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Cancer Caregivers Booklet

RECOGNIZING YOUNG PEOPLE AS CAREGIVERS TOO!

Fall Cancer Caregivers Conference

SATURDAY, OCTOBER 20, 2018

Cancer Caregivers Education Program™ (CCEP®)

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

~Terry Tempest Williams

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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.

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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

8-9am Breakfast and Registration

9-10 am Welcome and Introductions -Barbara Kavanagh, Founder and CEO, AzMN and Cancer Caregivers Education Program, CCEP

"Recognizing Young People as Caregivers Too!" - Suzanne Hyde, LCSW

10-11:30 am Panel: The role of the Cancer Caregiver as part of the cancer treatment team: Dr. Donald Northfelt, Mayo Clinic Cancer Center; Bodour Salhia, PhD., USC; Amy Mirabella, PhD, RN, Honor Health; Lorraine Tallman ,Founder & CEO, Amanda Hope Rainbow Angels, and Suzanne Hyde, Moderator

11:30-11:45 am Snack Break and 'Stretch'

11:45-12:15 pm Meet our Cancer Caregivers: Informal discussion with the 'caregivers' themselves, Barbara Kavanagh, Moderator

12:15-1 pm: Thank you to our Sponsors, Faculty, Volunteers, and all of the Caregivers and Patients in attendance!

. Evaluations, Raffle, and Closing Remarks

We are Family!

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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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Meet the Faculty

Suzanne Hyde, LCSW - Private Practice

Suzanne Hyde is a Licensed Clinical Social Worker specializing in assisting adults and caregivers coping with chronic and acute illnesses and practices psychotherapy and counseling at her private practice in Scottsdale, AZ. Suzanne also serves as a support group facilitator at the Cancer Support Community Arizona running multiple support groups including the Multiple Myeloma Monthly Support and Learn Group. Suzanne also supports the Cave Creek, Carefree community as the Community Social Worker working with Neighbors In Need Arizona assisting individuals and families facing needs and concerns which exceed the current local resources.

Suzanne practiced Oncology Social Work at the Virginia G. Piper Cancer Center from 2005 until 2014. During that time, Suzanne oversaw the rollout of the Oncology Psychosocial Distress Program and Co-Chair of the Virginia G. Piper Cancer Center Patient Care Council. Major accomplishments in her career development include receiving the Barbara C. Dow Oncology Clinical Excellence Award in 2009 and the Scottsdale Healthcare Case Management Recognition in 2010.

Barbara Kavanagh, M.S.W., Founder & CEO, Arizona Myeloma Network & CCAZ

Barbara B. Kavanagh 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.

AzMN is 501(c)(3) nonprofit organization started in 2004 by Barbara and her husband Jack who is a 27-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 Living with Myeloma Roundtable and Conference, which 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.

In 2009, she developed the Cancer Caregiver Education Program (CCEP®). The goal of this free program is to 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 to provide onsite training for employees and constituents.

Barbara and AzMN have been recognized by the Governor of Arizona and also 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, and the 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.

Amy Mirabella, PhD, RN - Oncology Clinical Research Nurse, Honor Health

Amy has worked in various nursing roles over the past 25 years. She holds a BSN from the University of Arizona, a MSN-Leadership from Grand Canyon University and most recently earned her PhD in General Psychology with an Emphasis in Cognition and Instruction from Grand Canyon University. Currently, Amy works as an Oncology Clinical Research Nurse at HonorHealth Research Institute where she delivers holistic care to patients and their families. Amy also provides staff education and helps lead nursing research and evidence based practice throughout the Research Institute. In addition, Amy is an assistant professor at West Coast University. She is also a member of the Arizona Hospital and Healthcare Association Thoughtful Life Conversations Coalition and a trainer for the End-of-Life Nursing Education Consortium.

Meet the Faculty

Donald W. Northfelt, MD - Professor of Medicine, Mayo Clinic College of Medicine

Dr. Northfelt has been engaged in the clinical practice of breast medical oncology over the past 25 years, and Dr. Northfelt has been associate medical director of the Breast Center at Mayo Clinic in Arizona for the past 10 years.

During this time Dr. Northfelt has been an investigator on numerous clinical trials of breast cancer therapies, including therapies employing anti-HER2 agents such as trastuzumab. His routine breast cancer clinical practice also involves conventional treatments employing anti-HER2 agents and other cardiotoxic therapies.

