

National Behavioral Health Network for Tobacco & Cancer Control:

Master Class Community of Practice



National Behavioral Health Network
For Tobacco & Cancer Control

Cancer Education, Support, & Survivorship Groups

May 29th, 2018, 2:00pm ET

Housekeeping

Please do the following **two** steps.

1. Turn **off** or **mute** your computer speakers.

2. GoToWebinar INSTRUCTIONS:
Join the webinar:

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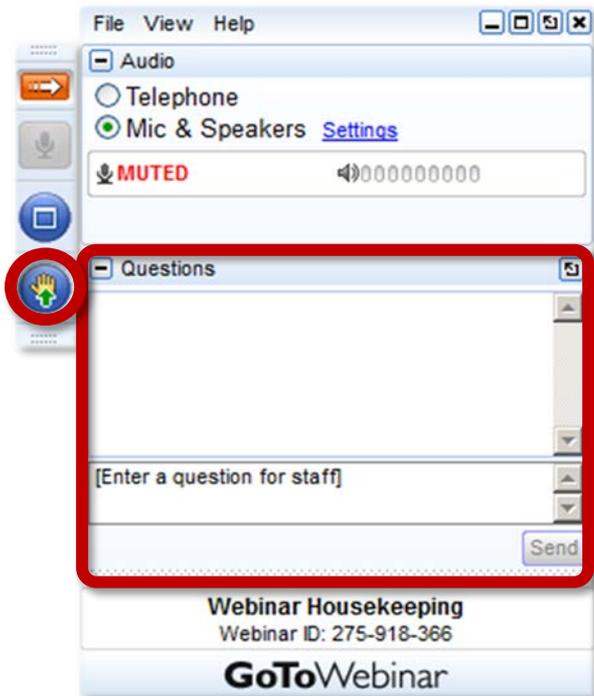
Access Code: 342-870-198

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The best way to ask a question is to use the question box in your GoToWebinar window.

We will have a brief Q&A session following the presentation.





Agenda

- **Rachel Landefeld, MPA, *Strategic Management Services, LLC***
- **Rebecca McIntyre, MA, M.Ed, LCSW, Inova Life with Cancer, Inova Schar Cancer Institute**
- **Ali Vogt, Manager, Psychotherapy Programs, Women's Cancer Resource Center**
- **Stacey Balkanski, Gilda's Club, South Florida**
- Q & A
- Wrap-up

Rebecca McIntyre, MA, M.Ed, LCSW - *Oncology Therapist, Inova Life with Cancer, Inova Schar Cancer Institute:*

- Rebecca is a licensed clinical social worker with over 15 years of experience in health and mental health. At Life with Cancer, she provides individual, couples, and family counseling and facilitates various support groups. Her interests include new diagnosis, adjustment to cancer, mind-body wellness, role transitions, caregiver stress, anticipatory grief, loss, and end of life.
- Prior to joining the Life with Cancer Family Center in 2015, Rebecca provided oncology counseling and therapeutic support for patients and families at Duke University Medical Center, The Children's Hospital of Philadelphia, and The Emily Couric Cancer Center at The University of Virginia.





Inova Life with Cancer Supports for Survivors and Families

Rebecca S. McIntyre, MA, M.Ed., LCSW





Support Groups at Inova Life with Cancer

| | | |
|--------------------------------|---------------------|------------------|
| Brain Tumor | Carcinoid | Lung |
| Breast | Just for Guys | Gynecological |
| Advanced Breast | Colorectal | Melanoma |
| Young Women w/ Breast | Colorectal Advanced | Multiple Myeloma |
| Women Survivorship < 3 years | Cutaneous | Waldenstrom |
| Women's Survivorship > 3 years | Head and Neck | Prostate |
| Living with Advanced Disease | Leukemia & Lymphoma | Spirituality |
| Caregivers | Young Adults | |





