What is a Caregiver?
What does it mean to be a caregiver?

- A caregiver is anyone who provides physical, emotional, spiritual, financial, or logistical support to a loved one with a chronic, disabling or life-threatening illness, like cancer.
Caregiving has Many Faces

- Caregiving may have multiple roles:
  - Going to doctors visits
  - Making meals
  - Helping your loved one cope with feelings
  - Being a sounding post
  - Taking over other tasks
  - Running interference
  - Putting your own needs aside
What are the challenges of being a caregiver for you?
Caregiving is Challenging

- Many caregivers feel stressed and overwhelmed.

- Many caregivers have little time for themselves.

- Many caregivers feel as much, if not more, distress than the patient.

- Many caregivers feel an intense desire to ‘fix’ things which are difficult to fix in the ways they know how.

- Many caregivers feel out of control at times.

- Roles and responsibilities and expectations shift, adaptations are essential.
How have you been feeling about the challenges of being a caregiver?
Feelings and Caregiving

- Sadness and loneliness
  - Anger
  - At yourself
  - At family members
  - At patient
  - At cancer
- Grief
  - Loss of loved one’s health
  - Loss of day to day normalcy
- Guilt
  - That you aren’t helping enough
  - That you are healthy
  - That you can’t relieve suffering
How has your family been dealing with your loved one experiencing a cancer diagnosis?
“Family” Emotions

• A family functions as a unit. A cancer diagnosis will effect each member differently.

• Everyone has different ways of coping.

• People adjust and incorporate information at different speeds.

• People have varying needs for information.

• Some families arrive at the same stage of acceptance of cancer and some don’t.

• Conflicted relationships may remain difficult.

• Illness rarely resolves long-standing family problems
What have been some of the more difficult times for your loved one and you during this experience?
Transition Points

- Diagnosis
- Initiation and cessation of treatment
- Hospitalization
- Follow-up appointments
- Scans
- Recurrence
- Treatment changes
What Helps?
Strategies to Cope
What May Help

- Caregiving is an imperfect process, you will make mistakes along the way. Be gentle on yourself.

- Conserve energy, let small things go for now.

- Allow some time for feelings. They won’t hurt you!

- Maintain some routine and structure (meal times, recreation etc..)
Delegate

• Give people tasks
  • cooking, cleaning, yard work etc..

• Have a system for returning calls. Going over the same story over and over is exhausting

• Say no (nicely) to people who can’t add something helpful to the situation (Aunt Millie, Uncle Milt)

• Find a simple way to update people on how the patient is doing (BLOG, e-mail, phone tree)
Caring for You

- Find some time for yourself, even a few minutes can help.
- Be active, even light exercise can reduce fatigue and lift your mood.
- Stay connected with friends.
- Take time to rest.
- Take care of your own health.
- Acknowledge your limits.
- Distraction (humor/music/TV)
Speaking to Each Other

- Nearly all caregivers and their partners feel more stress than usual in their relationship.
- Try to make some time to talk about how each of you is coping.
- Look at modifiable things that are causing you both stress and problem solve around choices you can make together.
- Focus on things besides cancer.
- Talk about intimacy and changes you may be experiencing.
- Maintain some normalcy.
- Allow your partner to participate in things she feels able to do.
The ‘Tyranny of Positive Thinking’

- There is no good evidence that ‘positive thinking’ increases survival.
- People have a range of emotions in response to any serious illnesses. This is normal.
- Studies have shown that patients and caregivers who have 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 the particular challenge being faced.
- Unrelenting pressure --either internally or externally --to be positive is draining and counterproductive.
‘Managing’ Emotions

• You don’t control your emotions. You control what you make of them, how you interpret them and what you do with them.

• You control whether you express or contain them, where you talk about them and how much you allow yourself to experience them.

• Feelings are not a call to action.

• Feelings you ignore will eventually resurface. Unfortunately, by that time they are often disguised which makes them harder to recognize, understand and address.
What We Know

- Talking about distress often helps to relieve it.
- A listener doesn’t have to have the answer. Just listening to the questions will help.
- Talking about fears does not create them where they didn’t exist before.
- Retelling the story helps to process and incorporate it.
Burnout/Depression/Anxiety

- Symptoms to watch for
  - Extreme fatigue
  - Insomnia
  - Withdrawal
  - Loss of appetite/weight change
  - Extreme anxiety
  - Feeling empty
  - Loss of interest in things you enjoy
Strategies for Coping with Cancer

• Pacing, modifying and reworking daily schedules to shift focus from worrying about illness and focusing on uncertainty to more constructive, manageable tasks.

• Educating yourselves, learning as much as possible about the management of your disease.

• Aggressively treating side effects and symptoms (pain, nausea, insomnia, anxiety), understanding where symptoms originate and anticipate side effects of any new treatments.
Strategies cont.

- Making downward ("this could be much worse") and upward ("others have survived a similar illness") comparisons.

- Setting goals: identifying short-term goals as focal points for certainty.

- Compartmentalizing: being a caregiver or cancer patient is not your primary identity. Focus on other elements of your identity and engage in non-cancer discussion, activities, relationships, etc.

- Find a safe place to let down, to share distress with those who are able to understand and support. Choose a supportive network, selectively sharing illness and care giving information with those who are likely to offer support rather than create more distress.
Strategies cont.

• Patients and caregivers who are in active collaboration with their medical team have less distress than those who are more passive.

• Take care of yourself with exercise programs, dietary modifications, support groups, mind-body techniques etc. This helps people regain some sense of mastery and control over your life.

• Think about what resources (internal and external) you have used in the past to help you cope with uncertainty and stress.
Strategies cont.

• Keep life as predictable and normal as possible.

• Reduce as many current stressors as possible. Pay attention to close relationships, engage family members in your efforts to cope.

• Think about any other past or present stressful events that may be contributing to how you are feeling currently. These may be heightening your feelings of uncertainty. Talk to someone about these if you find that helpful.

• Rituals reduce feelings of uncertainty and provide some structure and support (support groups, classes, spirituality, social outings).
GRATITUDE
is the vitamin for the Soul.

emmanueldochier.com
Selected Resources and Reading

• National Cancer Institute www.cancer.gov
• The Cancer Support Community (cancersupportcommunity.org)
• Cancer Care (Cancercare.org)
• Cancer Caregiving A-Z (American Cancer Society (in print))