Survivorship and Advanced Cancer

Sydney Dy, MD, MSc
Department of Health Policy & Management
Primary Care for Cancer Survivors Program

JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH
Whole-person care

- Common symptoms to watch out for and how to approach them if they come up
- Services and resources that may be available to you and your family
- Ideas for communicating about difficult issues
- Thinking about values and goals and what’s important to you and your family
Common Quality of Life Issues

- Pain
- Weakness
- Fatigue
- Trouble breathing
- Trouble sleeping
- Weight loss or gain, trouble eating, issues around food
- Memory and concentration issues
- Diarrhea
- Constipation
- Nausea / vomiting
- Anxiety / worry
- Depression
- Trouble with daily activities
Supportive care approach to symptoms

• Prioritize
  – What is most affecting your quality of life and keeping you from doing what you want to do

• Is anything being caused by treatments or medications that we can adjust

• Respect your preferences
  – Often several possible options

• If there is a procedure or treatment, what are the side effects/risks, is it worth it, other options
  – Side effects and risks often higher in advanced cancer
Supportive care approach to symptoms

• Balance treating a symptom with other symptoms and what else is going on
• Use nonmedical approaches when possible (eg, talking about worries instead of handing you an antidepressant)
• Keep it simple: change one thing at a time if possible
• Time-limited trial: try it regularly a few days
• Stop things soon if we can
• Think about the psychological and social aspects also and how to work with the family
And that's really frustrating to me, 'cause ... in my mind I can do all these things. You know, my body should be able to keep up with me. I should be able to do these things. And it's frustrating when I can't.

- person living with advanced lung cancer
Example symptoms: fatigue - causes

- Most common symptom
- Can be related to
  - other symptoms (poor sleep which can be due to pain, depression/ stress, muscle weakness)
  - cancer itself
  - medications
- Cancer treatment and burdens (travel, stress)
- Common in long-term survivorship – not well understood
Symptoms: Fatigue - evaluation

• Basic bloodwork, thyroid
• Current activity, preferences, and future goals that may be limited by fatigue (such as an upcoming trip or event)
• Future goals
• Full symptom evaluation
  • Fatigue vs sleep issues, fatigability (caused by activity)
• Review of medications that may contribute
• Review of burden of treatment and what might be simplified
Symptoms: Fatigue - management

• Evaluate and treat possibly associated symptoms first (eg, untreated pain)
• Energy management
  • Be kind to yourself
  • Adapt (simplify life, handicapped placard)
  • Manage family expectations, educate
  • Exercise as/ if tolerated (can be challenging)
  • Rest when needed
  • Plan goals and save energy/ rest for those
  • Oncology physical therapy sometimes helps
• Stimulant medications sometimes worth trying especially if there is a goal event: Ritalin, steroids
Example need: Issues around food

• Weight loss, weight gain
• Appetite and taste, enjoyment
• Challenges with eating
• Body image
• Family and social concerns

• Universal in the cancer experience
• Food is part of every culture and how we care for and love each other

• Caregivers may feel rejected or like person with cancer is not “trying”
Approach: Issues around food

• Frustrating process, sometimes no easy answer
• How to work with providers (including counseling):
  • Communicate what matters to you
  • Explore positive aspects of eating, how to emphasize these
  • Your providers can support family in how to help constructively and find other ways of caring
• Oncology nutrition review sometimes helpful for tips and support
It’s okay to ask for help. It’s okay to ask people to listen. It’s okay to need people. It’s okay, it’s okay, it’s okay.
Anxiety, stress, sadness, grief, anger

• Everyone has it (patient and family)
  • Living with uncertainty
  • Loss of control
  • Dignity, respect, being treated like a person
  • Scans, appointments
• Little irritations can become giant sources of stress
• Illness and stress bring out many family issues
Anxiety/stress: resources

• Be kind to yourself
  • Ways to plan your cancer treatments
  • Know what may help (music, distractions)
• Sometimes hard to talk to family or friends
  • Social workers/ counselors
  • Support groups (online)
  • Chaplains (hospital or personal)
• Other providers
  • Case managers/ work programs
  • Patient advocates (eg, Lungevity)
“The single biggest problem in communication is the illusion that it has taken place.”
George Bernard Shaw
Communicating with providers

• Think about how you want to hear news, what you want to hear (everything vs specifics), who in your family should be involved; tell your doctor

• Prepare a list of questions before your appointments (American Cancer Society has templates) and let your doctor know

• Ask the doctor to explain an answer differently, if you don’t understand. Call the doctor later.

