

allycon 2022

colorectal cancer alliance

**Caring for the Caregiver
&
Understanding Caregiver Fatigue**

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Who am I?

- Licensed Clinical Social Worker – Pennsylvania + New Jersey
- Oncology Social Worker serving the GI-oncology, melanoma, and sarcoma population at SKCC of Jefferson Health
- Past experience in hospice & palliative care

- No financial or non-financial relationships to disclose.

Thank you, caregivers.



Many caregivers feel...

- like they are carrying a heavy load, sometimes for the whole family
- like their pre-existing role in their loved one's life (spouse/sibling/child/friend) is overshadowed by caregiving duties
 - Shifting expectations and adapting to change - *essential*
- stressed and overwhelmed
- like they end up having little time for themselves
- as much, if not more, distress than the patient
- a desire to "fix" things - yet can't do so in the ways they know how
- like a punching bag or an easy target for stress/anger
 - Associated guilt with pushing back or setting boundaries

Sources of Stress – Care Transition Points

- Diagnosis/Genetic Testing
- Initiation and cessation of treatment
- Hospitalization/Procedures
- Follow-up appointments
- Scans
- Recurrence
- Treatment changes

Sources of Stress – Other Life Stuff

- Holidays, birthdays, graduations, family celebrations
- Making/cancelling plans
- Managing other health issues
 - Your PCP and dental cleanings are important too!
- Childcare during doctor's appointments
- Keeping the house clean/Preparing meals/Grocery shopping
- Unexpected home/care repairs
- Financial stress - loss of income, increased expenses
- *Life does not stop in the face of a serious illness.*

Expected feelings

- Sadness and loneliness
 - Quality time often looks different when someone isn't well
- Grief
 - Loss of loved one's health
 - Loss of day-to-day normalcy
- Guilt
 - That you aren't helping enough
 - That you are healthy and they aren't
 - That you can't relieve suffering
- Anger
 - At yourself
 - At family members
 - At the patient
 - At cancer

Family Emotions

- Cancer is a "family illness", and will affect each family member differently
- Everyone has different ways of coping, which may cause friction
- People adjust to and incorporate information at different speeds
- People have varying needs for information
- Some families will arrive at the same stage of acceptance, and some won't
- Complicated relationships may remain strained
- *Illnesses rarely resolve long-standing family problems*

Nutrition

- Disease and treatment-related appetite and digestive issues can make eating and preparing meals a challenge
 - This is especially prevalent in GI-related cancers and patients receiving chemotherapy or recovering from GI-related surgeries
- Preparing meals is often a foundational role of caregivers, and if the patient can't or won't eat, this can create friction and/or feelings of *inadequacy* or *helplessness*
 - Culturally, sharing food is a sign of love
- Generally, the ability to eat and maintain adequate nutrition feels like something that should always be within our power to control
 - Easy to get frustrated as a caregiver when this doesn't go well, but also emotionally charged for patients
- *What helps?*
 - Adjust your expectations
 - Approach mealtimes with gentle encouragement, but don't push or get angry
 - Try smaller portions and more frequent meals, lots of snacks
 - Capitalize on foods that are found to be well-tolerated and liked
 - Don't take it personally if the patient doesn't eat what you prepare

Sexuality and Intimacy

- There are lots of ways to connect and maintain intimacy if physical expressions of sexuality are difficult due to illness.
- Talk about your feelings with your partner. Express your concerns. Set aside time to do this regularly.
- Speak to the oncology team about any related physical symptoms.
- Go slowly, there is no rush! Realize that it will take time and communication to reestablish intimacy.
 - Finding a sense of humor will help!

Caregiver Fatigue

Not at all surprising given everything discussed so far!



So, what can we do about it?

Prioritizing your needs isn't selfish

- It's easy to get caught up in the idea that your needs are less important and shouldn't be prioritized
- Remember, *you are not alone*. As much as it may feel that way, everything you are feeling and experiencing is normal, expected, and happening with caregivers everywhere all the time
- Maintaining your physical and mental health is one of the best things you can do for your loved one – so you can be at your best in their time of need – and for yourself, because as we know, *life can throw you curveballs at any time!*
- Basic needs are the first to go (eating well, drinking enough water, sleep)
- Secondary needs are just as important (intimacy, recreation, socialization, spirituality, exercise)
 - What brings you joy? What gives your life meaning?

