

Together We Are Not Alone: **Oncology and Palliative Support Groups**

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"It's my support group for Zoom Fatigue Syndrome."

It's simple, really...



*People help you, or you help them,
and when we offer or receive help,
we take in each other. And then we
are saved.*

Anne Lamott

*American novelist, progressive activist,
public speaker and writing teacher*

Types of Support Groups Facilitation

- **Professional-led support groups**
 - Led by a counselor, social worker, psychologist, RN/NP, MD/DO
 - Facilitate supportive conversation among the participants
 - May, or may not, encourage participants to express difficult emotions
 - NOT a psychiatric/psychotherapy service
- **Informational support groups**
 - Led by a professional or paraprofessional
 - Aimed at providing illness-related information and education
 - Often have speakers, such as doctors and nurses, who provide expert general advice
- **Self-help groups**
 - Run by those experiencing or recovering from illness
 - Supportive without professional facilitation

Types of Support Group Venues and Forums

- **In-person Support Groups**
 - Live group sessions
 - Limited by geography, transportation resources, and schedule
- **Videoconference / Telephone**
 - Live group sessions over WebEx-type platform that is HIPAA compliant
 - Limited by internet connection and tech literacy
- **Online / Chat Forums**
 - Asynchronous participation, but with 24/7 access by website for group posting and/or private messaging
 - Generally monitored and participants must join as group member
- **Apps**
 - Social support and professional networking communities related to disease groups

Benefits of Support Groups

- Feel more connected and understood
- Reduce distress, depression, anxiety or fatigue
- Improve skills to cope with challenges
- Stay motivated to manage chronic conditions or stick to treatment plans
- Gain a sense of empowerment, control or hope
- Improve understanding of a disease and your own experience with it
- Get practical feedback about treatment options
- Learn about health, economic or social resources

How and Which Types of Support Groups Benefit Patients?

- Support groups improve overall quality of life (apart from prolonging life). ¹
- Support groups provide different types of benefits and outcomes depending on whether they are therapist-facilitated, and on whether they are therapist-led and supportive-expressive **vs.** therapist-led and patient-active **vs.** non-therapist led and informational. ²
 - An initial version of the Group Experiences Questionnaire (GEQ) could be used for future research, such as whether the GEQ could predict which type of group a person would benefit from the most

Family Involvement Ensures Best Outcomes

Support groups benefitted women with breast cancer *and their caregivers* who attended by:

- lowering levels of anxiety, depression and psychological distress, and
- improving overall well-being and perception of positive change, and family involvement ensures the best positive outcomes. ³

Bereavement Support Groups Did *Not* Significantly Change Participants Grief, Anxiety, or Depression *BUT* Participants Still Reported that Groups Were Beneficial

- Participation in bereavement groups did not produce any effects on grief, anxiety, or depression in comparison to non-participants who were unable to participate. ⁴
- Non-participants who did not want to participate reported lower levels of grief and anxiety than the other two groups. ⁴
- Participants' satisfaction ratings were mostly positive, mentioning feelings of joint experiences and increased understanding of others' reactions; ⁴

Video Teleconference Support Groups Produce Similar Outcomes as In-Person Groups

Video teleconference groups are feasible and produce outcomes similar to in-person treatment, with high participant satisfaction despite technical challenges. ⁵

- Additional research is needed to identify optimal methods of video teleconference group delivery to maximize clinical benefit and treatment outcomes.

Individual and Group Factors that Impact Participation in Cancer Support Groups

There are both individual and group factors that contribute to people **NOT** attending cancer support groups. ⁶

- Individual factor themes:
 - resisting the identity of “cancer patient”
 - personality factors
 - currently having enough support
- Group factor themes:
 - lack of knowledge about groups
 - avoidance of negative aspects of groups
 - not finding the right group
 - practical issues

Psychosocial and Medical Factors *Don't* significantly Affect Participation in Cancer Support Groups

NO significant differences were found between those who self-selected to participate in support groups and those who do not participate related to:

- Patients' levels of anxiety, fear of recurrence, depression, distress, QoL, social support as well as coping strategies at the end of the rehabilitation program, or
- The presence of specific problems as measured on the NCCN Distress Thermometer. ⁷

