

# SPRING CANCER CAREGIVERS CONFERENCE



*Cancer Caregivers AZ*™

Educating Cancer Caregivers for their wellbeing & improved patient outcomes



*Cancer Caregivers Education Program*™ (CCEP®)

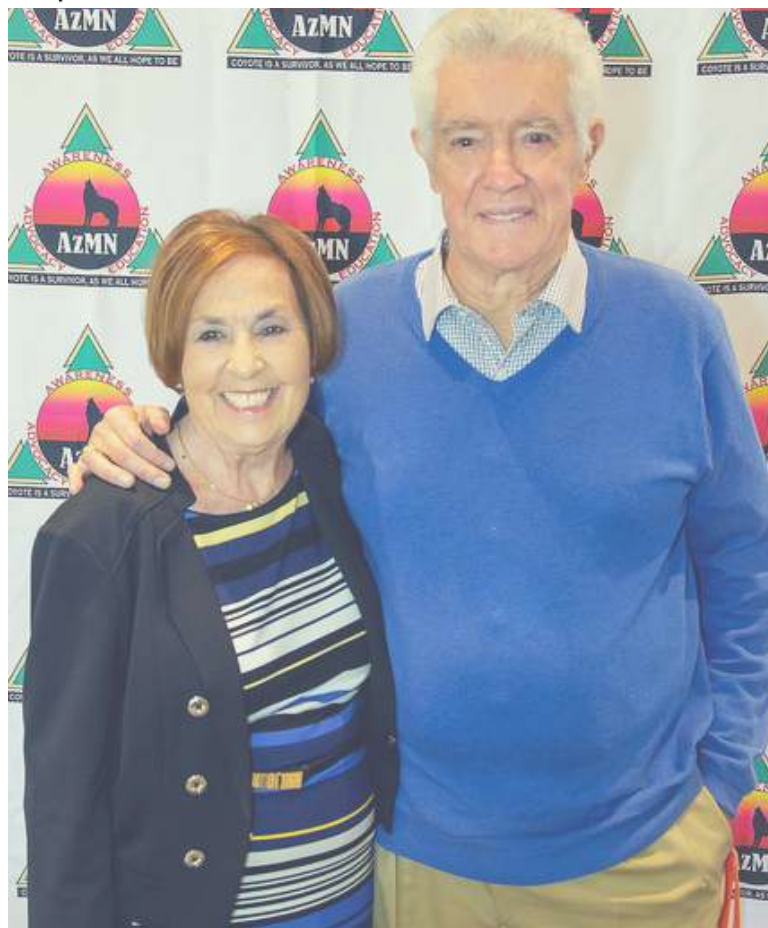
**"AN INDIVIDUAL DOESN'T  
GET CANCER...  
A FAMILY DOES."**

*-Terry Tempest Williams*

**CANCER CAREGIVERS BOOKLET**

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 underserved: African American, Asian /Pacific, Hispanic American and Native American.

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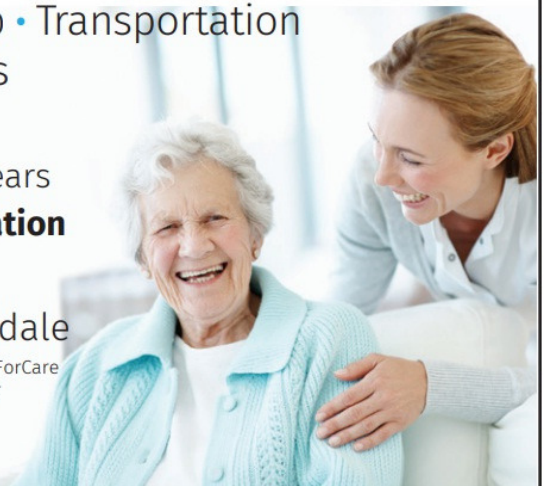
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*"Our mission is to optimize patient health through  
a relentless devotion to clinical excellence."*

# IMPORTANT WORDS

## ***Try to keep these in mind...***

- CareGIVER not CareTAKER
- Delete "Should" from your vocabulary
- Being "self-ish" is not BAD
- If you don't care for "you" then you can't care for "him/her"

An Exercise in Reflection:  
Take a moment to think of what other "words" or "thoughts" that create stress for you, the caregiver. Write them down below.