Dr. Northfelt is also a member of the medical staff at the Phoenix Indian Medical Center, which is an Indian Health Service facility. The patient population served at that facility also includes a number of individuals with breast cancer, some with HER2-overexpressing disease who receive trastuzumab and other cardiotoxic therapies.

Dr. Northfelt genuinely believes that the family is a critical part of the treatment team and provides support to the caregivers as much as possible.

His Honors include the 2002 Above and Beyond Award from the American Cancer Society, Desrt Palms Area and the 2015 Clinician of the Year Award from Mayo Clinic.

Bodour Salhia, PhD - Assistant Professor, Department of Translational Genomics Keck School of Medicine, University of Southern California

Dr. Salhia is a translational genomics scientist with extensive knowledge and expertise in mechanisms that underlie tumorigenesis and tumor biology. She merges cutting edge genomics/epigenomics analyses with cell biological and functional studies towards the investigation of clinically relevant problems in human cancer. Her post-doctoral work focused on the genomics and epigenomics of breast cancer metastasis and multiple myeloma. Her lab is in the process of validating a DNA methylation liquid biopsy for breast cancer recurrence which would indicate patients with evidence of micrometastatic residual disease that are therefore likely to experience a recurrence. Dr. Salhia's lab also has research efforts in experimental therapeutics of brain metastasis by utilizing patient-derived xenografts and cell lines to identify novel treatment methods for this dismal disease.

Dr. Salhia has always believed in connecting with the people her research is attempting to serve. She has volunteered with the Arizona Myeloma Network, The Wellness Community, and Susan G. Komen affiliate in Phoenix. She has worked with underserved minorities on the Navajo Nation in Arizona. She has received numerous community awards including a service award by the Arizona Myeloma Network. She was also named one of 20 Faces of Komen in 2012 and 2013 and in June 2014 was the recipient of the Phoenix Business Journal's Top 40 under 40 award. Dr. Salhia is not only a researcher, but also has an understanding of how cancer and other serious health conditions affect a person's life and their family's.

Lorraine Tallman, Founder & CEO, Amanda Hope Rainbow Angels

Lorraine is the driving force behind Amanda Hope Rainbow Angels. Her personal experience in the pediatric cancer treatment world, sparked her lifelong devotion to advocacy and support for children with cancer and their families. She is committed to fulfilling Amanda's last wish to provide dignity and comfort to every Oncology and Hematology patient through the gift of their very own Comfycozy. She is a member of the Steering Committee for the Arizona Childhood Cancer Coalition. She serves on the Family Advisory Council and the Memorial Service Grievance Committee at Phoenix Children's Hospital. She also teaches the 'Family Centered Care' class to their new healthcare professionals. She is a sought after speaker for Mother's Grace, MASK magazine, the Child Life Specialist Association, and many other organizations. Lorraine was awarded the Phoenix Business Journal's Healthcare Heroes Innovator Award in 2018. She also shared Amanda's experience with Bard to inspire the AllPoints Port Access System Port Stabilizer.

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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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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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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Story from AARP Family Caregiving™

Younger caregivers face unknown futures, unexpected joys

Abbie Kopf, for AARP Published 11:04 a.m. ET Dec. 6, 2017 | **Updated 1:35 p.m. ET Dec. 7, 2017**

With a new wife and daughter, this millennial took on caregiving for two.

(Photo: Dustin Cesarek via AARP)

For the first part of their relationship, Dustin and Kim Cesarek were like any young couple. They met, fell in love and had a daughter named Reagan. Then, their idyllic story took an unexpected turn.

When the Cesareks' infant leaned against Kim's chest, the new mom felt pain that seemed out of the ordinary. When Kim's doctor suggested she get a mammogram, the results showed a potential abnormality and, after a biopsy, it was revealed Kim had breast cancer that had already spread to her sternum, liver and spine.

The news came as a total shock. "It really shakes your foundation," Dustin said. "It threw our family's plans out the window."

Kim, left, initially learned about breast cancer following the birth of her daughter Reagan, right. *(Photo: Dustin Cesarek via AARP)*

The couple's time was consumed by doctors' appointments and procedures to determine the extent of Kim's illness, which would later be diagnosed as metastatic, stage IV breast cancer. For Kim, everything became about her health. For Dustin, everything became about Kim.

"I wanted to make sure that Kim was getting the best care she could get," he explained. Dustin stepped into the role of primary caregiver for his wife by taking on additional household duties, driving her to and from appointments and making sure she ate despite a waning appetite. With an 8-month-old at home, Dustin became the caregiver to both ladies in his life.

