

**The Cancer Survival Toolbox[®]:
The First Step to Cancer Survival[™]**



Training Manual for Group Facilitators

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Welcome Letter

We are very pleased that you are interested in learning how to teach the skills of ***The Cancer Survival Toolbox®***. This self-advocacy training program was developed through a unique collaboration among three oncology professional organizations: The National Coalition for Cancer Survivorship (NCCS), the Association of Oncology Social Work (AOSW), the Oncology Nursing Society (ONS), and later, the National Association of Social Workers (NASW).

It is our hope that your training and your use of this manual will help enhance the lives of cancer survivors through providing self-advocacy skills training to them. The manual that follows provides detailed information on conducting skills-building groups and offers suggestions for group activities and for promoting your group. All of the material that follows is copyrighted material. You are free to download handouts, exercises and content from this website, but we ask that you abide by the following provisions.

- *Use the manual to conduct an interactive skill-building group for cancer survivors and those touched by cancer.*
- *Assist the Toolbox development team with the evaluation of the Toolbox by providing data from the evaluation included in the manual.*
- *Help make this training available to others by distributing brochures and information about the free Cancer Survival Toolbox to individuals and organizations in your local community.*
- *Tell at least two colleagues about the Toolbox and this training manual.*

Welcome to the Cancer Survival Toolbox team. Included in this manual, you will find step-by-step guidelines and materials to assist you in planning, marketing, conducting and evaluating groups to teach essential self-advocacy skills for survivors. Along with these, you will also find master copies of handouts, flyers, press release information and certificates of attendance, which you may reproduce and distribute in your groups. We thank you for your efforts and hope you find this Manual and the Cancer Survival Toolbox helpful.

Sincerely,

The Cancer Survival Toolbox Development Team

Introduction to Self-Advocacy and the Cancer Survival Toolbox®

Advocacy is not just about activism, and is not only for those who are energetic, vocal and assertive. It begins at a very personal level. Self-advocacy includes the ability to understand information, to find appropriate resources and therapy, to get second and third opinions, and to make informed choices about treatment, including no treatment.

A major challenge, then, is to educate survivors to access information and resources appropriate to their individual needs, values, and beliefs in order to feel confident they have made the right choices (Leigh, 1994).

What is the Cancer Survival Toolbox?

The ***Cancer Survival Toolbox*** (CST) is an audio program that teaches self-advocacy skills to cancer survivors. The CST is comprised of twelve programs. All of these programs are available free by calling 1-887-TOOLS 4 U or visiting www.canceradvocacy.org/Toolbox.

Programs 1-6 are called the *Basic Skills* set and cover the topics of Communicating, Information seeking, Problem solving, Decision-making, Negotiating and Standing up for Yourself. The *Basic Skills* are also available in Spanish and Chinese. This training manual will also focus on the *Basic Skills* set.

Additional programs available in the CST include:

- Program 7 – First Steps for the Newly Diagnosed
- Program 8 – Topics for Older Persons
- Program 9 – Finding Ways to Pay for Care
- Program 10 – Caring for the Caregiver
- Program 11 – Living Beyond Cancer
- Program 12 – Dying Well – The Final Stage of Survivorship

This training manual is designed to make it possible for cancer survivors to also learn the self-advocacy skills of the ***Cancer Survival Toolbox*** in interactive groups.

Who can benefit from the training provided in the Cancer Survival Toolbox?

The number of people with histories of cancer in the United States is estimated to be about 12 million, according to the National Cancer Institute (NCI, 2008). “From the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor” (Mullan and Hoffman, 1990). According to this definition, used by the National Coalition for Cancer Survivorship (NCCS), each of these individuals is considered a cancer survivor. Self-advocacy training can benefit every cancer survivor as well as the people who care about them. The training can be especially helpful soon after an initial diagnosis of cancer is made, but it can also be helpful to those who have already experienced treatment or recurrence.

Why are self-advocacy skills needed?

The Cancer Survivor's Bill of Rights states:

Survivors have the right to assurance of lifelong medical care, the right to the pursuit of happiness, [including] the right to talk with their families and friends about their cancer experience, if they wish, the right to freedom from stigma, and the right to equal job opportunities and the right to adequate health insurance (Spingarn,1988)

Yet, the literature indicates that many survivors encounter difficulties in communication with family, friends and care providers (Lerman et al, 1993; Northouse & Northouse, 1987, Sheilds,1984; Foley,1995). They report experiencing stigma (Welch-McCaffrey, et al., 1989) discrimination in employment (Hoffman, 1991) and obstacles in accessing health insurance (Calder & Card, 1996; Welch-McCaffrey, et al., 1989; Hoffman, 1991; Leigh, 1994). These continuing difficulties have motivated the growing number of voices from within the survivorship movement and oncology professional organizations identifying the need for advocacy training for survivors (Walsh-Burke & Marcusen, 1999).