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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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# HOW TO HELP YOUR LOVED ONE WHO HAS CANCER

- *Try to "fix" it by taking over as much as possible*
- Go Into Hiding
- Become an emotional mess
- Yell OR...
- Ask them what they would like to do
- *Gather a support network of family, friends, and neighbors to help*
- *Develop a plan to help with physical care and household chores*
- *Be there emotionally*
- *Take Care of Yourself*
- *Laugh*
- *What other ways do you cope with being a caregiver?* \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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# SUCCESSFUL ATTRIBUTES OF THE CANCER CAREGIVER

- *Percieves, Believes*
- Stays Calm
- Thinks, Analyzes, Plans
- Takes Correct, Decisive Action
- Celebrates their Success
- *Counts their Blessings*
- *Plays*
- *Sees the Beauty*
- *Believes they WILL Succeed*

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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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# 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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# 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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## RESOURCES

AARP 866-448-3616 [www.aarp.org/az](http://www.aarp.org/az)

Apphia Home Care 602-863-4437 [www.apphiahomework.com](http://www.apphiahomework.com)

Arizona Caregiver Coalition 800-813-4673 [www.azcaregiver.org](http://www.azcaregiver.org)

CancerCare 800-813-4673 [www.cancercare.org](http://www.cancercare.org)

Cancer Legal Resources Center (CLRC) 866-THE-CLRC [www.CancerLegalResourceCenter.org](http://www.CancerLegalResourceCenter.org)  
Information related to Disability Rights

Cancer Survivors Circle of Strength of Arizona 602-566-9101 [www.azcscs.org](http://www.azcscs.org)  
Provides peer support

Caring Bridge 651-452-7940 [www.caringbridge.org](http://www.caringbridge.org)

Caring Connections 800-658-8898 [www.caringinfo.org](http://www.caringinfo.org)

Caring from a Distance [www.cfad.org](http://www.cfad.org)

Celgene Patient Support 800-822-2496 [www.CelgenePatientSupport.com](http://www.CelgenePatientSupport.com)

Family Caregiver Alliance 800-445-8106 [www.caregiver.org/long-distance](http://www.caregiver.org/long-distance)

HomeCare Resources 602-443-4700 [www.homecareresources.net](http://www.homecareresources.net)

National Alliance for Caregiving 301-718-8444 [www.caregiving.org](http://www.caregiving.org)  
Searchable Database for Resources

Needy Meds 800-503-6897 [www.needymeds.org](http://www.needymeds.org)  
Prescription Assistance

Partnership for Prescription Assistance 888-477-2669 [www.pparx.org](http://www.pparx.org)  
Assistance includes Medicare & Medicaid

Patient Access Network Foundation (Medical Assistance) 866-316-PANF (7263) [www.panfoundation.org](http://www.panfoundation.org)  
Assistance for the "underinsured"

Patient Advocate Foundation 800-532-5274 [www.PatientAdvocate.org](http://www.PatientAdvocate.org)

Saving Lives On the Go (CPR) 480-707-7916 [www.savinglivesonthego.com](http://www.savinglivesonthego.com)

Together Pink Network 480-233-5406 [www.togetherpinknetwork.org](http://www.togetherpinknetwork.org)

ComForCare Home Care 480-570-2439 [www.comforcare.com/scottsdale](http://www.comforcare.com/scottsdale)



*EAZ*

SAVE THE DATE....

# October 20, 2018

**Fall Cancer Caregivers Conference**  
"Young People ARE Cancer Caregivers TOO!"

Registration is FREE and opening soon

[www.azmn.info/care](http://www.azmn.info/care)

All are welcome to attend!

*Cancer Caregivers Education Program™ (CCEP®)*

Special Event focused on the YOUTH affected by cancer. Whether they be cancer patients themselves, survivors, family members or friends of a cancer patient; this conference is specifically for them.

This a FREE event and ALL are encouraged to register. For More Information Visit [www.azmyelomanetwork.org](http://www.azmyelomanetwork.org) or Call our office at (623) 466-6246

or  
Email us at [admin@azmyelomanetwork.org](mailto:admin@azmyelomanetwork.org)

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# Cancer Caregivers AZ™

Educating Cancer Caregivers for their wellbeing & improved patient outcomes

## Cancer Caregivers Education Program™ (CCEP®)

### 2018 CALENDAR

April 28, 2018 Helping a Loved One Deal with Side Effects  
October 20, 2018 Young People ARE Caregivers TOO!  
December 2018 To Be Determined

Register at [www.azmn.info/care](http://www.azmn.info/care)

#### "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

# AZMN THANKS

Our Amazing Board Members & truly essential Staff for their commitment to our vision and our mission.



**Donate**



Please continue to show your support for the Arizona Myeloma Network and Cancer Caregivers AZ and help us continue to provide our FREE Cancer Caregivers Education Program™, CCEP® to all cancer patients, families, and caregivers! To DONATE visit [www.azmyelomanetwork.org](http://www.azmyelomanetwork.org) or Shop online for everyone at

<http://smile.amazon.com/ch/32-0169742>



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For more info contact: Barbara Kavanagh, M.S.W. Founder & CEO  
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