LIFE LUNG LEARNING

Resources for Persons with Lung Cancer and their Families

University of Chicago Medical Center

THE 3 C's OF CANCER CARE

- Coping
- Communicating
- Connecting

COPING

Ramona Behrendt, LCSW, OSW-C

Coping

"You are in charge of your state of being. You have learned to be exactly the way you are and you have the remarkable human capability to learn to be another way. Choosing ways of thinking, feeling, and doing which contribute to your health pleasures rather than your health problems is the nitty-gritty of being well."

Ronald J. Pion

Coming to Terms with Lung Cancer

 Facing cancer is one of the most difficult challenges a person can experience

- There is no right or wrong way to feel about your diagnosis
- What matters is being able to cope

Definitions

- "Coping" refers to the attitudes and behaviors that you use to maintain your emotional well-being and to adjust to the stresses caused by cancer.
- "Coping strategies" reflects the process of coping and the ways of meeting goals and challenges.

Initial Reactions

- Most people experience a wide range of strong emotions.
- The number and intensity of these emotions can feel overwhelming at first.
- ALL of these feelings are normal and completely justified.

Initial Reactions

 The first reaction many people have after being diagnosed with lung cancer is shock.

 The whirlwind of thoughts and feelings make some people wonder, "Am I losing my mind?"

Roadblocks to Successful Coping

- Denying Your Feelings
 - There is no "right" or "wrong" way to feel about having lung cancer.
 - Trying to pretend you are not scared, sad, or apprehensive (when you are) is far more stressful and detrimental to your well-being than honestly acknowledging your feelings.

Source:

Lung Cancer Caring Ambassadors Program, 2004. Caring Ambassadors.

No one EVER deserves to get lung cancer!

Dr. Jimmie C. Holland's "Do's and Don'ts for Coping with Cancer"

- DON'T believe the old adage that "cancer equals death."
- DON'T blame yourself for causing your cancer.
- DO rely on ways of coping that helped you solve problems and handle crises in the past.
- DO cope with cancer "one day at a time."
- DON'T feel guilty if you cannot keep a positive attitude all the time.
- DON'T suffer in silence.

Dr. Jimmie C. Holland's "Do's and Don'ts for Coping with Cancer"

- DON'T be embarrassed to seek counseling.
- DO use any methods that aid you in getting control over your fears or upset feelings.
- DO find a doctor who lets you ask all your questions and for whom you feel mutual respect and trust.
- DON'T keep your worries or symptoms secret from the person closest to you.
- DO re-explore spiritual and religious beliefs and practices such as prayer that may have helped you in the past.

Dr. Jimmie C. Holland's "Do's and Don'ts for Coping with Cancer"

- DON'T abandon your regular treatment in favor of an alternative or complementary treatment.
- DO keep a personal notebook with all your dates for treatments, laboratory values, X-ray reports, symptoms, and general status.

Source:

Jimmie C. Holland, MD and Sheldon Lewis, 2000. <u>The Human Side of Cancer</u>.

Hope

"To live with hope is a reflection on our attitude and perspective of life. To rebuild our foundation of hope we need the courage to live. How we live and what we do with our lives is our choice and can be within our control subject to fate and good fortune."

Anonymous

Hope

Patients with Hope...

- Live in the present.
- Accept their new problems and attempt to solve them through introspection, understanding, and sharing.
- Set reasonable, achievable goals.
- Consciously try to focus on feelings of love and hope.
- Surround themselves with supportive friends and family members.
- Actively search for ways to help others.

Source:

Ernest H. Rosenbaum, MD and Isadora R. Rosenbaum, MA. "An Essay on Hope"

COMMUNICATING

Sarah Conning, LCSW

Communicating

Do we understand each other?

Communication Breakdowns

- Leaving Things Unspoken
 - Unspoken fears, hopes, or expectations
 - Unspoken values
- Talking Without Understanding
 - Language Barriers
 - OPlaying "telephone"

Communicating with Your Health Care Team

- Bring someone with you.
- Write out a list of questions beforehand; organize your thoughts and mention your top concerns first.
- Write down the answers you get, or have your companion write them down.
- 4. Make sure you understand key treatment recommendations by repeating them back.

What are your communication preferences?

- Ask yourself, "How much do I want to know?" (details or big picture?)
- Do you want your friend or family member to speak for you, or do you prefer to speak for yourself?

