DID THEY REALLY JUST SAY THAT?

Navigating Conversations About Your Cancer Diagnosis

Jamie Newell, LCSW April 28, 2024 Ovarian Cancer Alliance



TALKING ABOUT YOUR DIAGNOSIS CAN BE EMOTIONALLY FRAUGHT

Who to Share With

- Personal preferences around privacy vary
- Some people share with a select inner group; others share more widely
- Identifying at least a core group can be helpful
- Important to share information with kids timing, amount of info and developmental stage are all important considerations
 - Helpful for schools to know what is going on



HOW MUCH TO SHARE

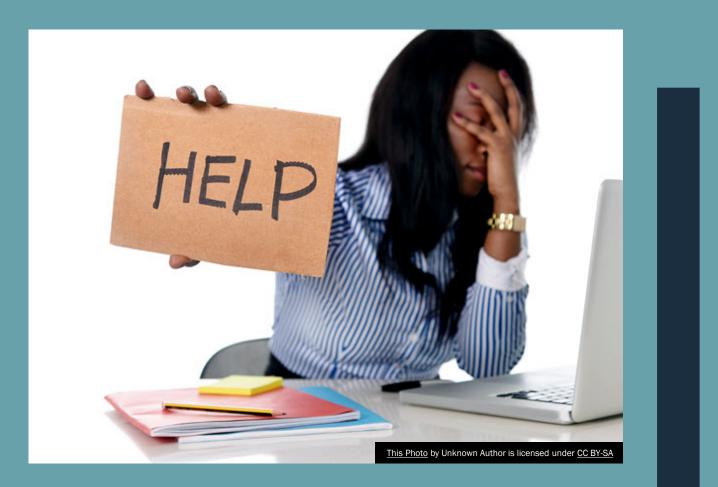
Timing of Sharing Information

Personal preference!

- Initial diagnosis
- After scans and staging
- As more information is gathered
- Important changes and updates

Ways to Share Information

- Websites like Caring Bridge, Meal Train, Lotsa Helping Hands
 - www.caringbridge.org
 - <u>https://www.mealtrain.com/</u>
 - <u>https://lotsahelpinghands.com/</u>
- Identified Family Member or Friend to disseminate info



HOW TO MANAGE REACTIONS QUESTIONS ADVICE Are you someone who enjoys the unsolicited opinions of strangers and acquaintances? If so, I can't recommend cancer highly enough. You won't even have the first pathology report in your hands before the advice comes pouring in. Laugh and the world laughs with you; get cancer and the world can't shut its trap.

Stop eating sugar; keep up your weight with milkshakes. Listen to a recent story on NPR; do *not* read a recent story in *Time* magazine. Exercise—but not too vigorously; exercise—*hard*, like Lance Armstrong. Join a support group, make a collage, make a collage *in* a support group, collage the s@#t out of your cancer. Do you live near a freeway or drink tap water or eat food microwaved on plastic plates? That's what caused it. Do you ever think about suing? Do you ever wonder whether, if you'd just let some time pass, the cancer would have gone away on its own?

Caitlin Flanagan



"Omg you have cancer?! But you don't look sick!" Well, do you have PET scan vision?

How to Manage Reactions/Questions/Advice

- Assume best intent
- Budget your emotional energy
- Set boundaries
- Use designated people as buffers
- Tell people what you need!
- Ask for help communicating with facilitated discussions

Identify Supports and Acknowledge Losses

- Who is showing up that you didn't expect?
- Who is not able to show up that you expected to be there for you?
- Identify people's strengths and capacity for helping (or delegate someone else to!)
 - The Organizers: organizing schedule, appointments, tasks for people, disseminating info
 - The Doers: help with cleaning, groceries, meals, childcare, rides
 - The Distractors: Movie watching, planning things to look forward to, people who make you laugh
 - The Core Group: people who you feel safe to be vulnerable, scared, and not okay with

Support for you

- People you can confide in
- Friends/Family who have dealt with cancer
- Your oncology social workers!
- Community counselors
- Peer Mentors
- Support groups
- On-line communities
- Palliative Care

Coping Strategies

- Acknowledge and honor your feelings: be curious and wonder about your feelings and attempt to identify them. When we acknowledge and name our feelings it helps to understand and sit with them.
- Share how you are feeling: share your feelings with people you trust who are good listeners and don't judge you or try to fix it.
- Practice self-care: Be sure to take care of yourself with healthy eating, enough sleep, and some physical movement/exercise.
- Breathe: pause at different points in your day to take a deep breath. Practice taking time out of your day to do 3 deep breaths at different times during the day.

Coping Strategies

- Budget Your Energy: identify what outings or events are important to you and consider fewer commitments. Consider your emotional energy with whom you choose to spend time
- Ask for What You Need: people are not mind readers
- Be present in the moment: slow down and be intentional about enjoying moments and noticing details and how you feel
- Find gratitude: find a time to be quiet to_think about what you are grateful for and write it down
- Laugh: It is important to find humor and laugh. Watch a funny movie, tell a joke; find humor where you can and share it.

Coping Strategies

- Practice Spirituality: this can embody many things
- Seek professional support: if you are experiencing significant sadness, anxiety, depression, talk to your doctor and see a counselor
- <u>Complementary therapies</u>: acupuncture, massage, reiki, naturopath
- Nutrition
- Exercise
- Survivorship Programs

Support for Loved Ones

- Your oncology social workers!
- Support groups
- Counseling
- ACS website: <u>https://www.cancer.org/</u>
- Literature for kids, partners, family members, loved ones
- Recognition that cancer diagnosis impacts all of you role changes, schedule changes, financial considerations, physical limitations, cognitive challenges, impact on intimacy



QUESTIONS AND DISCUSSION

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