“This emerging literature on cancer survivorship suggests that those survivors equipped with a set of coping skills to confront these challenges will experience more positive adaptation to cancer.” (Clark & Stovall, 1996).

How was the Cancer Survival Toolbox developed?

The Cancer Survival Toolbox was developed through a unique collaboration among three oncology organizations: the National Coalition for Cancer Survivorship (NCCS), the Association of Oncology Social Work (AOSW), the Oncology Nursing Society (ONS) and later, the National Association of Social Workers (NASW).

In the early stage of development, NCCS sought assistance from the AOSW and ONS since their members are frequently involved in helping individuals affected by cancer to access care. A development team of three representatives of NCCS, two representatives of AOSW, and two representatives of ONS was established and a joint proposal for an educational grant was submitted to Genentech BioOncology to fund the development of the self-advocacy skills training program. Currently, there are seven development team members representing the four organizations, and the program receives funds from multiple sources.

Establishing the Need

In order to determine the need for the self-advocacy training and the content it would include, the development team used a literature search, focus groups and surveys:

- A literature search was conducted which both supported the need for self-advocacy training and identified important self-advocacy skills. These articles are included in the reference section of the manual.

- Focus groups held at ONS Fall Institute and an intensive workshop on the CST at the AOSW annual conference solicited input from professionals on the content and format of the training program.
- Three surveys were conducted to establish the validity of the training program.
 - The first survey of 569 cancer survivors was conducted in Coping Magazine in the spring of 1998.
 - The second survey was conducted by the Oncology Nursing Society of attendees at The ONS Fall Institute and Annual Conference.
 - A third survey was conducted among members of the Association of Oncology Social Work at its Annual Conference.

A total of 833 oncology nurses and social workers completed the surveys. The results supported the need for the Cancer Survival Toolbox self-advocacy training.

Input from Review Organizations

The CST development team utilized the assistance of more than a dozen review organizations to ensure the relevance and utility of the content of the initial Cancer Survival Toolbox. Some of these review organizations included the Intercultural Cancer Council, The R.A. Bloch Cancer Foundation, the Lymphoma Research Foundation of America, the National Ovarian Cancer Coalition and the Children's Brain Tumor Foundation. As new modules are added, additional stakeholders are asked to provide input.

Group Models

Types of Groups

There are several types of group services provided to individuals and families affected by cancer. One of the most common group models is a **psychoeducational group**. Another common group model for people affected by cancer is a **support group**. A Psychotherapy group is a third, less common, group model for people affected by cancer.

Psychoeducational Groups

A **psychoeducational group** is a group whose primary purpose is to provide education to group members. It is distinguished from a support or therapy group by its purpose and method. While a supportive environment is helpful in facilitating learning, the *main purpose of a psychoeducational group is to provide education*, not emotional support. This differs from a support group. It is very important to be clear with group participants about the purpose of your group. Misunderstanding may create disappointment or frustration. Most psychoeducational groups have a set number of sessions, a predetermined time frame, and a clear agenda for each session with topics to be covered. Most participants benefit from attending all the sessions of a predetermined psychoeducational group, but this may not be necessary, since some participants may be interested only in the content of selected sessions.

This manual will assist you in conducting a psychoeducational group, which will enable participants to learn the self-advocacy skills of the Cancer Survival Toolbox.

Support Groups

A support group's primary purpose is to provide social and emotional support to its members. Many support groups are open to any cancer survivor who wishes to attend. Support groups may be led by trained professionals, such as social workers and nurses, or by peer leaders. The members gain support from sharing their feelings and experiences with others. Learning may take place through this sharing but the members primarily come to the group to receive and provide support, not education. However, some support groups may decide that they would like education on specific topics. They may ask that a group leader provide this education or invite speakers in to present information at one or more of their meetings.

Providing the Cancer Survival Toolbox training in the context of a Support Group

The skill training of the Cancer Survival Toolbox may be requested by a support group in your community. If you provide this training to a support group, it is important to be clear with the group about the purpose of the skills training and establish the timeframe for the sessions in which the training will take place. It is also important that support group members understand and agree to the change in agenda for those group sessions. In this context, many support groups may benefit from the skills training of the Cancer Survival Toolbox.

Theories of Group Development and Facilitation

Group facilitation is informed by a wide body of literature about the development of groups, group dynamics and group facilitation methods. Although psychoeducational and support group facilitators are not necessarily expected to be expert in group theory, it is important to be aware of some basic theories in facilitating successful groups. Section IV addresses facilitation methods.

Group Development

All groups, even time-limited groups such as psychoeducational groups, are thought to go through common stages of development. These stages are conceptualized a bit differently by different group theorists. A common model is that proposed by Tuckman (1965) and correlates with other group theorists, includes the following stages:

- Forming- the initial stage when group members come together and establish a common purpose
- Storming- members of the group may question the guidelines or test the limits of the group
- Norming- guidelines are established for roles and how the group will carry out its purpose
- Performing- the members carry out activities to achieve the goals of the group
- Adjourning- complete task, reduce dependency and terminate

It is helpful for group facilitators to be aware of the stages of group development so they may assist the group in accomplishing its goals or purpose.

