Information and Support for Caregivers

The American Cancer Society and
Congregational Health Ministry Team

September Module

To access this module via the Web,
visit www.cancer.org and
type in congregational health ministry in the search box.

TOPIC: Information and Support for Caregivers

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TOPIC: Information and Support for Caregivers

OVERVIEW

TALKING POINTS

- Everyday living is stressful. When an illness such as cancer disrupts an already full life, the additional stressors may seem overwhelming.
- Caregivers should be attentive to the signs and symptoms of stress they may be experiencing, such as:
  - Sleeplessness or an increased need to sleep;
  - Withdrawal from others;
  - Overeating or loss of appetite;
  - Guilt feelings;
  - A sense of lack of control;
  - Crying easily;
  - Depression;
  - Impatience; and
  - Irritability and anger.
- If a caregiver is experiencing some of these symptoms – tired, angry, or confused in their caregiver role – it does not mean that they are weak, doing a poor job, or being unsympathetic. They are reacting normally to a new role – caring for an ill person.
- Caregivers may display many different emotions. Everyone reacts differently to stress.
- The best way to deal with these emotions is to expect, identify, acknowledge, and talk about these emotions with someone. Talk to a family member, friend, another caregiver, a support group, a health care professional, or a volunteer.

BULLETIN BOX

While supporting someone who is ill, caregivers should try to simplify life. Remember, this job can seem overwhelming. Help is available!

For more information, call 1-800-ACS-2345 or visit www.cancer.org.

RESOURCES

American Cancer Society Web site: www.cancer.org
American Cancer Society phone number: 1-800-ACS-2345
National Cancer Institute Web site: www.cancer.gov
National Cancer Institute phone number: 1-800-4CANCER
Family Caregiver Alliance Web site: www.caregiver.org

Join us for an informative discussion on information and support for caregivers.

Location:

Date: Time:

For more information, contact:

Join Us for an Informative Discussion on Information and Support For Caregivers

Learn about:
Resources for caregivers as they support people with cancer
Caring for the caregiver
Stress reduction tips

Location:

Date:

Time:

For more information, contact:

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SAMPLE NEWSLETTER:

DEALING WITH THE EMOTIONS OF A CAREGIVER

During a caregiving experience, individuals may display many different emotions. Everyone reacts differently under stress.

- The best way to deal with emotions is to expect, identify, acknowledge, and talk about them with someone else. Talking to a family member, friend, another caregiver, a support group, a health care professional, or a volunteer can be very helpful.
- Many caregivers experience the following emotions:
    - Anger – The caregiver should find someone to listen to his/her feelings. They should be encouraged to write their thoughts down. Physical activity may be helpful (walking, swimming, yard work, or pounding a pillow). Releasing and dealing with the anger is important.
    - Guilt and resentment – These feelings are normal. Caregiving interferes with normal activities and routines. The caregiver may feel guilty that he/she can do things that the patient cannot do or may resent the lifestyle changes brought on by the illness. The caregiver may feel guilty if he/she cannot meet all the demands of caregiving. They may resent the fact that they are in a caregiving role and have less time for their own needs.
    - Fear or anxiety – These are common emotions for caregivers and are usually based on unknowns, misconceptions, or a lack of information. Seeking information may reduce these fears. The caregiver should be encouraged to talk with their health care provider and ask any and all questions until they have an understanding of the issue. Record (write or audio tape) the health care provider's comments so they can be shared more completely with other family members.
    - Depression – Caregivers may feel sad, blue, or down during the caregiving experience. It is very normal to have these feeling off and on. However, if these feelings are present most of the time and interfering with sleeping, eating, or decision making, the caregiver may need to seek professional help.
- Three out of four American families experience cancer. In order to deal with the stresses of a life-altering illness and caregiving, it is important that families seek support. Caregivers should make a list of their personal network – family, friends, church members, physicians, nurses, social workers, and volunteer organizations. Listing resources increases a caregiver's control. Encourage caregivers to call local organizations for information and current resources available in their area.

For more information, call the American Cancer Society toll-free at 1-800-ACS-2345 or visit their Web site at www.cancer.org.

