



Cancer Caregivers Booklet

CANCER CAREGIVERS SEMINAR

Coping with Cancer for the Holidays

SATURDAY, DECEMBER 7 , 2019

Cancer Caregivers Education Program™ (CCEP®)

"An individual doesn't get cancer... a family does."

~Terry Tempest Williams



GOVERNOR DOUGLAS A. DUCEY

STATE OF ARIZONA

PROCLAMATION

WHEREAS, according to the American Cancer Society, in 2019 there will be an estimated 37,490 new cases of cancer in Arizona and an estimated 12,470 deaths will result due to cancer; and

WHEREAS, for every new cancer patient diagnosed, there will be at least one new cancer caregiver to care for that patient; and

WHEREAS, according to the National Alliance of Caregiving, a vast majority (85 percent) of caregivers care for a relative, 42 percent care for a parent (31 percent for a mother, 11 percent for a father), and 15 percent care for a friend, neighbor, or other non-relative; and

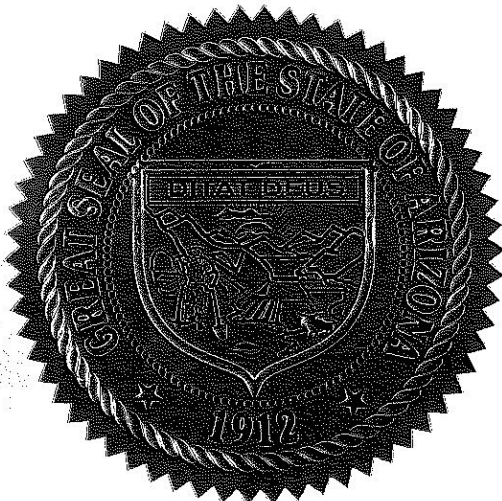
WHEREAS, according to the National Alliance of Caregiving, family caregivers who reside with their care recipient spend 40.5 hours per week caring for this person, and those caring for a spouse/partner spend 44.6 hours per week performing caregiving tasks; and

WHEREAS, the Arizona Myeloma Network's and Cancer CareGiversAZ' s mission is to promote collaboration, awareness, education, and advocacy for improved treatment and quality of life for all cancer patients, their families, and all cancer caregivers; and

WHEREAS, the Arizona Myeloma Network established the Cancer Caregivers Education Program, CCEP© for all cancer caregivers who are unsupported and under-represented.

NOW, THEREFORE, I, Douglas A. Ducey, Governor of the State of Arizona, do hereby proclaim November 16 – 23, 2019, as

CANCER CAREGIVERS AWARENESS WEEK



IN WITNESS WHEREOF, I have hereunto set my hand and caused to be affixed the Great Seal of the State of Arizona

Douglas A. Ducey
GOVERNOR

DONE at the Capitol in Phoenix on this fifteenth day of October in the year Two Thousand and Nineteen and of the Independence of the United States of America the Two Hundred and Forty-Fourth.

ATTEST:

[Signature]
SECRETARY OF STATE

WELCOME

Mission Statement

COLLABORATION • AWARENESS • EDUCATION • ADVOCACY

The Arizona Myeloma Network (AzMN) 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.



Arizona Myeloma Network & Cancer Caregivers AZ was founded in June 2004 by Barbara B. Kavanagh and Jack Kavanagh. They wanted to help other cancer patients and families like their own. Our mission is to promote awareness, education and advocacy for improved treatment and quality of life, for ALL Cancer patients, their families and caregivers. Our members are patients, families, healthcare professionals, volunteers and others concerned about cancer in its many forms. We are a nonprofit charity (501)(c)(3) organization that conducts outreach Events and Educational programs for ALL cancer patients, their families and caregivers, with special consideration for the under served: African American, Asian /Pacific, Hispanic American and Native American.

TODAY'S AGENDA

"Coping with Cancer For the Holidays"

9:00am-12:30pm - Free and includes breakfast and printed materials

Purpose of the Seminar:

To Foster an informed and educated "cancer caregiver" community

Attendees will gain knowledge and learn skills that support the physical and emotional health of the cancer caregiver and an improved quality of life for the patient and family.