"It was a lot of adjustment," Dustin acknowledged. "Kim wasn't able to do as much of the heavy lifting as she probably would have preferred."

Beyond the additional duties Dustin took on, he also began to grapple with the gravity and implications of Kim's illness and what it meant for his future. "When you realize that someone you care for deeply is probably not going to get the amount of time that you expected, it's difficult," Dustin admitted. "It's very difficult."

Reagan, left has been a "point of light" for dad Dustin and mom Kim. *(Photo: Dustin Cesarek via AARP)*

Faced with uncertainty and grief, Dustin turned inward, not wanting to burden others with his ordeal. "Cancer is not something that very many people can relate to," Dustin explained. "It can be isolating as an individual or as a couple." Kim began attending a support group for patients which brought Dustin's seclusion into stark contrast. "All of a sudden, she had friends and was having lunch with people – I was so jealous!" he joked.

Dustin reached out to an online social networking group and found two men in his area who were also caring for their wives. They met for coffee and after speaking for more than an hour, realized that they had only been talking about their wives and kids – none had shared a thing about themselves.

"We wanted to continue to have these meetings and focus it more on our own experiences," Dustin explained. The group grew and eventually morphed into a Minnesota-based nonprofit called Jack's Caregiver Coalition.

Although Dustin initially felt alone in his challenges as a young caregiver, he isn't – according to AARP, 24% of unpaid family caregivers are between 18-34 years old. This demographic differs in key ways from others who provide care. For example, younger caregivers are more likely to experience positive emotions in the role.

This holds true for Dustin, who believes that being a caregiver has made him a better father to Reagan. "I think it's helped me be more present with her because of the perspective shift I've experienced with the cancer diagnosis."

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The family has found strength and support throughout Kim's health struggles. *(Photo: Dustin Cesarek via AARP)*

As his role as a husband and father has changed, Dustin has learned the value of gathering information to help him cope, and has visited the AARP Family Caregiving site (https://usat.ly/2nuoCWP) for its caregiving guides and resources. "Whether it's articles, tips, advice columns, that's all kind of helped me."

Now, Dustin hopes to share what he's learned in a professional capacity. Currently, he is pursuing a law degree with the hopes of specializing in estate planning, so he can help people prepare and plan for end-of-life situations.

AARP has information and resources to help caregivers – download their Prepare to Care Planning Guide (https://usat.ly/2nAk4hJ) to get help and support today.

Members of the editorial and news staff of the USA Today Network were not involved in the creation of this content.

Read or Share this story: https://usat.ly/2nyl6ul

AMONG OUR RESOURCES ARE: **(For more visit our website: www.azmyelomanetwork.org)**

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Amanda Hope Rainbow Angels (602) 755-2090 www.amandahope.org
Arizona Caregiver Coalition 800-813-4673 www.azcaregiver.org
CancerCare 800-813-4673 www.cancercare.org
Cancer Legal Resources Center (CLRC) 866-THE-CLRC www.CancerlLegalResourceCenter.org (Information related to Disability Rights)
Cancer Survivors Circle of Strength of Arizona 602-566-9101 www.azcscs.org (Provides peer support)
Cancer Warrior Alliance www.cwa.life
Caring Bridge 651-452-7940 www.caringbridge.org
Caring Connections 800-658-8898 www.caringinfo.org
Caring from a Distance www.cfad.org
Family Caregiver Alliance 800-445-8106 www.caregiver.org/long-distance
Needy Meds 800-503-6897 www.needymeds.org (Prescription Assistance)
Partnership for Prescription Assistance 888-477-2669 www.pparx.org (Assistance includes Medicare & Medicaid)
Patient Access Network Foundation (Medical Assistance) 866-316-PANF (7263) www.panfoundation.org (Assistance for the "underinsured")
Patient Advocate Foundation 800-532-5274 www.PatientAdvocate.org
Saving Lives On the Go (CPR) 480-707-7916 www.savinglivesonthego.com
Together Pink Network 480-233-5406 www.togetherpinknetwork.org

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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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Cancer Caregivers AZ™

Educating Cancer Caregivers for their wellbeing & improved patient outcomes

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

AzMN expresses its' sincere appreciation for our generous sponsors and grantors for their dedication to cancer patients and families.

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For more info contact: Barbara Kavanagh, M.S.W. Founder & CEO
Phone: 623-466-6246 | Fax: 623-243-6580 Email: barbarak@azmyelomanetwork.org
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