movies or rent them
- Watch comedy shows on TV
- Collect funny jokes and stories
- Send funny cards and emails (as appropriate!)
- Look for humor in the ordinary routines of your day or the unexpected mix-ups of your life
- Let yourself laugh

Laughter is the best medicine!

😄 Every 😄 Laugh 😄 Matters
# Cancer Caregiver Resources

Arizona Myeloma Network (AzMN®) website: [https://azmyelomanetwork.org/](https://azmyelomanetwork.org/)

Cancer CaregiversAz™ website: [https://cancercaregiversaz.com/](https://cancercaregiversaz.com/)


Share Your Story: [https://cancercaregiversaz.com/share-your-story/](https://cancercaregiversaz.com/share-your-story/)

**Videos** – testimonials, AzMN® Research Roundtable presentations, other AzMN® and CCEP™ conference presentations, promotions, TV coverage, etc.

[https://www.youtube.com/watch?v=J215V4cGdWw](https://www.youtube.com/watch?v=J215V4cGdWw)
[https://www.youtube.com/user/ArizonaMyeloma](https://www.youtube.com/user/ArizonaMyeloma)

A selection of organization and agency resources are provided below:

<table>
<thead>
<tr>
<th>Organizations and Agencies that assist patients and families</th>
<th>Phone</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>AARP</td>
<td>866-448-3616</td>
<td><a href="http://www.aarp.org/az">www.aarp.org/az</a></td>
</tr>
<tr>
<td>CancerCare</td>
<td>800-813-4673</td>
<td><a href="http://www.cancercare.org">www.cancercare.org</a></td>
</tr>
<tr>
<td>Caring from a Distance</td>
<td>800-204-7132</td>
<td><a href="http://www.cfad.org">www.cfad.org</a></td>
</tr>
<tr>
<td>Cancer Hope Network</td>
<td>877-HOPENET (467-3638)</td>
<td><a href="http://www.cancerhopenetwork.org">www.cancerhopenetwork.org</a></td>
</tr>
<tr>
<td>Caring Bridge</td>
<td>651-452-7940</td>
<td><a href="http://www.caringbridge.org">www.caringbridge.org</a></td>
</tr>
<tr>
<td>Caring Connections</td>
<td>800-658-8898</td>
<td><a href="http://www.caringinfo.org">www.caringinfo.org</a></td>
</tr>
<tr>
<td>Caring from a Distance</td>
<td>800-204-7132</td>
<td><a href="http://www.cfad.org">www.cfad.org</a></td>
</tr>
<tr>
<td>Family Caregiver Alliance</td>
<td>800-445-8106</td>
<td><a href="http://www.caregiver.org/long-distance">www.caregiver.org/long-distance</a></td>
</tr>
<tr>
<td>National Alliance for Caregiving</td>
<td>301-718-8444</td>
<td><a href="http://www.caregiving.org">www.caregiving.org</a></td>
</tr>
<tr>
<td>Medical Assistance Tool (formerly Partnership for Prescription Assistance)</td>
<td>888-477-2669</td>
<td><a href="http://www.mat.org">www.mat.org</a></td>
</tr>
<tr>
<td>Patient Access Network Foundation</td>
<td>866-316-PANF (7263)</td>
<td><a href="http://www.panfoundation.org">www.panfoundation.org</a> (assistance for the underinsured)</td>
</tr>
<tr>
<td>Patient Advocate Foundation</td>
<td>1-800-532-5274</td>
<td><a href="http://www.patientadvocate.org">www.patientadvocate.org</a></td>
</tr>
<tr>
<td>Bag It-Cancer Support</td>
<td>520 240 7805</td>
<td><a href="http://www.bagitcancer.org">www.bagitcancer.org</a></td>
</tr>
<tr>
<td>Lung Cancer Center</td>
<td>(720) 583-4099</td>
<td><a href="www.lungcancercenter.com">www.lungcancercenter.com</a></td>
</tr>
</tbody>
</table>
Topics may be mixed and matched without pre-requisites. All may be tailored to specific audiences. Bring these topics into the medical/cancer center, workplace, your church/synagogue, school, and community center.

- Each is great as a live class, webinar or a series of 50-minute ‘Munch and Learn’ seminars onsite
- Breakfast or Lunch seminar OR half- or full-day conferences can be tailored to your organization and budget
- Pick your topic or topics, time, date and place, we will do the rest!

<table>
<thead>
<tr>
<th>TOPIC</th>
<th>LEARNING OBJECTIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer is a Family Disease</td>
<td>Cancer happens to the immediate and extended family. How to get everyone to share the care.</td>
</tr>
<tr>
<td>Communication Skills</td>
<td>Provides tips for effective communication skills to keep relationships cooperative and less stressful.</td>
</tr>
<tr>
<td>When Cancer Enters the Workplace</td>
<td>Learn your rights, how to approach your employer, and more.</td>
</tr>
<tr>
<td>Recognizing Young People as Cancer Caregivers</td>
<td>An individual doesn’t get cancer, a family does. Helping young cancer caregivers cope and adapt to the challenges.</td>
</tr>
<tr>
<td>Cancer Caregiver Self-care</td>
<td>Understand and deal with challenges throughout various phases of the cancer experience and how they may significantly impact how you function daily and your quality of life.</td>
</tr>
<tr>
<td>Palliative Care and End of Life Issues</td>
<td>Helpful advice and resources for providing comfortable care and for arranging legal and financial tasks.</td>
</tr>
<tr>
<td>How to Help Your Loved One with Side Effects</td>
<td>Provides insights on drug side effects and what to do to minimize one’s discomfort. Understanding why the patient’s behavior changed.</td>
</tr>
<tr>
<td>Self-Care</td>
<td>Addresses the caregivers needs from the following perspectives: physically, emotionally, socially, and spiritually.</td>
</tr>
<tr>
<td>Navigating the Healthcare System</td>
<td>Provides the cancer caregiver with understanding on how to navigate the healthcare system to find information.</td>
</tr>
<tr>
<td>Cancer Caregiver Survivorship</td>
<td>What happens when the Caregiving ends?</td>
</tr>
<tr>
<td>For Men ONLY! – The Caregiver Role</td>
<td>Men give care and accept care differently – and that’s a good thing!</td>
</tr>
</tbody>
</table>

Contact us at: [www.cancercaregiversaz.com](http://www.cancercaregiversaz.com) or call 623-466-6246
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“Blessed are the Caregivers”

Blessed are the caregivers who refuse to compare their responsibilities with others.
Blessed are the caregivers who have learned to laugh, for it is their only chance for sanity.
Blessed are those caregivers who accept the disabilities of their charges, letting each person develop at their own speed.
Blessed are the caregivers who can redirect negative behavior, without anger.
Blessed are the caregivers who involve their charges in the world around them, for it develops the whole person.
Blessed are the caregivers who are teachable, for understanding brings love.
Blessed are the caregivers who love their task, for love is the greatest gift they give.
Blessed are the caregivers, for all the blessings they bestow upon their world.

Yes!!! BLESSED ARE THE CAREGIVERS!

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