- Registration and light Breakfast
- Welcome: Barbara Kavanagh and Viridiana
- Meditation... Take Time to Breathe!
- Review Program Goals
- Introduce the guest Faculty
- Who are You? Group Discussion
- Self- Assessment task
- Your Biggest Stress
- Break and Stretch
- Q&A and Resource Panel
- Share a Holiday Wish
- Strategies and Tips to Help De-Stress the Holidays
- Cancer Caregivers Survey

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FACULTY



Barbara B. Kavanagh, Founder & CEO, Arizona Myeloma Network & Cancer Caregivers AZ

Barbara is the Founder and CEO of Arizona Myeloma Network (AzMN®). She is a published author and served as faculty for 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. Her first business, People to People Associates, Inc., (specializing in counseling, consulting, and training) operated for fifteen years in Lexington, Mass.

AzMN is 501(c)(3) nonprofit organization started in 2004 by Barbara and her husband Jack who is a 28-year survivor of multiple myeloma. In 2003, they moved to Arizona to be near the Mayo Clinic for his ongoing treatments. In 2005, Barbara organized the first of many Living with Myeloma Roundtable and Conferences in Scottsdale, AZ. The conference attracted more than 300 attendees annually. All AzMN programs are designed to educate cancer patients, cancer caregivers, oncology healthcare professionals, researchers, and the public on the newest in cancer treatments and how to give and receive the best possible care. AzMN has delivered hundreds of cancer patient and caregiver conferences throughout the State. Conferences are free and open to the public. They provide cancer patients and their caregivers the practical knowledge, skills and strategies necessary to effectively care for themselves. CCEP™ is a customizable program for companies and healthcare organizations that want provide onsite training for employees and constituents.

AzMN is recognized by Great Nonprofits as a "Top-Rated Nonprofit" for multiple years. Barbara, herself, continues to receive awards for her work. She is the recipient of the prestigious Hon Kachina Outstanding Volunteerism Award, The Phoenix Business Journal's Healthcare Hero Award, the Arizona Rural Healthcare Association Volunteer of the Year award and the 2014 Arizona Business Magazine's Healthcare Leadership Award for Community Outreach. She was profiled as a Woman of Distinction in the 2016 edition of WOD Magazine. She is featured on radio, television, and in publications. Barbara and Jack are mentioned 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 reflect a life dedicated to teaching and mentoring others to achieve their goals and transform their own lives and those they touch. She is currently working on her next book "Living with Cancer: A CareGivers Journey". Her intent is to provide practical information on how to navigate the complex world of cancer patient and caregiver survivorship.



Heather Chapple, Hospice of the Valley

Heather has worked in the health care field in physician's offices for over five years and has been with Hospice of the Valley as a Community Liaison since 2009. Heather has her degree in Elementary Education and has spoken to groups ranging in size from five people to over 150, as well as appearing on several radio interviews. She volunteers with Hospice of the Valley's SALUTES program, which honors patients who are Veterans of the Armed Forces. Heather served as an Executive Assistant in the US Navy for four years.



Jessica Wells - Licensed Master Social Worker

Jessica is a Licensed Master Social Worker who graduated from Arizona State University with a Masters Degree in Social Work in 2011. Jessica also received a Bachelor of Arts in Psychology, as well as a Bachelor of Science in Justice Studies from Arizona State University. She has 12 years experience in the following sectors: child welfare, general pediatrics, pediatric intensive care, pediatric hematology/oncology, and the acute mental health/behavioral healthcare setting. Jessica's passion for working with patients and families whose lives have been affected by cancer is fueled by her own personal cancer journey. She is a firm believer in "meeting the patient where they are at" while providing patient-centered care.

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CARING FOR YOURSELF WHILE CARING FOR A LOVED ONE

Caregiving for someone with cancer presents its own unique challenges. Cancer treatments can be technical, with lengthy and very specific directions. Often, decisions about short-term care, long-term care, and even hospice and death planning, may arise. Even for short-term care needs, the caregiver can be challenged with fatigue, conflicts with work or school, a sense of being overwhelmed by the volume of tasks to be performed, doubts of personal skills, stamina, and knowledge, and issues related to the caregiver's own life. Below are a few tips to help you care for your loved one while caring for yourself.