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SAMPLE NEWSLETTER:

SUPPORT PROGRAMS EASE THE BURDEN OF CANCER

The time following a cancer diagnosis can be exhausting, emotional, and confusing. The cancer patient—as well as his or her family—may feel overwhelmed by the many choices and responsibilities that come with navigating the cancer experience. When a family member is affected by cancer, the American Cancer Society helps caregivers offer assistance in many ways. These include:

Cancer Information
The American Cancer Society provides cancer information whenever, wherever people need it. Specially trained staff at our free resource line, 1-800-ACS-2345, listen and answer questions 24 hours a day, seven days a week. Volumes of information are available at their Web site, www.cancer.org, where users can also send in questions via email.

Cancer Survivors Network
Cancer Survivors Network is a "virtual" online community created by and for cancer survivors and their families to address their need to connect with others who have been touched by cancer.

Hope Lodge Centers
Located in Kansas City and St. Louis, these centers provide free housing for patients receiving treatment away from home. Guest room programs are also available in other metro areas.

I Can Cope
In this series of educational classes for people with cancer, as well as their families and friends, doctors and other health care professionals provide information, encouragement, and practical tips.

Look Good…Feel Better
This program teaches women undergoing cancer treatments special beauty and appearance techniques to help restore one of their most important resources: self-image.

Man to Man
This self-help prostate cancer program offers community-based group education, discussion, and support to men with prostate cancer in a setting where they can feel comfortable.

Reach to Recovery
In this one-on-one peer support program, trained volunteers who have survived breast cancer respond to individuals concerned about or facing a possible diagnosis, as well as those who are going through a breast cancer diagnosis or treatment.

Road to Recovery
Road to Recovery provides volunteer drivers to transport patients to and from treatment facilities.

For information on these programs in your area, call the American Cancer Society at 1-800-ACS-2345 or visit their Web site at www.cancer.org.

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SAMPLE NEWSLETTER:

BE AN EFFECTIVE CAREGIVER

Caregiving is the most important and challenging job an individual will ever have. Below are some steps that individuals can take to be effective caregivers.

Work and communicate effectively with the patient. Caregivers care for patients who must deal with the physical effects of the disease and medicine, as well as the psychological and social challenges of living with cancer. Support for the cancer patient includes efforts to:

- Create a climate that encourages and supports sharing feelings.
- Understand that men and women often communicate in different ways and make allowance for those differences.
- Help the patient to deal with anxiety and depression.
- Let the patient make as many of his/her own decisions as possible.

Support the patient's spiritual concerns. Spiritual concerns raise fundamental questions about life. Why are we here? Why me? What is a good life? What happens after death? A caregiver can support the patient in thinking about his/her own answers to these questions.

Work with health professionals. Here are some practical suggestions to keep in mind when a caregiver needs information and help from health professionals:

- Be clear about what is wanted and get to the point as soon as possible.
- Have all the information that health professionals may need ready when a call is made.
- Write down the answers.
- Be firm and straightforward about getting the information and the help that is needed.

Work with family and friends. Caregivers should not try to do everything themselves. They should ask for help. Others may want to help but need to be told how. It is important to be clear with these helpers about what they could do to be helpful, as well as the limits of what is expected of them. Friends and family can go grocery shopping, pick up children at school, etc.

Take care of your own needs and feelings. Caregivers need to be at their best if they are to provide the best care. Caregivers must pay attention to their own needs as well as those of the person they are helping if they are to be effective. Caregivers should set limits on what can be reasonably expected of them. They should take time off to care for themselves and ask for help before stress builds.

- Try not to make important decisions while upset.
- Talk over important problems with others.
- Get away from the situation for a while.
- Learn as much as possible about what is happening and what may happen in the future.
- Do not expect perfection.
- Do not dwell on mistakes.

For information on these programs in your area, call the American Cancer Society at 1-800-ACS-2345 or visit their Web site at www.cancer.org.