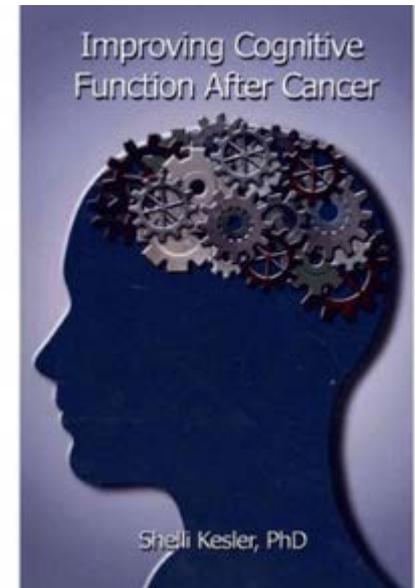
Research Created Groups

- ▶ Couples
- ▶ Resilience
- ▶ Feeling Irritable
- ▶ Good Grief



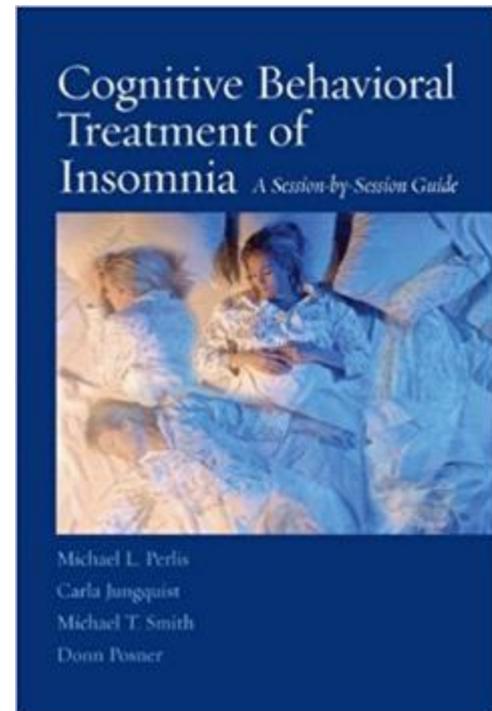
Cancer Related Cognitive Impairment

- ▶ **Session 1**: Your experience, what we know
- ▶ **Session 2**: Depression, anxiety, insomnia, medication
- ▶ **Session 3**: Cognitive behavioral, Impact of stress, self-regulation/arousal reduction, changing your relationship with your chemobrain
- ▶ **Session 4**: Compensatory strategies and personalized plan



CBT-I

- ▶ **Session 1:** Background information, sleep architecture, sleep diary
- ▶ **Session 2:** Sleep restriction, stimulus control
- ▶ **Session 3:** CBT/mindfulness
- ▶ **Session 4:** Sleep Hygiene
- ▶ **Session 5:** Relapse Plan



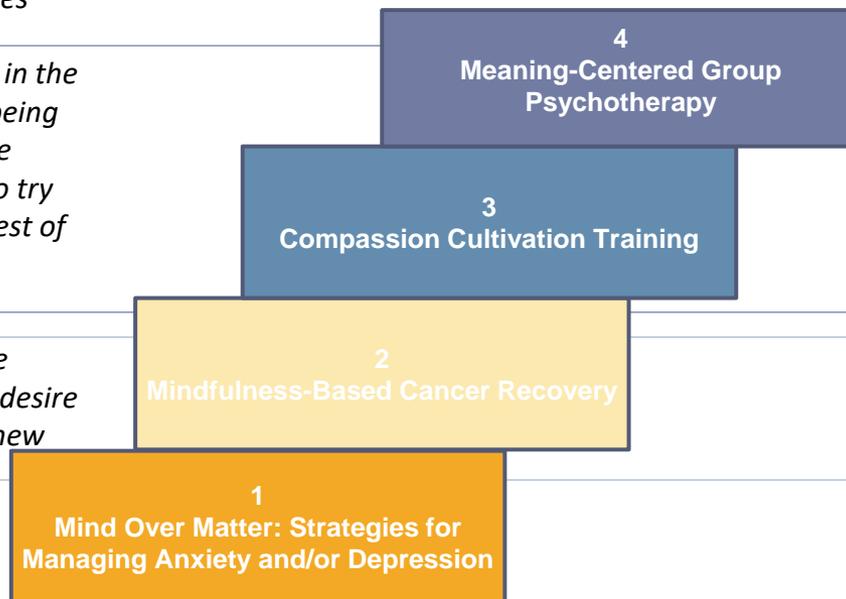
Integrative Psycho-Oncology Program: A Series of Classes to Help Patients Thrive Beyond Cancer



Testimonials

"I strongly recommend all cancer patients take this series.. The classes taught me that I can accept my condition, move on and be present in the moment, now. I also believe that being actively mindful has made me more grateful for what I have. I intend to try to practice what I learned for the rest of my life." – Stage III Ovarian CA"

"These classes have given me some stability and hope in my life, and a desire to reconnect with others. I have a new way of looking at life and some tools so that can help when your negative thoughts get out of control." Stage II Breast CA



8-Week Meaning-Centered Psychotherapy [MCP]

Developed by Dr. William Breitbart and his team at Memorial Sloan Kettering, MCP aims to decrease feelings of sadness and increase hope by teaching patients how to focus on creating, experiencing, and keeping a sense of meaning in life.