Stage I: Forming. Be sure to state or re-state the purpose of the group-learning self-advocacy skills - and let group members know how this will be accomplished. You can share the agenda for each group session and review the skills that will be taught and the ways they will be taught.

Stage II: Storming. As the group leader, you will also need to be aware of any conflicts or confusion expressed by group members and objectively try to help the group move through rough spots. A very effective intervention during these times is to remind the group of its purpose and to ask for, and review the plan for how the group can accomplish its learning goals.

Stage III: Norming. As the group leader, you will need to help the group establish guidelines for how they will conduct the group sessions. Clarifying the role of the facilitator (or leader) is important as well as discussing with the group some guidelines for member behavior. (For example, you may want to state that a certain amount of time will be allotted during the group for discussing examples the group members bring, but encourage group members to be sensitive to others so that all who wish to get a chance to contribute.

Stage IV: Performing. Once the group members are able to identify their common goals, and establish ground rules, they will be able to more fully participate in achieving their learning objectives. They may be excited or anxious about gaining new information and trying new skills. As facilitator, you can sensitively encourage and reinforce attempts by members to practice and share what they are learning.

Stage V: Adjourning. In this stage, having completed their tasks, the group terminates. It is important in this phase to review what has been accomplished and for the facilitator to help group participants say goodbye and move toward independence.

Helping Your Group to Close

Closing or ending is a very important part of every group. It is important to allow time at the end of each group session to summarize what has taken place in the group and identify any issues that need to be addressed in the next meeting. At the final group meeting it is essential to provide the group participants with a time and a method to review what they have learned, to identify how they will get their learning or support needs met in the future, and to say goodbye. There are several effective ways to do this, which are described in the following section.

Refreshments and Socialization

While psychoeducational groups are focused on the tasks of learning, group participants often derive support from the social interaction and exchange that takes place during the group. The relationships that develop among group members and the facilitators are also important to acknowledge. Group members may express their feelings of loss about these relationships ending and it is important for facilitators to help participants acknowledge these feelings. Providing refreshments and a time to acknowledge the importance of social support and interaction is an effective method for completing this aspect of group termination.

Planning for the Future

Many participants in groups express a desire to continue the group even after the planned termination session. This usually is because participants appreciate the social support and learning that has taken place in the group. While it is often unrealistic or unnecessary for the facilitators to continue leading the group, the facilitators can help the group participants identify ways they can have their needs met in the future. Some group members may wish to exchange telephone numbers or addresses to keep in touch with one another after the group ends. Some may even decide to meet for continued exchange of support and information without a designated facilitator.

The final handout for session 6 identifies ways that survivors can be involved in self-advocacy efforts on an individual, community or national level. Survivors can be encouraged to use the resources they have identified in the group to become involved in advocacy organizations where they can continue to exchange information and undertake advocacy activities. They can be reminded of the community resource list that is included in the Cancer Survival Toolbox and encouraged to connect with organizations that provide supportive services and information. Becoming involved in advocacy activities contributes to a sense of empowerment for many survivors and can diminish the natural feelings of loss that can be experienced when a group terminates.

Some group members may appreciate or need a referral to a specific organization in their local community for counseling, support or information.

Certificates of Completion

This manual contains a master copy of a certificate, which can be duplicated and distributed to group members at the final session. An “awards ceremony” or special time allocated to distribute these certificates provides an opportunity for group facilitators and members to express appreciation for each member’s contribution to the group. It also provides an opportunity for the members to express what they accomplished or gained through participating in the group. If you choose not to award certificates, it is still important to include time for the participants to express these thoughts, since this is an important part of the termination process that helps participants manage the feelings of loss they may experience at the end of a group. Ending the group with this is a positive way to help members say goodbye and leave with something to remember.

Marketing Your Group

Marketing is a key element in the success of your group. This involves distributing information about the Cancer Survival Toolbox training groups, through a variety of media, to reach the wide audience of people in your area who could benefit from the training.

Types of Notices to Distribute

Flyers can be mailed or posted where survivors are likely to see them. Sites include community, church, social service and health care organization bulletin boards. A sample flyer is included in this manual. These can be customized to provide information about your organization, the dates, times and meeting places of your program.

Television, radio and newspaper announcements and stories are very important. A sample press release, developed by public relations specialists who worked with the CST development team, is also included in this manual for your use.

Internet bulletin boards are visited by many survivors, and it may be possible to post notices about your group on relevant local web sites.

Who to Contact to Assist you in Marketing your Group

If your agency has a **media relations office**, the personnel can make contact with your local media to arrange for public notices and stories featuring the Toolbox training. The health reporter of your local newspaper or television station is an important contact.