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FACT SHEET

- A cancer caregiver is an individual who has a personal connection and commitment to someone with cancer and provides care outside of a hospital setting.
- More than 1.3 million new cases of cancer are expected to be diagnosed this year. At least an equal number of family members or loved ones will be introduced to the extremely challenging role of being a cancer caregiver.
- According to an Ortho Biotech study published in the Journal of Family Nursing (November 1998, vol. 4, issue 4), the following profile describes American cancer caregivers:
  - 82 percent are female.
  - 71 percent are married.
  - 61 percent have been providing care for less than six months.
  - 54 percent live with the patient for whom they are caring.
  - 47 percent are more than 50 years old.
  - 36 percent reported caregiving took more than 40 hours of time per week.
- In addition to conducting daily tasks, such as preparing meals, cleaning, and providing transportation, caregivers virtually become an extension of the cancer treatment team by frequently talking to health care providers, administering medication, and assessing treatment. Unfortunately, this busy schedule often does not leave time for cancer caregivers to take care of their own needs.
- Consequences of cancer caregiving:
  - Physical
    - 70 percent reported taking between one and 10 medications per day.
    - 62 percent said their own health is suffering as a result of caregiving.
    - 25 percent reported having significant physical limitations of their own.
  - Emotional
    - 85 percent reported they resent having to provide care.
    - 70 percent said their families are not working well together.
    - 54 percent visit friends and family less since assuming their caregiving role.
    - 35 percent said they are overwhelmed by their caregiving role.
  - However,
    - 97 percent said their roles are important.
    - 81 percent stated they want to provide care and could not live with themselves if they did not assume caregiving responsibilities.
    - 67 percent said they enjoy providing care.
  - Financial
    - 46 percent reported inadequate financial resources.
    - Caregivers frequently miss as many workdays as those patients for whom they are caring.
- Evidence shows that community-based education and support for caregivers may help relieve the stresses associated with providing care for a loved one with cancer. Caregivers who participate in such programs report significant increases in the degree to which they feel informed about and confident in their ability to provide care.

For more information, call the American Cancer Society at 1-800-ACS-2345 or visit their Web site at www.cancer.org.

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INFORMATION SHEET:

HOW CAN I HELP?

Caregivers need to use the resources available to them. When people ask, "How can I help?", caregivers need to use that opportunity. Caregivers should identify opportunities that friends can help with. This list may include:

- Running errands – drive to a doctor appointment or pick up medicine, groceries, and/or items at the cleaners.
- Providing meals – to be eaten now or put in the freezer for later.
- Visits to provide relief for the caregiver. Sit with the patient for a 20-minute break or stay all night with the patient so the caregiver can sleep.
- Doing laundry at the patient's home or their home.
- Providing lawn care or snow removal.
- Transporting children to school or activities.
- Cleaning the house – vacuum, wash dishes, mop floor, etc.
- Spending time with the caregiver away from the patient so the caregiver can talk and relax.

For more information, call the American Cancer Society at 1-800-ACS-2345 or visit their Web site at www.cancer.org.

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INFORMATION SHEET:

TALKING TO YOUR DOCTOR ABOUT CANCER-RELATED PAIN

About one-third of patients being treated for cancer have pain. More than two-thirds of patients with advanced cancer (cancer that has spread or recurred) have pain. For these patients, controlling pain and managing symptoms are important goals of treatment.

Pain affects all aspects of quality of life. Patients who have chronic pain may not be able to participate in their regular activities as much; may have sleeping and eating problems; and may be frustrated that family and friends do not always understand how they feel.

Caregivers can assist the cancer patient in advocating for good pain management. Providing support by listening and understanding are important to the patient and caregiver, as well. Each patient is unique, their pain is real, and they deserve as much pain relief as possible.

Cancer pain is a common problem, but it is one that the cancer care team can treat. The team often includes a social worker, psychologist, oncology nurse, pastor, psychiatrist, medical oncologist, surgeon, and anesthesiologist. Questions to ask your doctor and pain management team include:

- What can be done to relieve the pain?
- What can be done if the medicine doesn't work?
- What other options are available for pain control?
- Will the pain medicines have side effects?
- What can be done to manage the side effects?
- Will the treatment limit activities such as working, driving, etc.?

It is important that patients make informed decisions related to their pain management. Caregivers often help ensure that patients receive the necessary information and understand it so that the best decision for the individual patient may be made.

For more information about healthy living, contact the American Cancer Society at 1-800-ACS-2345 or visit their Web site at www.cancer.org.