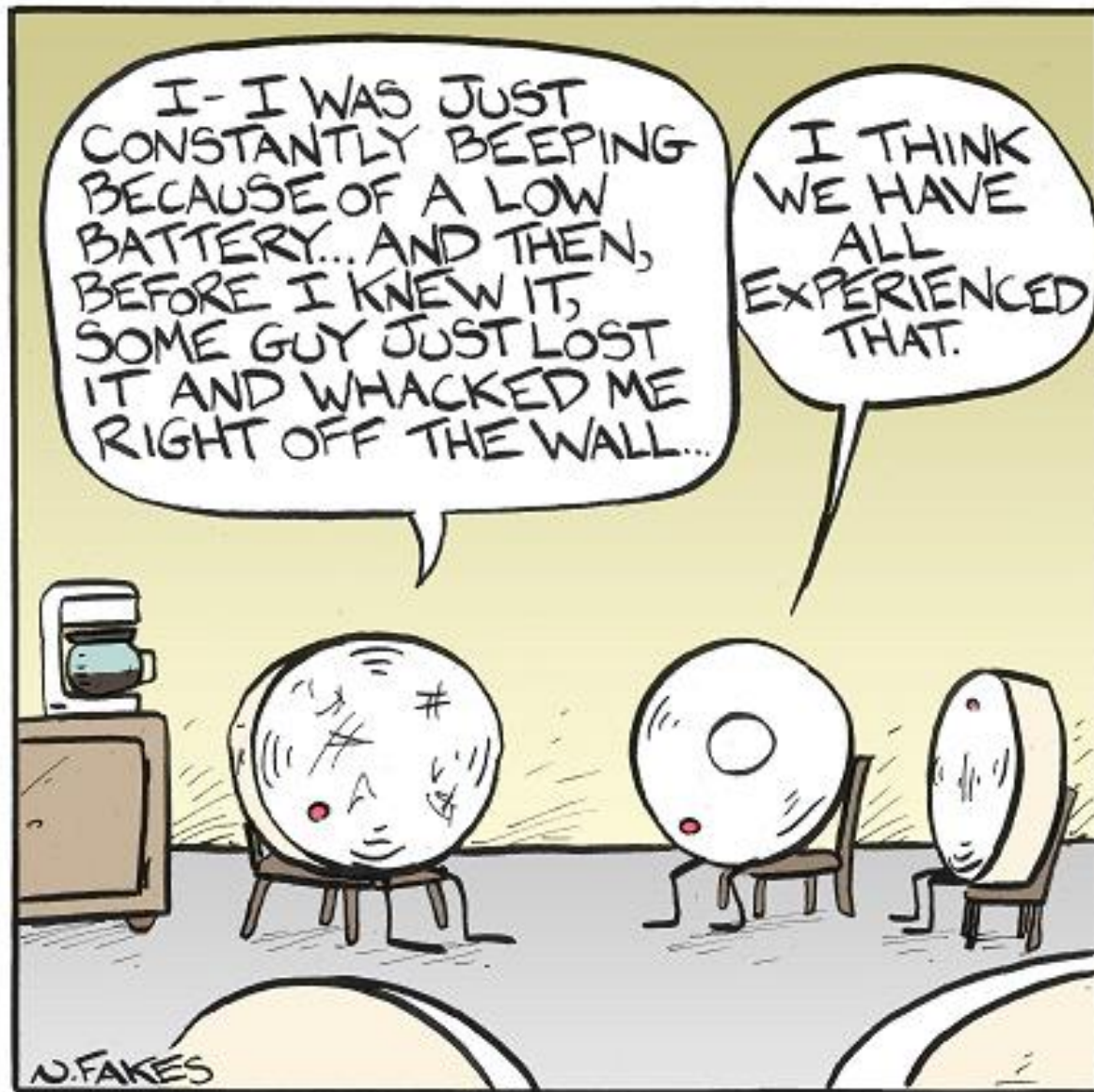
As a trend, group participants showed higher levels of active problem-oriented coping, active emotion-oriented coping, and less avoidance. ⁷

Potential Drawbacks of Support Groups

- Disruptive participants
- Conversation dominated by complaints or venting
- Religion or prayer focus taking over
- Lack of confidentiality
- Inappropriate or unsound medical advice
- Comparisons of whose condition or experience is worse



Sadly, Barbara was the only one to show up at the support group for those with abandonment issues



Smoke Detector Support Group

Support Group and Social Forum Resources

Cancer Support Groups and Resources

- <https://unclineberger.org/ccsp/counseling/>
- <https://www.rexhealth.com/rh/care-treatment/cancer/support-services/support-groups/>
- https://www.cancercare.org/support_groups
- <https://www.mdanderson.org/patients-family/diagnosis-treatment/patient-support/support-groups.html>

Grief and End of Life Support Groups and Resources

- Support after the death of a child
<https://www.compassionatefriends.org/find-support/>
- Support throughout NC for grieving children
<https://childrengrieve.org/find-support/9-find-support/40-programs-in-north-carolina>
- Support after the death of a senior
<https://www.aarp.org/caregiving/grief-loss-end-of-life/?cmp=RDRCT-bf1da46e-20210730>

Support Resources Continued

Grief Support Continued

- Support for men grieving loss of a spouse
<https://nationalwidowers.org/>
- Widowed Parents
<https://widowedparent.org/>
- Support for suicide survivors
<https://afsp.org/chapter/north-carolina>
- Support for adults grieving a loss
<https://icwb.com/grief-center>
- Support for adults and teens
<https://www.hospiceandcommunitycare.org/grief-and-loss/adult/>

Support Resources Continued

Apps and Social Networks

- **Belong – Beating Cancer Together**
https://landingpage.belong.life/cancer_support?campaignid=15707247970&adgroupid=132408293700&gclid=EAlaIqobChMIus3Nru6n9QIVD4nICh3ivgm7EAMYAiAAEgJYAPD_BwE
- **This is Living with Cancer**
https://www.thisislivingwithcancer.com/get-support?cmp=42bb81fb-166b-483b-8f9c-856913816dd1&gclid=EAlaIqobChMIueG-6u-n9QIVggaICR09mASzEAAYASAAEgJWNPD_BwE&gclsrc=aw.ds
- **Survivor Net**
https://www.survivornet.com/?gclid=EAlaIqobChMIus3Nru6n9QIVD4nICh3ivgm7EAMYASAAEgJB8fD_BwE

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Thank you