Professional **oncology and survivor organizations** in many communities which have mailing lists and/or newsletters. You can contact them to publicize your group.

The **newsletter editors** of religious organizations, community centers, medical clinics and physicians offices are all contacts who can promote your program.

Existing **cancer support groups and programs** can also be contacted to publicize your self-advocacy training program. The American Cancer Society and the Leukemia & Lymphoma Society and others often have listings in their area offices.

Conducting a Successful Group

Structured Format

The self-advocacy training of the Cancer Survival Toolbox is designed to be provided within a six-session psychoeducational group model, although it can be adapted to fit into an existing psychoeducational or support group. Organizing instruction in the same format of the Toolbox program is an efficient method for conducting the group. This format includes an agenda for each session, learning objectives, exercises and handouts as well as evaluation. Facilitating a successful group involves helping participants stay on task to accomplish their learning objectives. This includes encouraging participants to offer their ideas but also making sure the group begins and ends on time, that each participant has an opportunity to contribute without dominating, and that each agenda item is accomplished in the allotted time.

Interdisciplinary Collaboration

Nurse/Social Work Co-Facilitation Teams

It is suggested that you use a co-facilitation model, if possible, of an oncology nurse/social worker facilitator team. This model has been successfully utilized to conduct other cancer-related groups. Nurse/social worker co-facilitation works well because the co-facilitators bring a breadth of specialized knowledge to the group, as well as experience that prepares them well for the kinds of questions and challenges facing survivors and those who care about them. Nurse/social worker teams have the general knowledge to effectively address group participants' questions and concerns. In addition, nurses have specialized expertise about cancer care and social workers have specialized expertise in group dynamics and individual behavior that is very important in this type of program.

Another advantage is that co-facilitator team can share the responsibilities of planning and implementing the group. You may choose to rotate the lead instructor for each session so that the other can focus on each member's feelings, help clarify and summarize group members' statements and attend to silent or less assertive group members.

Guest Speakers

Inviting in guest instructors can also be helpful. For example, in the information-finding session a librarian or a computer expert can be an excellent instructor and may allow the co-facilitators more time to focus on support issues or assisting those who may need extra help. Another session that lends itself to a guest instructor is the communication session. One group invited a physician to this session. Another group invited a lawyer and an insurance expert to the negotiation session. A cancer survivor who has experience with self-advocacy or who is involved with an advocacy organization can also be an excellent guest speaker.

Multimedia Presentation of Information

The more creative you can be in teaching these skills, the more successful your groups can become. Using printed handouts, hands on computer exercises and role playing experiential methods addresses the varied needs of adult learners.

The CST audio programs are a unique asset to this group training. Utilizing the audio programs in the group, and encouraging group participants to utilize them between groups and following completion of the groups, provides them with a way to reinforce and continue to practice what they have learned.

A Microsoft PowerPoint slide presentation is also available for this manual. This slide presentation can be reproduced in your facility and used to help provide visual aids for your group participants as they learn the material in the Toolbox.

Use of Computers for Session II: Information-seeking, can help participants learn through the experience of exploring the internet and evaluating information they find.

Experiential Exercises

Many people learn new skills best when they have an opportunity to practice them. Participants in the pilot groups for the Cancer Survival Toolbox indicated that experiential exercises helped them to feel more confident in using the new skills they were learning, as well as in applying skills they already had to the new situation of cancer.

In the following section of this manual, information is provided for each group session, which includes experiential exercises. These vary from role play exercises to hands-on exercises that teach participants the computer skills of searching the Internet for information. Few of them require special equipment or materials with the exception of the computer exercises in Session II. Even if your group does not have access to computers during the group session, the handout included for Session II on Finding Information on the Internet can assist participants in using the Internet outside of the group. The other experiential exercises are designed to be completed within the group so that participants can practice new skills. Any of these exercises could also be assigned as homework.

Experiential exercises are an effective adjunct to a lecture and discussion format but often require some encouragement, and perhaps even participation, on the part of the facilitator(s) to engage group participants.

Group Facilitation Skills

Group facilitation skills are important in any group, whether you are conducting a support group or a psychoeducational group. It is important to help all participants to feel welcome through ensuring that each participant has an opportunity to contribute as they feel comfortable. Clearly stating the purpose and objectives as well as agenda for each group session at the outset will help in guiding you and participants through the session and keeping the group on task.

Some common challenges to group facilitators and possible responses

An individual member seems to need a great deal of attention. When an individual issue is raised, it can be referred back to other group members for them to share their ideas or experiences. Questions such as, “Has anyone else experienced a similar situation?” or “Are there suggestions others have that might help us think about how to handle such a situation?” The facilitator can offer to assist them with individual issues following the closing of the group session.

Members have strong emotional reactions to the topic under discussion. It is important to acknowledge expressed emotions and to acknowledge that anger, sadness, frustration, as well as relief, are all common emotional reactions to cancer. It is also important to point out that Session I of the Cancer Survival Toolbox addresses skills for communicating effectively about emotional issues.