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INFORMATION SHEET:

ARE YOU DEPRESSED?
TAKE OUR CAREGIVERS AT RISK FOR DEPRESSION QUIZ

When someone is diagnosed with cancer, the patient is not the only one affected. The person responsible for care is also affected. Providing care for a loved one with cancer can be very demanding. When caregivers don't attend to their own needs and allow other pressures to take over, they may become depressed and lose the ability to continue to care for their loved one.

Spotting depression as soon as possible can stop a downward spiral of sadness and inability to function. Many successful ways of treating depression are now available to help people regain joy, hope, and the ability to cope.

Do you know the signs and symptoms of depression? Take our quiz to find out how you're doing.

Check Yes or No next to each question.

Yes	No	
☐	☐	Do you feel sad or "empty" almost every day for most of the day?
☐	☐	Do your days bring little or no pleasure?
☐	☐	Are you either too restless or slowed down most of the time?
☐	☐	Do you have trouble making decisions or have problems concentrating?
☐	☐	Have you lost interest in eating or are you overeating? Have you gained or lost weight without dieting?
☐	☐	Do you have trouble sleeping, wake up early, or find yourself oversleeping?
☐	☐	Do you feel many aches and pains that don't go away?
☐	☐	Have you lost interest in sex?
☐	☐	Do you cry often?
☐	☐	Do you feel tired or a lack of energy almost every day?
☐	☐	Have you ever attempted suicide?

0 – 4 "Yes" answers: You may be at risk for becoming depressed. Therefore, you may want more information about managing caregiver responsibilities, including how to talk about cancer and how to find a support group. Call the American Cancer Society's Cancer Survivors Network, 1-877-333-HOPE, where you can trade information and experiences with other patients and caregivers.

5 or more "Yes" answers: You may have some signs of depression. If these symptoms last for two weeks or longer, or are severe enough to interfere with normal day-to-day life, see a doctor or mental health professional to be checked for depression.

For more information about healthy living, contact the American Cancer Society at 1-800-ACS-2345 or visit their Web site at www.cancer.org.

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SUGGESTED MATERIAL

Title:	Caring for the Patient with Cancer at Home – A Guide for Patients and Families
Description:	Provides information on over 50 topics covering signs and symptoms; what to look for; when to call the doctor; and other handy tips.
Order#:	4656.00
Cost:	$0.63
Quantity:	Banded in 1

Title:	After Diagnosis – A Guide for Patients and Families
Description:	Provides general information patients and their families need to know after a cancer diagnosis.
Order #:	9440.00
Cost:	$0.23
Quantity:	Banded in 25

Title:	Cancer Pain – Treatment Guidelines for Patients
Description:	Presents information on the way pain is treated at the nation's leading cancer centers.
Order #:	9498.00
Cost:	$0.297
Quantity:	Banded in 25

To order, call your American Cancer Society at 1-800-ACS-2345.

Other References:
National Cancer Institute Web site: www.cancer.gov
National Cancer Institute phone number: 1-800-4CANCER
www.caregiving.com

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SPEAKER'S NOTES FOR PRESENTATION

Slide 1: Welcome to this presentation on Information and Support for Caregivers. My name is _____. I appreciate the opportunity to share this information with you and hope that you will find it useful.

Slide 2: none

Slide 3: The following is a list of tips to help combat the fatigue caregivers face. It is important to maintain your health and well-being so that you can provide the best possible care to your loved one.

Slide 4: Some people respond to stress with a loss of appetite; some eat anything in sight. We may not be able to sleep in spite of our physical tiredness, or we may want to sleep all the time. Be aware of changes in behavior. Stress is exhibited individually and a change in behavior may be the outward expression of the stress.

Slide 5: Take care of your physical being.

Slide 6: none

Slide 7: Take care of your emotional and spiritual being.

Slide 8: Twenty-four hours a day is all we get. It was meant to be enough time, so try some of these tips.

Slide 9: none

Slide 10: none

Slide 11: Activities that are meaningful and pleasurable to caregivers help renew their energy for another day.

Slide 12: How often do friends and family extend an offer to help? Caregivers should accept such offers and have a plan for how to use that help.

Slide 13: none

Slide 14: none

Slide 15: none

Slide 16: none