8-Week Compassion Cultivation Training

Developed by the Center for Compassion and Altruism Research and Education (CCARE) at Stanford University, this 8-week program combines traditional contemplative practices with contemporary psychology and scientific research to help participants cultivate compassion for oneself and others, through systematic meditations and experiential in-class activities.

6-Week Mindfulness-Based Cancer Recovery

Developed by Dr Linda Carlson and her team at the University of Calgary Cancer Center, this program uses proven Mindfulness-Based Stress Reduction [MBSR] skills to help calm feelings of fear, uncertainty, and lack of control through meditation and gentle yoga.

5-Week Mind Over Matter

Developed by oncology therapists at Inova Life with Cancer, this program uses proven strategies including: Cognitive Behavioral [CBT]; Acceptance and Commitment [ACT]; and relaxation techniques to help patients regain control, reduce anxiety, and promote healthier functioning.



5-Week Mind over Matter

Session 1 Understanding the mind/body connection: *thoughts-feelings-physical sensations-behaviors*; exploring the negative cycle of anxiety; *Sitting with Breath* meditation

Session 2 Understanding the ABC model and the power of thoughts/beliefs; body scan relaxation meditation

Session 3 Identifying maladaptive thoughts and unhelpful thought patterns; brief overview of thought record (homework); progressive muscle relaxation meditation

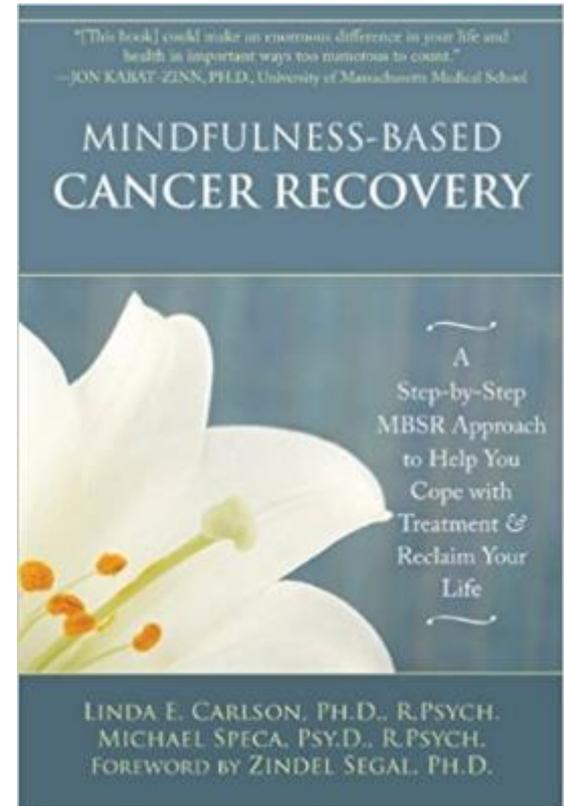
Session 4 Review of thought record; reframing and choosing alternate perspectives; mindfulness and detaching from thoughts; guided imagery relaxation meditation

Session 5 Identifying triggers; making a coping plan; integrating mind/body strategies



6-Week Mindfulness Based Cancer Recovery

- ▶ **Session 1** introduction to mindfulness; 7 helpful attitudes; “Big M” and “little m; first formal meditation - sitting meditation
- ▶ **Session 2** introduction to the negative cycle of anxiety; the physiology of balancing breath; first movement meditation-Hatha Yoga
- ▶ **Session 3** introduce the difference between stress reaction/stress response; the stories we tell ourselves; introduce the *Mountain Meditation* to experience a feeling of calm in the midst of the “inevitable storms of life.”
- ▶ **Session 4** 2nd formal movement meditation: walking meditation using a labyrinth
- ▶ **Session 5** mindfulness and symptom management, dealing with fears and difficult emotions; healing, self-care and self-compassion
- ▶ **Session 6** Cancer uncertainty and letting go