Tell the care recipient's treatment team (social workers, nurses, physician, etc.) about your family's specific situation. Include details about how prepared you feel for the role of caregivers. This can help the treatment team aim discussion and suggestions at a level you feel comfortable with.

Inform the treatment team of the emotional, community, and financial resources (or lack of resources) available to you and your family. This information will help the treatment team when considering options for your home-care situation.

If you don't understand something that has been suggested or implemented by the treatment team, do not be afraid to ask questions. Cancer caregivers can be precise and very technical. It is to your benefit and that of the care recipient to understand care instructions.

Pay attention to your spiritual self. Caregiving may trigger spiritual questions within the caregiver and care recipient.

Conduct important discussions, such as those about treatment and prognosis, in privacy and without interruption. These are important matters that deserve to be considered without outside distractions.

Pay attention to your feelings. As a result of the strain of caregiving, caregivers may experience symptoms of depression and anxiety as well as a sense of helplessness and fear. If you experience symptoms of any of these emotions, talk with your physician about how you address them.

Make financial preparations, if possible. If caregiving situations go on for an extended period, many families find their financial coffers depleted. While there is not usually much that can be done to increase income or savings, it might be helpful to check into assistance programs, should they be needed.

This article was adapted from the pamphlet,

Caring for Yourself While Helping a Loved one with Cancer created by Carrah L. Martin, BS

Rosalynn Carter Institute Fellow, 2004

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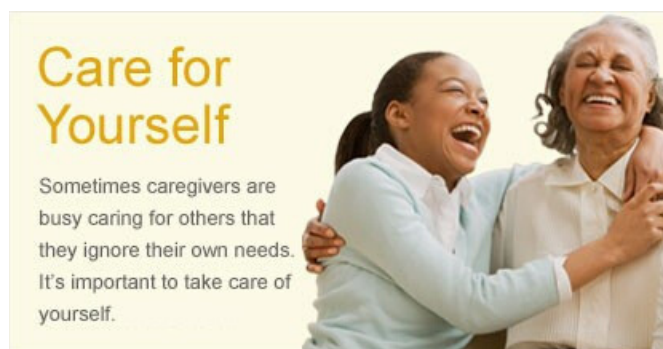


A CAREGIVER'S BILL OF RIGHTS

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.)



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SELF-CARE ASSESSMENT

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). _____

10.) I take time to do things that are important to me (e.g. go to church, spend time alone, garden, or read). _____

11.) I have an easy time sleeping at night. _____

12.) I have personal goals and am taking steps to achieve them. _____

Add the numbers you 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 moderately high risk for personal health problems.

A total score of 49 to 60: You are at extremely high risk for personal health problems.

Adapted from "Checklist For Caregivers: Do You Take Care of Yourself?"(Bass, 1990, p. 35) Bass, D.S. (1990). Caring families: Supports and interventions. Silver Spring, MD: National Association of Social Workers.

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USING YOUR SELF-CARE ASSESSMENT

Refer back to the Self-Care Assessment for Caregivers that you completed at the beginning of this session. Use this as a tool in taking care of yourself and preventing or recovering from burnout.

To use it:

1. Identify the factors and events over which you do have control and which you can manage.
2. Identify the categories in which you would like to do more to take care of yourself. What are some specific ways you can do that? Set specific goals for improvement.
3. Examine your goals. Be sure they are realistic and attainable. Remember to start small and not try to do everything at once. Otherwise, you set yourself up for failure and discouragement.
4. Don't take more responsibility than you need to in the caregiving situation.

Remember, "the healthiest way to take care of another is to take care of your self" (Miller, 1993).

In closing, consider this quote by Kenneth Doka from his book, *Living with Life Threatening Illness*.

"Caregivers have a unique role to play in an individual's struggle...That role might be compared to a candle. A candle can help illuminate an experience, provide a path in the darkness, and give courage to explore. Caregivers, at their best, can provide that light. That light can accompany individuals as they negotiate a sometimes treacherous and scary path. The journey [may] still be dark, but the light can make it less terrifying:" (Doka, 1993, p. 247).

Only the caregivers who make the time to take care of themselves can be "at their best" and be like the candle that continues to burn without burning out.

