AWARENESS ADVOCACY EDUCATION
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COYOTE IS A SURVIVOR, AS WE ALL HOPE TO BE

Cancer Caregivers AZ™

Educating Cancer Caregivers for their wellbeing & improved patient outcomes

GREAT NONPROFITS
2018 TOP-RATED
NONPROFIT

Cancer Caregivers Education Program™ (CCEP®)

> "AN INDIVIDUAL DOESN'T GET CANCER...
> A FAMILY DOES."
>
> ~*Terry Tempest Williams*

CANCER CAREGIVERS BOOKLET

MYELOMA PATIENT SUMMIT AGENDA
SATURDAY, MARCH 24, 2018

7:45-8:45 AM	Registration, Breakfast, & Exhibits
8:45-9:00 AM	Opening Convocation
9:00-9:15 AM	Opening Remarks - Barbara Kavanagh
9:15-9:30 AM	Introduction & Mission - Mary DeRome
9:30-9:45 AM	Welcome by P. Leif Bergsagel, MD
9:45-10:15 AM	Myeloma 101 with Jeremy T. Larsen, MD
10:15-11:00 AM	Cancer Caregivers - Suzanne Hyde & Barbara Kavanagh
11:00-11:15 AM	BREAK
11:15-11:45 AM	Chemotherapy & Stem Cell Amrita Y. Krishnan, MD
11:45-12:15 PM	Therapy: Newly Diagnosed Patients P. Leif Bergsagel, MD
12:15-12:45 PM	Treating Relapsed/Refractory Myeloma Saad Z. Usmani, MD
12:45-1:15 PM	LUNCH
1:15-1:45 PM	Immunotherapy-Kenneth C. Anderson, MD
1:45-2:15 PM	Supportive Care for Patients Angela A. Mayo, PA-C, MS
2:15-2:30 PM	Patient Speaker - Pat England
2:30-3:15 PM	HOT TOPICS - Kenneth C. Anderson, MD & Jonathan Keats, Ph.D.
3:15-3:45 PM	Panel Questions & Answers - All Faculty
3:45-4:00 PM	Closing-Mary DeRome & Barbara Kavanagh

Cancer Caregivers Education Program™ (CCEP®)

ARIZONA MYELOMA NETWORK & CANCER CAREGIVERS AZ
UPCOMING SPRING EVENT

SPRING CANCER CAREGIVERS CONFERENCE

"Helping a Loved One Deal with Side Effects"

SATURDAY, APRIL 28, 2018
REGISTER AT WWW.AZMN.INFO/CARE

LOCATION: EMBASSY SUITES BY HILTON
4415 E. PARADISE VILLAGE PKWY S, PHOENIX, AZ 85032
8:00AM REGISTRATION & LIGHT BREAKFAST
8:30-11:30AM PROGRAM AND CAREGIVER BOOKLET

HELPFUL CONSIDERATION

- *It is not uncommon to feel shocked, fearful, and angry after someone you love is diagnosed.*
- *There are many things you can do to help, even when you are not near: research, phone calls, listening, support with decision-making, and finding helpful resources, to name a few.*
- *You will feel more control as you gather information and assess the situation.*
- *It helps to break down problems into manageable parts.*
- *Remember that cancer affects your loved one's body and life most directly- their opinions matter most. Please ask what you can do to help-don't assume.*
- *You are not alone- valuable resources and organizations are available.*
- *If you cannot be present at all treatment or doctor's appointments, look at the overall treatment schedule to plan your visit(s).*
- *If your loved one is having surgery, discuss whether it's best for you to come when in the hospital or after discharged. Consider a support group for all involved to help manage treatment side effects and emotions.*
- *Secure proper authorization to allow you or a local caregiver to gather copies of medical and treatment records for your loved ones personal files. This will help with follow care plans and future medical needs. Consider uploading these into a secure online Personal Health record File.*
- *Understand that the recovery period can take a long time.*
- *As always, open doors to communication with everyone involved in for your loved one.*

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

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

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.)

Care for Yourself

Sometimes caregivers are busy caring for others that they ignore their own needs. It's important to take care of yourself.

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COYOTE IS A SURVIVOR, AS WE ALL HOPE TO BE

CAZ

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!

A legacy of *caring*

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Ask your doctor
about Freelite®

Freelite is a simple blood test for diagnosis and monitoring of multiple myeloma.

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During treatment, **Freelite** helps your doctor quickly evaluate how well you're responding.(3)

Freelite® is a registered trademark of The Binding Site Group Ltd, Birmingham, UK.
References
1. Rajkumar SV, Dimopoulos MA, Palumbo A, et al. International Myeloma Working Group updated criteria for the diagnosis of multiple myeloma. Lancet Oncol 2014;15:e538-e548
2. Referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Multiple Myeloma V.1.2017. © National Comprehensive Cancer Network, Inc 2017. All rights reserved. Accessed February 16, 2018.
3. Mead GP, et al. Serum Free Light Chains For Monitoring Multiple Myeloma. Br J Haematol 2004; 126: 348-354

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Proudly presented to the Mayo Clinic in gratitude for their dedication to all cancer patients and their families, as well as their continued support of the Arizona Myeloma Network and its' mission.

State of Arizona

DEPARTMENT OF STATE
Office of the Secretary of State

UNITED STATES OF AMERICA)
) ss.
STATE OF ARIZONA)

I, Secretary of State Michele Reagan, certify that this United States flag was flown over the Arizona State Capitol on March 17th, 2018 in honor of:

ARIZONA MYELOMA AWARENESS WEEK

SPECIAL RECOGNITION FOR BARBARA B. KAVANAGH, FOUND AND CEO, AND JACK KAVANAGH, SPOUSE AND TWENTY-SIX YEAR MYELOMA SURVIVOR, AND THE INSPIRATION FOR ARIZONA MYELOMA NETWORK.

The flag of the United States of America was officially adopted on June 14, 1777, when the Continental Congress resolved that "the flag of the United States be 13 stripes alternate red and white, that the Union be 13 stars white in blue field representing a new constellation." The colors red, white, and blue were clearly derived from British sources.

IN WITNESS WHEREOF, I have hereunto set my hand and affixed the Great Seal of the State of Arizona. Done at the Capitol this 17th day of March, 2018.

Michele Reagan

MICHELE REAGAN
Secretary of State

Cancer Caregivers AZ™

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2018 CALENDAR

March 24, 2018	Myeloma Patient Summit
April 28, 2018	Helping a Loved One Deal with Side Effects
October 20, 2018	Recognizing Youth as Cancer Caregivers TOO!
December 2018	To Be Determined

Register at 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.

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Barbara & Jack Kavanagh
Debra Beadle
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