The facilitator can then help group participants focus on the skills that can be used to help them cope effectively with the challenges of cancer, such as the communication and problem-solving skills.

Members wish to continue the group after the designated time for ending. Helping groups close is an important facilitation skill. Ending each group session on time is important for both participants and facilitators. If an individual needs more help at the end of a group session, the facilitator can provide assistance to that individual after the closing of the session.

At the conclusion of the six- week group program, the participants may express sadness about ending or express a wish to continue. The facilitator's role is to help the group complete their tasks, review what they have accomplished, take what they learned with them, and say goodbye.

Techniques for termination are included in the Group Models section of this manual.

These include:

- referring members individually for support, counseling or information
- holding a certificate awards ceremony
- providing time for group members to exchange telephone numbers or addresses

Content of the Cancer Survival Toolbox Self-Advocacy Training Sessions

Materials

The following section of this manual outlines agendas and content for the Cancer Survival Toolbox[®] *Basic Skills*. Documents/handouts for your group have also been included. You may reproduce these documents as needed; they have been designed so you can customize them for your group.

Format of Each Session*

The group training is designed to be provided in six two-hour sessions. Included in this manual under each of the Six Sessions are the following:

- **Agenda** (this can be used as a master copy for your group)
- **Learning objectives**
- **Supplies needed for the session**
- **Skills to be covered in the session**
- **Key messages**
- **Exercises to facilitate learning**
- **Handouts**
- **Sections of the Cancer Survival Toolbox Audio Programs** (which you may wish to play in the group)
- **Discussion questions**
- **Evaluation forms for the session** (optional)

* Session 1 also includes the Pre-test and Session 6 the Post-test

AGENDA

1. Welcome and introductions
2. Information gathering (pre-test)
3. Introduction to self-advocacy
4. Introduction to the Cancer Survival Toolbox
5. Communication skills:
 - Being assertive
 - Using "I" messages
 - Active listening
 - Checking the message
 - Expressing feelings
6. Exercises
7. Completing evaluation forms
8. Closing

OVERVIEW

Key Messages

- Communication is important for all the other survival skills
- Good communication takes practice
- Using one or all of the five communication skills can improve communication

Objectives

After completing this session, participants will be able to:

- Discuss the importance of good communication in surviving cancer
- Identify basic communication skills
- Demonstrate the ability to use these communication skills

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session I
- CD Player
- Copies of the Cancer Survival Toolbox Audio program for each participant (These can be bulk ordered by calling 1-888-Tools 4 U)
- Small pads (or several sheets) of paper for each participant
- Pencils for each participant

Handouts

- Communication Skills

Exercises

1. What types of communication are challenging for you?
2. Listening for communication skills
3. Role play

1. Welcome and Introductions

It is important to greet group participants as they arrive for the first session. It is also important to introduce yourself (and co-facilitator, if you have one) after members of the group have gathered. Next, you may want to ask participants to briefly introduce themselves, with their names and why they are interested in learning self-advocacy skills. (Name tags may be helpful)

- ✓ Explain that the purpose of the Cancer Survival Toolbox skill training is to learn self-advocacy skills that are helpful to cancer survivors.
- ✓ Distribute handouts or show slides which review the skills taught in the Cancer Survival Toolbox
- ✓ Distribute Pre-tests

2. Information Gathering (Pre-test)

It is important for group facilitators to gather data to evaluate the impact of programs offered to cancer survivors. This information can then be used to be sure that future needs are met. **Ongoing evaluation is an important part of the Cancer Survival Toolbox training**, so we have included all the tools you will need to evaluate your group. These include the evaluation forms for each group session, along with a pre-test and post-test to measure overall effectiveness. Most participants in educational programs such as the CST expect to be asked about its effectiveness and are willing to provide you with feedback. We ask that you provide the CST development team with data from these evaluations to help us evaluate the effectiveness of this program.

- ✓ The data (in raw form included on the evaluation forms or summary form) can be sent along with the Facilitator Summary Form (in the Evaluating Your Group section) to:

NCCS – Toolbox Evaluation
1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910

Since standard educational methods are being used in this program, it should not be necessary for you to obtain IRB (Investigation Review Board) approval for gathering this type of evaluation data. However, you may want to check with your IRB to be certain.

- ✓ It is important to distribute copies of the Pre-test to, and collect them from, each group member before you begin teaching the content of the Toolbox, just after a brief introduction by the group facilitator(s). It is also important to distribute and collect the Post-test forms prior to closing the final group session (Session 6). Pre-test and Post-test data are very valuable in promoting the usefulness of this type of self-advocacy training in the future. Also included in this manual are evaluation forms for each of the six sessions. You may want to ask participants to complete these in addition to the Pre-test and Post-test.