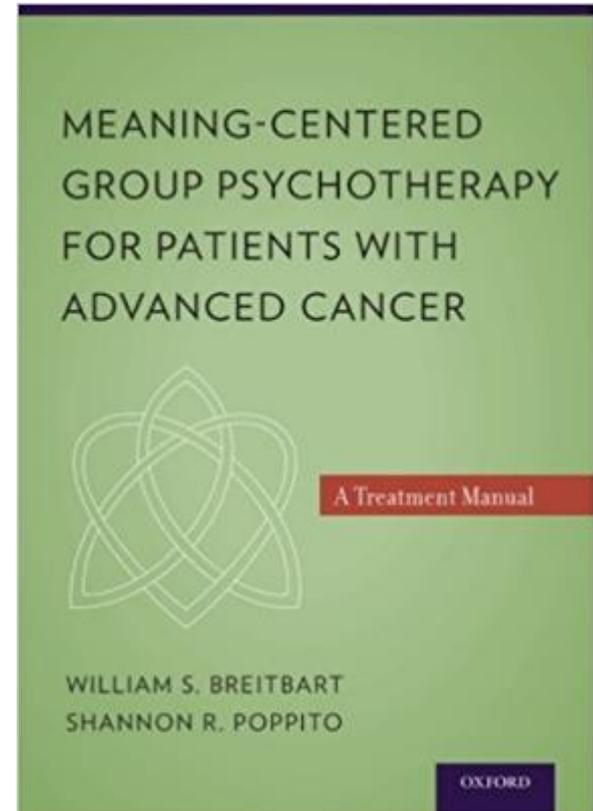
8- Week Compassion Cultivation Training

- Session 1** Orientation to compassion cultivation
- Session 2** Settling the mind and body
- Session 3** Loving Kindness and Compassion for a Loved One
- Session 4** Self Compassion (Part 1)
- Session 5** Self Kindness (Part 2)
- Session 6** Establishing the Basis for Compassion Toward Others/ Cultivating Compassion Toward Difficult Others
- Session 7** Active Compassion Practice
- Session 8** Integrated Daily Practice



8- Week Meaning Centered Psychotherapy

- ▶ **Session 1** Concepts and Sources of Meaning
- ▶ **Session 2** Cancer & Meaning
- ▶ **Session 3** Historical Sources of Meaning (past)
- ▶ **Session 4** Historical Sources of Meaning (present & future)
- ▶ **Session 5** Attitudinal Sources of Meaning
- ▶ **Session 6** Creative Sources of Meaning
- ▶ **Session 7** Experiential Sources of Meaning
- ▶ **Session 8** Transitions (endings and new beginnings)



Ali Vogt, Clinical Manager – *Psychotherapy Programs, Women’s Cancer Resource Center:*

- Ali is the Clinical Manager of WCRC’s psychotherapy programs, and a Marriage and Family Therapist. She manages the Free Therapy Program and Support Group Program, and collaborates in managing the Continuing Education Program for therapists, social workers and nurses.
- She has the privilege of facilitating the Complementary and Alternative Medicine Support Group as well as a Women with Cancer Support Group. Ali also has a private practice in Corte Madera, CA where she works with adults and adolescents.



For more than 30 years, the **Women's Cancer Resource Center (WCRC)** has served women with cancer and their loved ones in the San Francisco Bay Area.

WCRC provides culturally-aware psychosocial and practical support such as:

- ✓ patient navigation
- ✓ free psychotherapy
- ✓ support groups
- ✓ wellness workshops
- ✓ in-home client support



We provide 11 support groups at the WCRC:

- Sister to Sister - African American Women with Cancer - in two geographic locations
- Complementary and Alternative Medicine
- Latinas with Cancer - for monolingual Spanish speaking women
- LGBTQIA Cancer
- Lesbian-Focussed Caregivers
- Young Women with Cancer
- Women with Cancer - at two times - daytime and evening
- Women with Metastatic Cancer - at two times - daytime and evening





How did we build this program?

- Each support group has its own story of inception as each one serves a different community or intersectional identity.
- Most were built because there was a need stated by clients - clients started it as a group, or staff started it due to stated need.
- Most of our groups were peer led in the beginning.
 - They were led by women who stepped forward and wanted to lead the group. Most of these leaders did not have formal training in group therapy or they clients who were also therapists and were doing it pro-bono.