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12 TIPS FOR CAREGIVERS*

1. MAKE YOURSELF PART OF THE TREATMENT TEAM

Remind them of your needs – financial, emotional, transportation, etc.

2. SPIRITUALITY IS AN IMPORTANT PART OF CARING FOR YOURSELF. Don't lose hope.

3. PREPARE FOR SHORT-TERM CARE NEEDS

Become Educated. Explore pain control options early on. Talk with the insurance company. The prospect of sophisticated home care can cause apprehension in caregivers. Learning about treatment options, side effects and what is entailed in the home-care portion of medications and other interventions will benefit you and your loved one.

4. SHARE INFORMATION, FEELINGS & CONCERNS WITH YOUR FAMILY

Sharing care among family members often requires frequent information exchange.

5. FIND WAYS TO COPE WITH YOUR EMOTIONS

Try to stay involved in enjoyable activities – sports, crafts, gardening – it will help maintain life balance.

6. CONSIDER LONG-TERM CARE NEEDS

Watch for fatigue. Make financial preparations. Don't let cancer take over. The side effects of some treatments can erode patient self-esteem. Caring support can play an important role in sustaining your loved one's emotional well-being.

7. TAKE CARE OF YOUR OWN PHYSICAL AND MENTAL HEALTH (easier said than done)

When problems are detected early on they can be treated more easily.

8. WITH TERMINAL CANCER, KEEP THE FOLLOWING ROLES IN MIND

Coordinator, Decision-maker, Representative, Mediator, Friend

9. MAKE THE MOST OF THE CIRCUMSTANCES

Laughter is the best medicine. Sharing memories and funny stories can be fun and therapeutic for all.

10. CONSIDER PALLIATIVE & HOSPICE CARE WHEN EXPLORING END-OF-LIFE CARE

Plan the journey your loved one and you want, making sure physical and emotional needs are met. Accept outside, volunteer help.

11. GIVE YOURSELF & OTHERS THE TIME AND FREEDOM TO COPE/GRIEVE INDIVIDUALLY

Friends, volunteers and staff helping you/your loved one also feel emotions toward your circumstances.

12. LEARN TO RECOGNIZE THE RISK FACTORS OF UNHEALTHY COPING/GRIEVING

Sleeping difficulties, dreaming of the loved one, feelings of emptiness, sadness, uncontrolled crying, loss of purpose or energy, numbness, fatigue, muscle weakness, stomach and headaches, tightness in chest, throat, abdomen, weight loss or gain.

Some factors are more noteworthy: Being medically frail, death associated with a lengthy illness, death of a child (at any age), death perceived as preventable, death for which the survivor feels responsible, history of psychological vulnerability, multiple loss, perceived lack of social support/isolation, sudden or unexpected loss, violent or horrific loss.

Adapted from Johnson & Johnson Rosalynn Carter Institute Caregivers Program

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LEARN TO LAUGH

Humor and laughter can...

- ***Ease tension***
- ***Convey goodwill***
- ***Defuse negative emotions***
- ***Relieve stress and sadness***
- ***Help reassert control***
- ***Increase flexibility and creativity in problem solving***
- ***Perk up the immune system***
- ***Release natural painkillers***
- ***An occasional “drink” or piece of chocolate can help too!***



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MY TOP 10 HOLIDAY 'STRESS REDUCERS'