CANCER SURVIVAL TOOLBOX® PRE-TEST QUESTIONNAIRE

Thank you for answering this brief questionnaire. By answering these questions, you'll help us make this program better for people living with cancer.

Directions: Please answer the following questions and return this form to your group facilitator before you begin learning the skills of the Cancer Survival Toolbox. Each question is followed by a set of numbers that range from 0 to 5. The number "0" represent "not at all" and the number "5" represents "a great deal." Circle the answer that best fits your response to the question. There are no right or wrong answers.

	Not at all				A great deal
Program 1: Communicating					
Be assertive in telling your doctors about your needs?	0	1	2	4	5
Express your feelings?	0	1	2	4	5
Listen to the "I" messages in conversations with your doctors, nurses and social workers?	0	1	2	4	5
Listen actively to conversations with your doctors, nurses, family members and others?	0	1	2	4	5
Program 2: Finding Information					
Find information about your type of cancer?	0	1	2	4	5
Use information about your type of cancer?	0	1	2	4	5
Find information about your cancer treatment?	0	1	2	4	5
Find information about a clinical trial?	0	1	2	4	5
Learn how to use the Internet to find information on cancer?	0	1	2	4	5
Program 3: Making Decisions					
Identify how you prefer to make your decision?	0	1	2	4	5
Find out the benefits of getting a second opinion to help you make decisions?	0	1	2	4	5
Learn how much time you have to make a decision?	0	1	2	4	5
Understand that you are not a cancer statistic?	0	1	2	4	5
Program 4: Solving Problems					
Understand the importance of solving problems in surviving cancer?	0	1	2	4	5
Identify what problem-solving skills are useful when facing a cancer diagnosis?	0	1	2	4	5
Learn the steps in making a problem-solving plan?					
Program 5: Negotiating					
Identify your values?	0	1	2	4	5
Set your own personal limits?	0	1	2	4	5
Set aside your emotions when you negotiate?	0	1	2	4	5
Identify more than one solution to a problem?	0	1	2	4	5
Program 6: Standing Up for Your Rights					
Stand up for your rights regarding cancer?	0	1	2	4	5
Describe what cancer survivorship means?	0	1	2	4	5
Identify yourself as a cancer survivor?	0	1	2	4	5
Regain some control in your life?	0	1	2	4	5
Become your own best advocate?	0	1	2	4	5

Name _____

Address _____

(Please make sure your mailing address is legible)

Are you a cancer survivor? Yes No If not, are you a family member of a cancer survivor? Yes No

Type of cancer _____ Age of diagnosis _____

Ethnic Origin

- Caucasian
- African American
- Hispanic
- Asian
- Native American

Education

- Elementary
- Middle School
- High School
- College
- Graduate School

Age

- 18-30
- 31-45
- 46-60
- Older than 60

Session I: Communicating

Other

3. Introduction to Self-Advocacy

Ellen Stovall, former long-time Executive Director of the National Coalition for Cancer Survivorship (NCCS) and 3-time cancer survivor, delivers the introduction to self-advocacy training on the first Cancer Survival Toolbox audio program. Ellen is an inspiring and articulate speaker, so we suggest that you play the very beginning of the first CST audio program with Ms. Stovall's introduction on it as a way of introducing your group to self-advocacy training.

If you choose not to play the tape and wish to read Ellen's introduction instead, the text follows.

[Ellen Stovall] (From Program I of the Cancer Survival Toolbox)

“Cancer Survivor”

For nearly one and a half million people in the United States who will be diagnosed with cancer this year, that first word is most frightening. To the more than nine million who have already heard that word applied to us, the second word is ever so important. Survivor... a word that represents the strength, courage, and determination to face your worst fears and to move forward.

Hello, my name is Ellen Stovall and I am a cancer survivor. Back in 1971 I was diagnosed with Hodgkin's disease -- a cancer of the lymph nodes. I was one of the fortunate ones who received optimal treatment and quality care. Unfortunately, the disease recurred 12 years after my initial treatment, but again I was able to receive excellent cancer care. My experiences living with, through, and beyond these diagnoses of cancer taught me many things. Probably the most important among them is that each of us can do something to feel in better control during a very frightening time. Even when facing a diagnosis of cancer, we can, with the right tools, take charge of making informed decisions about how we will live our lives.

Since my diagnosis, I have met men and women who have taken their experiences with cancer and turned them into positive actions that help others in their communities deal with this difficult diagnosis. They write, speak, and testify about their lives with cancer. By doing so, they allow others, who may be living alone with this diagnosis, learn how others are surviving. Some of the more impassioned survivors have gone on to become advocates and activists at the national level. In my role as President and CEO of the National Coalition for Cancer Survivorship, I have had the good fortune to meet many of these extraordinary survivors, who, every day, help others find the tools that will help them survive. I am especially fortunate to bring you some of these tools that will assist you as you learn about cancer survivorship. Through an unrestricted educational grant from our sponsors, I am pleased and proud to present The Cancer Survival Toolbox®.