Communication is key

with yourself and others!

- Talk to your loved one
- Talk to someone else who can hold you accountable
- Use a calendar or reminder system
- Make a list and/or a schedule for your needs and stick to it
 - Allot protected time for self-care, whatever form that takes
 - Enlist your network to cover your caregiving needs for an hour or two a few times a week to make this happen

Emotions and "Positive Thinking"

- People have a range of emotions in response to a serious illness. *This is normal.*
- Patients and families who allow themselves a balanced emotional response to their illness do better psychologically than those who are overly optimistic or pessimistic
- Ideally, emotions will be mixed and proportional to the negative and positive aspects of whatever challenge is being faced
- Unrelenting pressure – either internally or externally – to "be positive" is draining and counterproductive
- *There is no good evidence that "positive thinking" increases survival.*
- *"Thinking the worst" doesn't make the worst happen.*
- *Talking about fears does not create them where they didn't exist before.*

Words Matter

How to Talk About What's Happening

- Talking about distress often helps relieve it – but the way you talk about what's happening and the benefit you get from those conversations is different depending on who you're talking to
- *A listener doesn't have to have the answer. Just listening to the questions will help.*
 - This applies to you as a listener and to you as someone in need of support
 - Retelling your story can help you process and incorporate it
- However, rehashing medical updates to acquaintances can be exhausting
 - Try writing one blurb for sharing overall info about your loved one's diagnosis, and another for updates along the way that you can tweak as necessary
 - Then reference that pre-written information when taking calls from folks wanting updates or information, and/or copy and paste it in texts/emails to reduce the amount of effort it takes to keep people informed
 - Consider a virtual network for updates (CaringBridge or closed Facebook group)
 - Screen calls and let them go to VM – not everyone needs your full attention immediately or at all
 - *If a person is not adding value to your situation, they do not need to be involved.*

Words Matter

How to Talk About What's Happening

- It's easy to shut out family and friends who "don't get it", but try to let them in because they love you and care
 - If they offer you support in a way that's not helpful, try offering an alternative *"Thank you for offering to bring dinner over, but really what I need instead is someone to come walk my dog tomorrow during my appointment..."*
- When someone says the wrong thing – and they will – speak up (with kindness), they most likely mean well!
 - Take a pause to let the heat of the moment pass, if you can, and revisit later
 - *"I wanted to talk about what you said earlier – It hurt my feelings, and here's why. What is more helpful for me to hear right now is something like..."*

Words Matter

How to Talk to Kids About What's Happening

- Be honest, yet age-appropriate
- Give them only as much information as they need to know
- You can't always protect them from the world – they will create their own explanation for unanswered questions that may be scarier than the reality
- Check in with them often, but don't push if they don't want to talk about it
- Answer the questions they ask without elaborating more than is necessary – certain things can remain on a "need to know" basis
- Be reassuring without making promises you can't keep
 - Q: *"Will mom get better?"*
 - A: *"I sure hope so. I trust her doctors, and we will do everything we can to ensure she gets well."*

Suggestions for Practical Support

- Meal Train www.mealtrain.org
- Caring Bridge www.caringbridge.org
- Give in Kind www.giveinkind.org
- Go Fund Me www.gofundme.com
- Home Healthcare
 - Insurance-covered
 - Private Duty
 - Medicaid Waiver services

Accessing Mental Healthcare

Oncology care team

Primary care
provider/Psychiatrist

Therapist
Directories

Teletherapy Apps

Peer Mentoring &
Support Groups

Member Services @
Insurance

Therapist Directories



Psychology Today

The logo for 'Psychology Today' consists of the words 'Psychology Today' in a white, bold, sans-serif font, centered within a solid blue rectangular background.

Teletherapy Apps



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