How did we build this program? (con't)

- Professionalization - The African American women support group and the Latina support group are both led by professionals who are patient navigator / nurses AND have group facilitator experience. The rest of the groups are led by licensed or pre-licensed therapists.
- Payment - in the past five years each of group facilitators has transitioned into being paid.
- Identity - We have found that the groups that serve specific identities - African American women, Latinas, LBTQIA - it is best to have a facilitator that also identifies in that group.
- It took two years - in general - to build each group so that we had a quorum
- Marketing is key



Marketing Support Groups:

- Oncology social workers - imperative as most patients meet with a social worker at some point in their cancer journey. They are often the ones who do the social /psych eval of clients.
- Oncologists
- Oncology surgeons
- Mental health professionals that specialize in psycho-oncolgy
- Other organizations that focus on cancer or the community in which the group focuses on - example: LBTQIA - market to other organizations focusing on gender and sexuality issues



Marketing Support Groups (con't):

- The list of support groups are listed in agency quarterly calendar
- Facebook posts - on agency page as well as other related pages
- Flyer that states what the groups are, where they are located, fee, time - these are sent to Social Workers and Oncologists and other cancer organizations on a quarterly basis. Not fancy: One-sheet 8 x 11 single sided. Something that can be edited frequently and quickly.
- Group flyer is in waiting room with other agency information.





A Closer Look: Complementary and Alternative Medicine (CAM) Support Group

- The CAM group started as a peer led group at some point prior to 1992. Many women were interested in alternative therapies and there was little information about it at that point in time. Organizations like ACS and most doctors were skeptical if not negative about women using these in conjunction with conventional therapies.
- The group went through many iterations from 1992 until when I started to lead it in 2013. It was always peer led - sometimes the leaders had group training of some kind.
- Since 2013 the group has met for an hour once a month and eventually we moved it to two times a month for two hours.
- The group's members are individuals who have cancer who are interested in integrative care. Some are treating their cancer with no Western Medicine.



How the CAM group works:

- It is a support group as well as information sharing group. Not a process or therapy group
- One of the guiding principles of the group is that we each support the others in their medical choices. This can be hard for all the members as some may disagree with the choices of another member. This is oftentimes when cultural humility is especially needed.
- Once a month we invite a specialist (nutritionist, cannabis expert, reiki practitioner, herbalist, acupuncturist, sound healer - etc.) who focuses on treating cancer in complementary or alternative ways.
- We do quick check ins when speakers are present - one minute max - that way the speaker knows who is in the room and how to tailor their remarks.
- When there is no speaker scheduled attendance is lower but those that attend get longer amounts of time to check in and talk about what is relevant.



Intended program impact

Our support groups hold space for women living w/ cancer so they experience:

- Less isolation (support groups based on level of disease & intersectional identities)
- Less invisibility/silenced (“When I tell people I have cancer, I feel like ‘The Boogeyman.’ Like I scare them because I’m what they don’t want to be.”)
- Improved quality of living (through educational events and peer support)
- Community



Challenges in Oncology Support Groups

- Group members die - so grieving has to be a part of the group process
- It is a club that no one wants to be a part of - so attendance is difficult at times
- Members are sick - so they may not be able to attend regularly
- There is often a lot of reactions about each other's decisions regarding treatment
- There needs to be groups during the day as oftentimes people don't have enough energy to attend later in the day
- And there needs to be groups at night for those that are also working
- Groups that take place in hospitals often remind clients of medical traumas
- How measure impact? We don't have a solution - if you know of one email me!



Recommendations for Sustainability for the Support Groups

- Pay the facilitators
- Train the facilitators in group therapy or hire therapists or individuals trained in group therapy
- It is best if the facilitators have some personal experience with cancer
- Have a regular time and place for the group
- Meet more than once a month - helpful but not necessary
- It takes a core of three people to make a group go
- Helpful to meet in a non-medical facility
- Email or call reminding members of the meeting
- Emails or google group - no Bcc's
- Memorialize those that have died



Lessons Learned

- Pay the facilitators for facilitation time but also administration time.
- Support groups that focus on intersectional identities must have a facilitator that identifies in that same group.
- Budget money for each group to go out for a meal each year or have food brought in.
- These are support groups and not process groups. This has meant that facilitators hold more of the process and do more group processing outside of group with individual members.
- Determine if your prospective group member has a personality disorders - if so group is not the best place for them - steer toward personal therapy.