For most of us, cancer is a crisis -- perhaps the most serious crisis we have ever faced. Like me, you were probably scared, confused, and overwhelmed. I was in shock. My whole world was suddenly turned upside down. Like you, I had vitally important decisions to make about my treatment. And, I didn't know where to start or what questions to ask in order to get the best information -- a critical first step after a diagnosis of cancer.

There is good news -- you can do something. Through the numerous resources available to people with cancer today, you can learn how to take charge in this important decision-making stage of your diagnosis. We hope this series of programs can assist you in becoming an expert about your own survivorship, to learn what to expect medically, how to work with the health-care system, and deal

Session I: Communicating

with cancer-related employment, insurance, and personal issues. Millions of us are living proof that you can develop the skills you need to get through this difficult time in your life.

If you are playing the CST audio program, turn it off now.

- ✓ You may want to invite group participants to share their reactions to what Ms. Stovall has said.
- ✓ You may also want to underscore her statement that there are now nearly 12 million survivors in the U.S. today who can join in the survivorship movement and advocate for care.

4. Introduction to the Cancer Survival Toolbox Audio Programs

After your group hears Ellen Stovall's introduction, you may want to:

- ✓ Distribute a copy of the CST audio programs to each participant for them to take home with them. Explain that the tapes can be used to reinforce what they will be learning in the group and that you will be playing sections of the audio program in each session, to help in their learning.
- ✓ Let participants know that the booklet packaged with each audio set contains learning objectives and references for each session as well as appendices that contain useful information.

The Appendices in the Booklet contain:

1. Other suggested Reading Materials
2. Important Telephone Numbers
3. Finding Information on the Internet
4. Laws Pertaining to Health Insurance

- ✓ Suggest that participants may find it helpful to bring their booklets with them to future sessions of the group for easy reference.

5. Communication Skills

These are six skills important in communicating:

BEING ASSERTIVE

Saying what you need to say in ways that make it clear to others that what you have to say is important.

USING "I" MESSAGES

This means making statements with the word "I" in them such as "I think" or "I feel", rather than making statements like "you should".

ACTIVE LISTENING

With this skill you listen to someone carefully and show them you are listening.

CHECK THE MESSAGE

When listening to someone, check with them to make sure that what you heard is what they actually meant.

MATCHING

If your facial expressions or actions send a different message from your words, like smiling when you tell someone you are in pain, people may be confused and not realize how un-comfortable you are.

EXPRESSING YOUR FEELINGS

This means letting others know how you feel, as well as what you think.

6. Experiential Exercises

Exercise 1: What types of communication are challenging for you?

Instructions to Group Participants:

This is a simple exercise to help you think about communication that may be important to you.

1. Take some paper and a pencil and write down all the things you would like to know about your cancer (or if you are a friend or family member of a cancer survivor, the things you would like to know about their cancer). Try not to think about it first -- just write your questions down as they come into your head. Any question that comes up is a good question.

2. When you have finished writing down your questions, look them over. Are there any that you have never asked?

3. Next to these questions, write down the name of someone who you think may be able to help you get the answer. That person could be your doctor, or a clinic nurse, social worker, support group member, home healthcare nurse, hospital educator, librarian, pharmacist or even a family member.

Exercise 2: Listening for communication skills

Instructions to facilitator(s):

Examples of communication are included in the first Toolbox audio program. Play the first example of Teri on Program 1-Communicating.

- ✓ Ask the group participants to discuss their reactions to the communication.
Here are some questions to stimulate discussion:

Q. When Teri was first informed of her cancer diagnosis, she says that she “saw the doctor’s lips moving, but didn’t hear what he was saying.” Have group participants ever experienced anything like this?

Session I: Communicating

Q. The second time Teri went back to see her doctor, she asked a friend to come along and take notes. Is this a strategy any of you have tried? Do you think it might be helpful?

Q. Do group participants have examples they would like to share of communication that was problematic for them?

Exercise 3: Role playing to practice communication

Participants can gain comfort and skill through practicing communication skills. There are two other examples of communication in the first CST program. One is Maria Elena who is having difficulty asking for a second opinion and the other is of the Neva family who are discussing whom to tell about their daughter's cancer diagnosis.

Instructions to facilitator(s):

- ✓ You may want to use these examples from the Toolbox and ask participants to play the roles, or pick examples that they have shared.
- ✓ Ask for volunteers to play the roles in the examples, using the communication skills of active listening. Or, if participants are more comfortable, they can divide into pairs to play the roles of Maria Elena and her doctor and/or the Neva Family.
- ✓ Ask them to practice using the following:
 - Checking the message
 - Using "I" messages
 - Matching verbal to non-verbal
 - Expressing feelings
- ✓ Ask the participants to observe and then write down what they noticed about the communication skills that were used. When the role play is completed, ask everyone to share their observations (including those who enacted the role play) and exchange their thoughts and feelings about using these skills.