Useful Questions in Cancer Care

- What are my treatment options?
 Which option do you recommend?
- What are the benefits of these treatments, and what are the risks?
- How often will I receive treatment, and what side effects should I expect?
- Who should I call if I have questions?

Express Your Concerns

 "I'm really nervous to begin this treatment."

"I'm worried I'll have to stop working."

 "It's hard to talk to my children about what's happening."

Communicating with Loved Ones

- Avoid secrets
- Share feelings
- Appoint a spokesperson if you feel overwhelmed by calls and questions from friends and relatives
- Ask for what you need
- Talk to the children in your life too

Communicating your Wishes

- What is an "Advance Directive"?
 - Communicating your health care choices and preferences before a crisis occurs is an advance directive.
- Advance Directives recognized by Illinois Law:
 - Durable Power of Attorney for Health Care
 - Living Will

Durable Power of Attorney for Health Care

- Ochoose an "Agent":
 - Someone you know and trust and who understands your beliefs and values.
- Talk with your agent:
 - In case your agent ever has to make a difficult health care decision for you in a crisis situation, give that person the gift of knowing your wishes.

Durable Power of Attorney for Health Care

- o Just do it:
 - Fill out the form.
 - Sign and date in the presence of a witness.
 - Make copies for your agent(s), your doctor, and the hospital if you are admitted.
 - Keep the original for yourself.
 - Ask your social worker if you have a question.
- Then relax, knowing you have helped your loved ones and your health care providers by documenting your wishes!

CONNECTING

Trish Parker, LSW

Connecting

Resources to help support persons affected by cancer and their loved ones

Connecting to Resources

- Support
- Information
- Financial Assistance
- Patient Programs
- Supportive Counseling
- Transportation Assistance
- Cancer Resource Center

Support

- What are your existing supports?
 - Significant other, including husband, wife, fiancé, significant other, partner, boyfriend, girlfriend
 - Family member, such as sibling, cousin, aunt, uncle, grandparent, child, adult child
 - Community member or neighbor
 - Co-worker or boss
 - Members of religious or spiritual community
 - Minister or pastor
- What other supports may be available?

Support

- Asking for support
 - Consider the areas where you need support
 - Identify support persons
 - Consider each support person's assets and how they can help you
 - Start small, ask for specific support (ie: ride to appointment, baby-sit kids for 2 hours)

Accepting support

- You are not dependent on others; you are accepting their support.
- Say "thank you" not "no thank you"
- Remember that others have asked you for support. Now it's your turn!

Information

- American Cancer Society
- National Cancer Institute
- Cancer Care
- American Lung Association
- Lung Cancer Alliance

Financial Assistance

- Grant applications
- Co-payment assistance
- Prescription assistance
- Utility company payment programs
- Social Security benefits
- Medicare and Medicaid insurance
- Discounted Lodging

Patient Programs

- Support for Recovery
- Massage Therapy
- Networking Group
- Look Good...Feel Better
- Facing the Mirror with Cancer

Supportive Counseling

- Short-term supportive counseling available with a licensed social worker
- Individual and group programs available in the community
- Cancer Health Alliance (Palatine, Northbrook, Hinsdale, Homewood)
- Gilda's Club (Chicago)
- Value of Support

Transportation Assistance

- American Cancer Society grant for costs associated with treatment appointments
- Cancer Care grant for transportation
- Paratransit available for all patients
- First Transit available to patients with Medicaid card

Cancer Resource Center

- Collaboration with the University of Chicago Hospital, the University of Chicago Cancer Research Center, and your American Cancer Society
- Located on the 1st floor (near 1A)
- Open Monday Friday from 9 am until 5 pm
- Phone #877-824-0660

Cancer Resource Center

- Information about diagnosis, treatments, support, and prevention
- Calendar of upcoming events
- Video and book library
- Relaxation audio recordings
- Wigs for patients with treatment related hair loss
- Internet and printing

Lung Cancer Networking Group

- Opportunity to talk to other persons with lung cancer
- OStarts Wednesday, 12/6 at 12 noon
- •Conference Room in 1D (Radiation)
- oFREE Lunch will be provided!
- oRSVP requested at 773-834-7206

Coping, Communicating, and Connecting

Questions?

THE 3 C'S OF CANCER CARE

Thank you for attending LIFE LUNG LEARNING!