Want more info? Free continuing education course on groups

The WCRC developed a series of continuing education workshops on psycho-oncology. You can view the list of courses by going here:

<http://www.wcrc.org/ceu/>

One of workshops focuses on oncology support groups entitled “Group Work with Cancer Patients”. **Mention this webinar and you can get this course (and 4 CE’s) for free by emailing ceu@wcrc.org.**



Stacey Balkanski, LCSW, Program Director –

Gilda's Club, South Florida:

- Stacey is the Program Director at Gilda's Club, South Fl, and a Licensed Clinical Social worker with 19 years of experience working in the field. She specializes in anxiety, depression, life transitions, family counseling, women's issues, chronic medical illnesses, and oncology.
- As Program Director, she is responsible for all clinical programming, as well as healthy lifestyle programs. She received her Master of Social Work (MSW) from the University of Central Florida and her Bachelor of Arts (BA) in Psychology from the State University of New York at Stony Brook.



SURVIVING SURVIVORSHIP

STACEY BALKANSKI, LCSW

STACEY@GILDASCLUBSOUTHFLORIDA.ORG

“PATIENTS WHO PARTICIPATE IN THEIR FIGHT FOR RECOVERY ALONG WITH THEIR HEALTH CARE TEAM, WILL IMPROVE THE QUALITY OF THEIR LIVES AND MAY ENHANCE THE POSSIBILITY OF RECOVER.”

-Dr. Harold Benjamin, Founder of the Wellness Community

WHO IS A CANCER SURVIVOR?



The transition from active treatment to post-treatment care is critical to long term Health.

WHAT SHOULD I EXPECT POST-TREATMENT?

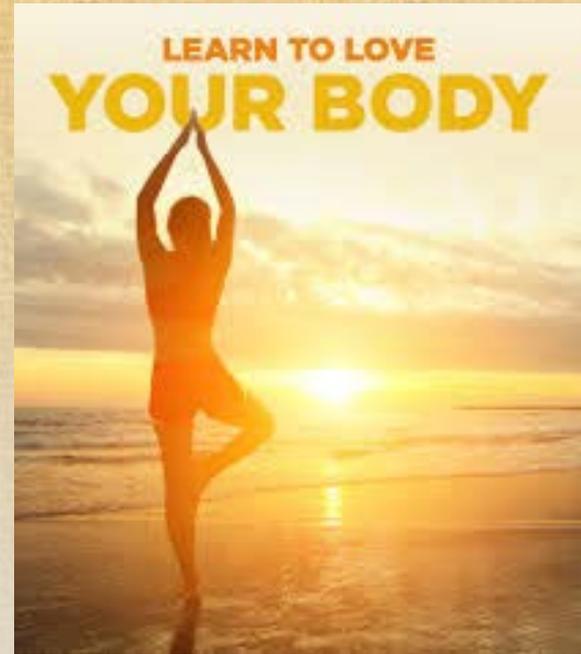
-
- Physical changes
 - Psychological changes



What are some lifestyle changes that can help me transition?

Exercise

- Learning about your new body



EMOTIONAL HEALTH AND WELL-BEING

- Distress Screenings measure practical problems, family problems, Spiritual/religious concerns, physical problems which may make survivors feel anxious or depressed.
- Let's talk about distress post-treatment and ways to address it.

GUIDELINES FOR GOOD HEALTH NUTRITION



Meal Preparation:

Whole Grains, Berries, Nuts, Citrus Fruit,
Colorful Vegetables, Fish, Yogurt, Tea, legumes.



MEDICAL CONCERNS

- Cancer survivors typically have many health issues to adjust to
- Communicating with Your Healthcare Team
- Follow Up Care
- Side Effect Management



SUPPORT

Throughout this presentation we have talked about what you can do to improve your survivorship experience. One of the most vital things you can do for yourself is to join a support group or have a cancer “buddy” who is going through similar experiences. You are not alone!

Why is this helpful?



Thank you!



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Next Steps

- > 1:1 coaching with Faculty
 - Calls with BHWP: *Signup via signup genius link*
 - Call with Tasha: *Signup via signup genius link*
- > Group Coaching Call #2
 - Wednesday May 30th 4-5pm EST
- > Peer Buddy Call #2
 - Anytime between May 31st – June 11th (to be scheduled by team leads)
- > Updated Action Plans due
 - Monday, June 11th 8:00pm ET
- > Wrap-Up Webinar
 - Thursday, June 14th 2:00-3:30pm ET



Questions? Contact Lea at
LeaS@thenationalcouncil.org