# Support for Patients and Caregivers



- Community members
- Staff of Indian health programs, including Community Health Representatives

#### <u>Contents of</u> <u>Learning Module:</u>

- Instructor's Guide with Pre/Post Self-Assessment
- PowerPoint presentation
- Glossary
- References

#### Lenath:

- Introduction of session/module overview (:05)
- Pre self-assessment (:07)
- Presentation of module including interactive activity (:30)
- Post self-

#### Goals

In this session, participants will gain an understanding of the psychological and social issues that affect cancer patients and their caregivers.

#### **Objectives**

At the completion of Learning Module 5, participants will be able to demonstrate the following:

#### Section 1

- a) Describe two emotions a cancer patient might experience after diagnosis.
- b) Describe two ways to provide support to a patient facing cancer.
- c) Describe two ways that make caregiving less stressful.

#### Section 2

a) Give two examples of how cancer survivors bring a sense of balance back into their lives after cancer treatment

#### **Measures of Objective Accomplishment**

The presenter will administer a pre self-assessment and a post self-assessment to measure participants' knowledge of the module's objectives. The pre selfassessment measures existing knowledge and the post self-assessment measures what was gained through the

#### NOTE

- Each major learning point is clearly identified by **boldface** type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in bold italics throughout the module.

#### **Pre/Post Self-Assessment**

#### **Support for Patients and Caregivers**

Do you agree (A) or disagree (D) with these statements, or are you not sure (NS)? Circle Choice A, D, or NS.

1.	A	D	NS	Feelings of denial, anger, stress, and anxiety are common for a person who has just been diagnosed with cancer.
2.	A	D	NS	Cancer is a disease that is best faced alone.
3.	A	D	NS	Sharing stories of survival is an important part of the healing process.
4.	A	D	NS	People who provide care for cancer patients may need periodic breaks to maintain their own emotional and physical health.
5.	A	D	NS	It is important for caregivers to put their emotions aside while caring for cancer patients.

#### Section 1

## Coping with the Cancer Diagnosis How to be Supportive



#### Coping with Feelings after the Diagnosis

The first few weeks after the diagnosis are often the most emotional time of the entire cancer experience. Feelings change rapidly from day to day or even hour to hour. A person may feel denial, anger, stress, and anxiety. At times people with cancer and the people closest to them may also feel depressed, guilty, or lonely. People who have faced cancer say that these intense feelings don't last long. After a time of adjustment to the diagnosis, most people are able to move on and look forward to healing. It is important to remember that more and more people are surviving cancer and living many years beyond their diagnosis.

#### <u>Tips for Helping Someone Face a Cancer Diagnosis</u>

Don't avoid me. Be the friend, the loved one you've always been.

Treat me like you always have. Be there for me as you've always been.

Touch me. A simple squeeze of my hand can tell me you still care.

Take care of my children for me. I need a little time to be alone with my loved one. My children may also need a little vacation from my illness.

Weep with me when I weep. Laugh with me when I laugh. Don't be afraid to share this with me.

Help my family. I am sick, but they may be suffering. Offer to stay with me to give my loved ones a break. Invite them out. Take them for outings.

Let's talk about it. Find out if I need to talk about my illness by asking me: "Do you feel like talking about it?"

Don't feel we always have to talk. We can sit silently together.

Don't tell me not to worry.

Bring me a positive attitude. It's catching!

Hope is important to me. Help me plan for the future.

(Adapted from Taking Time, NIH publication #98-2059, April 1999)



#### Sources of Support

No one needs to face cancer alone. Many people can help provide a cancer patient with emotional, spiritual, and practical support. They include family members, friends, other cancer patients, community members, and health providers. For many American Indians and Alaska Natives (AI/AN) traditional healers are also an important part of supportive care. Traditional healers may conduct ceremonies for patients and their loved ones. These ceremonies may help individuals express their feelings and increase the bonds of support between those affected by the diagnosis. Many AI/AN are also active in formal religious organizations. These organizations may serve as a source of support for both the patient and the family. In addition to offering special prayers for recovery, some churches may provide services such as meal preparation and house cleaning.

People facing cancer who receive support during their illness may find that they are often better able to cope with their problems. Many speak of how the support of other people cheered them and improved their outlook on life. Those who help also benefit. Having the chance to help with practical things can help put others at ease, and make them feel good about being able to do something meaningful.



#### Suggestions to make caregiving less stressful

People who provide care may need periodic breaks from caring for their loved one to take care of themselves both emotionally and physically. Offering caregivers regular relief from daily responsibilities can help them avoid overwork and burnout. Caregivers need to be realistic about their limits. Ease into helping and don't try to do everything at once. This will lessen the chance of becoming overworked and stressed. Attending a support group and talking to other caregivers can be helpful. Sharing emotions by trusting and talking to family and friends and making time for yourself is also important. Finding volunteers, community resources, or

#### Section 2

## Life after Cancer Treatment— On the Path to Recovery



**Facing a cancer diagnosis and surviving cancer treatment may** be the greatest challenge a person will face in their lifetime. It is an important time during which many individuals work through their own personal feelings about death and how they may want to live the rest of their life. Some cancer survivors use the time after treatment to evaluate the way they have been living and make changes to live a healthier, less stressful lifestyle.

Attaining and maintaining balance becomes an important part of recovery. Some people may find it easy to bring a sense of balance back into their lives by returning to work and getting back into a routine. Choosing activities that provide a sense of purpose may also be helpful. Having fun and spending time with family and friends is important. It is important to remember that energy levels may be low after treatment, and recognizing physical limitations will prevent becoming overly tired. Getting enough rest is important for keeping physical and emotional defenses strong.

Some people say that putting their lives in order makes them less fearful of cancer returning. Setting a daily schedule, being a participant in health care decisions, keeping appointments, and making lifestyle changes are among the things a cancer survivor can control.

Some cancer survivors become active in their community after recovery from treatment. Getting involved in cancer-related activities is like a two-way street. When survivors help others, they also help themselves.





## Some Benefits of Getting Involved in Cancer-related Activities

- · More acceptance and less fear of cancer.
- Meeting other people who share the same kind of experiences.
- · Making a positive difference in other people's lives.
- · Teaching others about cancer.
- · Discovering a new life path following the cancer experience.

(Adapted from the Facing Forward Series: Life After Cancer Treatment, NIH Publication No. 02-2424, April 2002; and Ways You Can Make a Difference in Cancer, NIH Publication No. 02-5088, June 2002)

#### Instructor's Notes



## **Resources for Cancer Survivors and their Families**

A comprehensive listing of resources that address general survivorship issues, (i.e., employment, financial concerns, assistance obtaining medications, health insurance), and survivorship issues related to specific cancers, are located in the two Facing Forward Series books (NCI) that are included with this curriculum.

#### References

National Cancer Institute (2002). Facing Forward Series: Life after cancer treatment (NIH Publication No. 022424).

National Cancer Institute (2002). Facing Forward Series: Ways you can make a difference in cancer (NIH Publication No. 02-5088).

National Cancer Institute (1999). Taking Time – Support for people with cancer and the people who care about them (NIH Publication No. 98-2059).

#### Please Note—



3 Use the Curriculum/Training Evaluation located in the Evaluation section, to get valuable participant feedback.



3 The Health Change Checklist, located in the Evaluation section, directs the participants new attitudes towards new actions and may be used as a take home exercise.



3 Please Complete the "Trainer Activity Report" in the Evaluation section of the curriculum. Your feedback allows us to track usage of the curriculum for reporting purposes and ensures you receive any updates to the material.

We look forward to hearing from you. Thank You.