• Take notes or record the discussion. You can also ask a family member or friend to go with you to take notes or simply listen.
Questions about treatments:

• What’s the best we can hope for by trying this treatment? What is the goal?
• Is this treatment meant to help side effects, slow the spread of cancer, or both?
• What’s the most likely result of trying this treatment?
• What are the possible side effects and other downsides of the treatment? How likely are they?
• Are the possible rewards bigger than the possible drawbacks?

Approaching illness the way things feel comfortable to you

• Taking risks vs being more conservative
• Having control, vs sharing with provider, spouse, adult children
• Planning vs taking it one day at a time
  • ideally some things like finances, organizing for your loved ones, communicating about wishes should be taken care of
• Sharing information vs being more private
  • Those closest to you, and children, should probably know
The most basic and powerful way to connect to another person is to listen. Just listen. Perhaps the most important thing we ever give each other is our attention.... A loving silence often has far more power to heal and to connect than the most well-intentioned words.

- Rachel Naomi Remen
Communicating with your family

• Decide what you want to talk about and with whom
• Having a facilitator may help (spiritual leader, hospital chaplain, health care provider)

• Share what is important to you and what you want to accomplish
• My biggest fears and worries about my future with this illness are... (pain, being in the hospital)
• What is most important to me is... (being at home, being with family)
• What makes me feel better... (types of music, talking about certain subjects, how to spend time)
Taking care of yourself and your family: Planning for emergencies

• Make sure they (and your provider) know what’s important to you and who to talk to if something happens
  • A real gift to your family to not have that burden

• Avoiding emergencies
  • Don’t worry about “bothering your providers”—they’d rather know early than have you have an emergency
  • Common things to plan for and medications you can have in the house or know about
Taking care of yourself and your family: Planning for emergencies

• Options (who to call, what emergency room to go to, oncology urgent care options, direct admission or other ways to make the process easier)

• At some point for people with advanced cancer... the best approach to an emergency may be not doing tests or something invasive
  • Options: medications before procedures
  • Sometimes, choosing quality of life or not having to go back to the hospital again
  • “Comfort emergency” – treating with medicines
Taking care of yourself and your family: what really matters

• Forgiveness
  • Forgive yourself first
  • Compassion for others, seeing things through their eyes

No one will respond perfectly to your illness. People—even people you love—will let you down. Friends you thought would be there won’t be there, and people you hardly know will reach out. Be prepared to give others grace. Be prepared to work through hurt and forgiveness at others’ reactions.
Taking care of yourself and your family

• Supporting the children in your life
  • Need time and attention
• Gratitude
  • Take time for the little things
  • Consciously be thankful for the good things
• Celebration
  • Special times together (small or large)
  • Be kind to yourself and others
Legacy and meaning

• Don’t stress about formal “legacy work” – writing letters, leaving things
  • This works for a few people but not for most
• Your legacy is your whole life and what you’ve done for and with those you love
• Do what is important to you to do for others, and what you can
• Let your family care for you – this is a real gift to them
• Celebrate your life and let others appreciate you
Websites


Handbook for Mortals
http://www.growthhouse.org/mortals/mor0.html

Guidelines for patients – treatments of different cancers and supportive care
https://www.nccn.org/patients/guidelines/cancers.aspx

15 things I wish I’d known about grief

American Cancer Society – advanced cancer

National Cancer Institute – advanced cancer

Practical guidance on cancer issues
Thank You

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• Questions or concerns, please contact Elissa Bantug ebantug1@jhmi.edu

• Thank you to Komen Maryland for their support in making this webinar possible