1. **Say 'No'...** if you don't want to go to Aunt Joan's Holiday Party for 35 people you don't even know, or your neighbor's boring New Year's Eve Party. Just 'say': 'We are going out of town or we have a prior engagement, or 'I have a headache'.
2. **Say 'Yes'...** if a friend offers to take you to lunch and share a 'spa day' or for a 'guy', meet a buddy and go to Turf Paradise, a sports event or an action movie that your wife doesn't want to see. Or, just having a 'day'/few hours to yourself.
3. If you always get long, detailed Holiday letters with pictures from people you haven't seen for years or don't recognize- don't feel obligated to read them or reply to them.
4. Make a Reservation for Xmas Dinner 'now' so you don't even have to think about it. Or, take a ride somewhere and find a restaurant or diner on your 'trip' and stop in and eat whatever you feel like, including dessert. Or, just order 'take out'!
5. If you don't feel like sending out cards, 'don't' call the people you really want to talk to and Wish a Happy Holiday. or send an email since no one uses the phone anymore! In my house, Jack-the 'patient', sends the Holiday cards, and I send the emails!
6. Division of Labor is another stress reducer Jack loves the Holiday 'stuff' so he puts up the Xmas tree, decorations, etc., and I make the reservations for Xmas dinner..! Basically, you/caregiver do what you 'can do' and let the 'patient' do what he/she 'can do'.
7. And, if you have other family members, and/or friends let them Help Too! If they offer to shop, take the dog for his shampoo, cook a meal, or give you 'time off', say 'Yes'. But let them know what you want and 'when'.
8. Take a 'trip' may be getting out of 'town' is the best way to reduce your stress and enjoy the Holiday Season. You don't have to go far... but just being away from the house and all of the usual tasks and stresses can really be fun and relaxing.. Jack and I like to drive up to Wickenburg and find a local restaurant or 'saloon' for Xmas dinner... and wear our 'jeans' and cowboy/cowgirl hat and no cellphones... stay at a local motel/hotel and drive home leisurely.
9. Or, go to a movie and out for a pizza or whatever you like... if you like to cook, cook what you both like. Or, for me, read a book, usually a mystery book or lie on the couch and watch HGTV or the Cooking Channel. Jack watches documentaries on Netflix... whatever works!
10. Do something you enjoy, take time for yourself, try to enjoy the moment... and as one of my more spiritual friend advises me: "Just Breathe"!

Add your own 'tips' for coping with the Holidays!

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NOTES

This image shows a full page of handwriting practice paper. It features a series of horizontal dashed lines spaced evenly down the page, designed to help children learn letter height and placement. The paper has a red border on the left side.

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BLESSED ARE THE CAREGIVERS

"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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Cancer Caregivers Education Program™ (CCEP®)

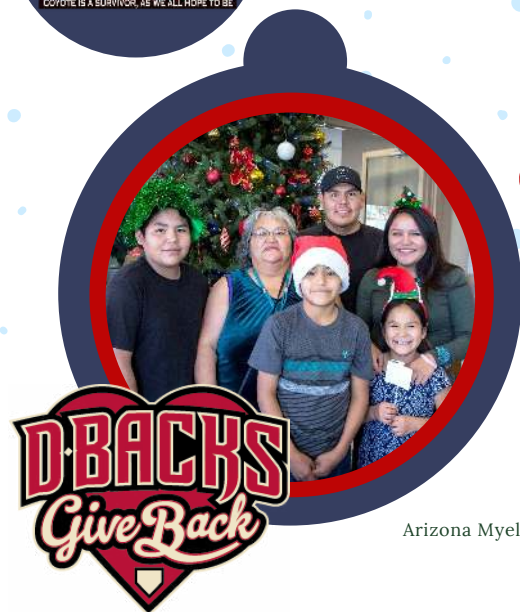
All proceeds benefit cancer patients and caregivers education
Help us raise money for FREE education and cancer resource conferences!



YOU ARE CORDIALLY INVITED
TUESDAY, DECEMBER 17, 2019 AT 6:30PM
MILLENNIUM RESORT HOTEL

7421 N SCOTTSDALE RD, SCOTTSDALE, AZ 85253

Strike Out Cancer



Join Us at Arizona Myeloma Network's Benefit Dinner to Honor
Cancer Patients and Caregivers, Title Sponsor by Derrick Hall,
President & CEO of the Arizona Diamondbacks.
Enjoy an evening of Music, Special Guests, Awards, a fun Ballpark Menu,
indulgent Ice Cream Bar, Silent Auction and a Super Raffle!
Tickets and Sponsorships are available for purchase.
For More Information & to RSVP today visit our website

www.azmyelomanetwork.org

Arizona Myeloma Network (AzMN) is a 501(c)(3) nonprofit charity organization, EIN 32-0169742.
To Attend an event, Volunteer, Sponsor, or Donate visit our website or contact us:
Call: (623) 466-6246 or Email: admin@azmyelomanetwork.org
www.azmyelomanetwork.org - www.cancercaregiversaz.com

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