When You or Someone You Love Has Advanced Cancer

Judith A. Paice, PhD, RN
Director, Cancer Pain Program
Division of Hematology-Oncology
Northwestern University; Feinberg School of Medicine
Chicago, IL

Cancer Connections
Northwestern Medicine
July 25, 2015
When You or Someone You Love Has Advanced Cancer

• Describe trends in cancer treatment that contribute to improved survival rates
• Examine myths associated with cancer and the persistent stigma related to this disease
• Discuss communication and planning that will assist you and your loved one
History
Advances in Cancer Treatment

Figure 1. Key advances in the history of cancer chemotherapy

Group 1900 – 1940 indicate surgery & radiation therapy major treatments

DeVita V T, Chu E. Cancer Res 2008;68:8643-8653
Advances in Cancer Treatment

DeVita V T, Chu E. Cancer Res 2008;68:8643-8653
Myths & Stigma
Cancer = Death
14 million people living in the US have or had cancer
Cancer = Chronic Disease
Stigma

• Why me?
• What did I do?
• Did I cause my cancer?
Why me?
What did I do?
Did I cause my cancer?

“Here, we show that the lifetime risk of cancers of many different types is strongly correlated with the total number of divisions of the normal self-renewing cells maintaining that tissue’s homeostasis. These results suggest that only a third of the variation in cancer risk among tissues is attributable to environmental factors or inherited predispositions. The majority is due to “bad luck,” that is, random mutations arising during DNA replication in normal, noncancerous stem cells.

Tomasetti C, Vogelstein B. Science 2015; 347 (6217): 78-81
Advanced Cancer
Living with Cancer – Educate Yourself
Living with Cancer – Educate Yourself

• Clinical trials
• Palliative radiation, chemotherapy
• Palliative care
• Hospice care
Educate Your Team

- Symptoms
  - Pain, anxiety, fatigue, constipation, loss of appetite, sadness, sleep problems

- Communication
  - Some people want to know a lot; others want family members to make decisions

- Your preferences

- Family wishes and needs
Living with Cancer – Express Your Feelings
Living with Cancer – Express Your Feelings

- Sadness
- Grief
- Denial
- Anger
- Stress
- Fear
- Guilt or regret
- Loneliness
Pandora’s Box
HOPE
Living with Cancer – Take Care of Yourself
Living with Cancer - Exercise

- Strengthens muscles
- Improves balance
- Maintains mobility
- Reduces fatigue
- Increases memory
- Improves sleep
- Increases appetite
- Boosts mood
- Decreases stress
Living with Cancer – Reach Out
Living with Cancer – Focus on What You Can Control

- Expressing your feelings can help you feel more in control rather than overwhelmed.
- Frees energy
Living with Cancer – Focus on What You Can Control

• Planning for your family
  – Organize personal affairs
    • Important legal, insurance documents
    • Safety deposit boxes, keys
    • Pensions, retirement plans
    • Names of advisors – attorneys, accountants
  • Veteran, member of fraternal organization
  • Passwords
Living with Cancer – What You Can Control

• Advance care planning
• Ensure your wishes are understood and honored
• Advance directives
  – Durable power of attorney for healthcare
  – Choose someone you can trust to follow your preferences
  – Talk to them about your wishes!
  – This is not giving up!!
Living with Cancer – What You Can Control

- Look for meaning in your life
- Celebrate your life with loved ones
Living with Cancer – What You Can Control

• Make a video
• Photo albums
• Family history
• Family tree
• Journal
• Record funny or meaningful stories (StoryCorps – Chicago Cultural Center)

• Write notes or letters to loved ones and children
• Create art
• Give meaningful objects to loved ones
• Plant a tree or garden
• Mix of favorite songs
• Favorite recipes
Living with Cancer – What You Can Control

• Ethical will
  – Reflect on who you are and who you want to be
  – Examine your life experiences
    • Your past and present history
    • Lessons learned
    • Values and beliefs
    • Hopes
  – Wisdom to share
Caregivers
What Not to Say

- You look awful
- Everything happens for a reason
- Maybe it happened for the best
- Everyone’s dying. No one knows how long they’ll live. You could be hit by a bus tomorrow.
- You’re so brave
- What doesn’t kill you makes you stronger
- God works in mysterious ways
- God doesn’t give you us more than we can handle
What to Say

• Tell me what’s helpful and what’s not
• Tell me if you want to be alone and when you want company
• Tell me what to bring and when to leave
Empathy

- https://www.youtube.com/watch?v=1Evwgu369Jw
Take Care of Yourself

• Cope with your feelings
• Care for your mind and spirit
  – Exercise
  – Connect with others
  – Laugh
  – Journal
  – Watch a movie
Take Care of Yourself

- Communicate with loved one
  - Talking, touching
- Communicate with others
Resources
Our unique **Patient Navigator Program helps guide, support, and inform thousands of cancer patients through every step of their journey.**

**Find Support & Treatment**

Learn about making treatment decisions, coping with side effects, handling financial matters, caregiving, and living well after cancer. The American Cancer Society also has programs and services to help you manage cancer treatment and recovery and find the emotional support you need. And best of all, our help is free.

Watch: Introduction Video
Chicago Area Cancer Support and Resource Centers

The Lurie Cancer Center works closely with support centers that provide opportunities for learning, discussion, and fellowship. These organizations offer resources and guidance for people who are dealing with cancer.

Cancer Resource Centre
Munster, IN
219.836.3349

Cancer Wellness Center
Northbrook, IL & Grayslake, IL
847.509.9595

Cancer Support Center
Homewood, IL & Mokena, IL
708.798.9171

Gilda's Club Chicago
Chicago, IL
312.464.9900

Living Well
Geneva, IL
630.262.1111

Wellness House
Hinsdale, IL
630.323.5150
Fostering Better Communication

By providing a platform for the sharing of information, resources, communication and experiences of those living their final days fully, the vision of Life Matters Media is to create a community for those facing the end of life and for those that care for them. Ultimately, we seek to foster a greater understanding of the capacity that end of life decisions have to nurture the human spirit.

**Stories**
Personal narratives of challenges, decisions and triumphs.

**Medicine**
Clear, concise analysis of research impacting you and your family.

**Experts**
Columnists provide multi-disciplinary expertise to help you plan ahead.

**Newswire**
One-stop, comprehensive aggregate of end of life issues in the media.

---

**Your Guide To The Digital Afterlife**

Protecting your online property and ensuring loved ones can access the digital data and passwords they need is a vital step in comprehensive end of life planning. Here, you’ll find resources to make this process a little easier.

WBEZ’s Director of Digital Content, Tim Akimoff, and attorney Ronette McCarthy advised during Life Matters Media’s “Your Digital Afterlife” program at Revolution Brewing that we all can take the following steps now to secure our online lives: [http://bit.ly/1SCMX2U](http://bit.ly/1SCMX2U)

Thomas Owen, a WGN Web producer, summed up the challenges we face and some solutions in these stories: [http://bit.ly/1cZyrkW](http://bit.ly/1cZyrkW)


---

**What’s New**

**Six Years After ‘Death Panels’ Debate, Medicare To Pay For End Of Life Talks**
By Daniel Gaitan

Medicare plans to reimburse physicians for counseling patients about their end of life care options.

The unexpected change comes nearly six years after similar proposals were dropped from President Obama’s health reform law and inaccurately compared to “death panels” by some conservative politicians, most notably former Alaska Gov. Sarah Palin.

[Read More](http://bit.ly/1LwFAn)
“What lies behind us and what lies before us are tiny matters compared to what lies within us.”

Ralph Waldo Emerson