7. Evaluating the Session

- ✓ Distribute the Evaluation for Session I. Ask participants to complete them and collect them before the closing.

8. Closing

Review the six communication skills once again and suggest that participants keep these in mind as they go through the next week. Ask them to feel free to bring any examples next week of times they used any of these skills.

Session I: Communicating

Evaluation

Instructions to Participants:

Please circle the response that best represents what you have gained as a result of this program:

1. Has your awareness of the importance of communication skills for cancer survivors increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

2. Has your understanding of communication skills increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

3. Has your confidence in using communication skills increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

4. Has this training session been helpful to you?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

Additional Comments: Please tell us anything else you would like about what you thought of this training session or how you might use what you learned.

Session II: Finding Information

AGENDA

1. Welcome and introductions
2. The importance of information
3. Finding information
4. Computer assisted exercises
5. Completing evaluation forms
6. Closing

OVERVIEW

Key Messages

- Having and understanding the facts can help you care for yourself better, give you self-confidence, reduce anxiety, and help relieve distressing symptoms.
- The need for good information goes on after treatment starts and even after it ends.
- Sometimes it may feel like too much information is coming at you. It is okay to say, “I have what I need right now.”

Objectives

After completing this session, participants will:

- Know how to find information in their community
- Know about information that is available from other sources
- Judge the quality of the information they find about their cancer and its treatment.

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session II
- An audiocassette or CD player
- The booklet that accompanies the Cancer Survival Toolbox

Handouts

- The Community Resource list from the Cancer Survival Toolbox

Exercises

1. Hands-on experience finding information via computers can be a valuable learning tool in this session. If at all possible you may want to schedule this Information-Seeking session at a site that enables learners to actually sit at a personal computer and learn to navigate the Internet. Such sites include the computer lab or patient resource room of your hospital or agency, your local library, or a high school or college computer lab in your community. If you are using one of these locations, be sure to schedule it with the appropriate staff. Other options include bringing a laptop computer to the group (if the group is not too large) or bringing handouts with instructions for computer use.

1. Welcome and Introductions

As the facilitator, greet participants as they arrive and distribute name tags again. If the group is composed of all the same members as the first week, first name introductions are all that will be needed. However, if anyone new has joined the group, reintroduction of everyone with their names and why they came to the series will be helpful.

2. The Importance of Information

You may wish to play the introduction of the Cancer Survival Toolbox audio program, which reviews the importance of finding information. If you do not choose to play the CD, you may want to review the following points with your group.

[Narrator]

We will start off by reviewing the many reasons why good information can be so important to you in helping you get the best treatment and knowing what to expect from the treatment you choose. Then, we'll talk about how to find information, who to ask, and what resources may be available to you in your area. We will also talk about how you should judge good information from information that may not be as good. Finally, we will hear how three cancer survivors faced their challenges, learned to ask important questions, and get the information they needed to make their best choices.

First, let's talk about why good information can be so important to you. Many people feel a sense of panic when their doctor tells them that they have cancer. They might feel a need to rush to make a decision and start treatment as soon as possible. One of the first things to know about cancer is that, most of the time, cancer is NOT an emergency. Almost everyone with a new diagnosis of cancer has time to look for information and make careful, thoughtful decisions. Take time to find the best information and to think it through carefully. Your doctor, nurse, or social worker can give you some guidance on how quickly you will need to make decisions.

Having and understanding the facts can help you care for yourself better, give you self-confidence, reduce anxiety, and help relieve distressing symptoms. Most people with cancer, and their family members, want to be involved in their care, and to be true partners with the health-care team. To become involved you need to understand the information you find. In many ways, this is like learning a new language -- we could call it the "language of cancer." Information lets you and your family members take your rightful roles as partners on the health-care team. Let's hear what Joan, an oncology nurse, says about how information can be important to you.

If you are playing the audio program, you may wish to stop it here and ask group participants the sources of information they have already identified or used which have been helpful.

3. Finding Information

Cancer Professionals

Doctors are usually the first to talk with new cancer survivors about treatment options, to give information about how this cancer is treated, and what treatment offers the best opportunity for

Session II: Finding Information

success. The doctor should describe what can be expected as "best" and "worst" case results for your treatment options. Be sure to talk about how to manage side effects of treatment before you choose a treatment plan.

Advances in cancer treatment are the result of new ideas, and so, you may want to keep looking to see what's new for your type of cancer. For example, you might be given the opportunity to take part in a clinical trial, which is a study that compares a new treatment with a standard, or usual, treatment. Medical researchers run clinical trials to find out if new ways of treating cancer are more effective and have fewer side effects than standard cancer treatments. All new treatments must be proven safe in clinical trials before these treatments can be prescribed for people with cancer.

While most survivors receive their first information about their cancer from their physicians, other professionals- nurses, social workers, pharmacists and others along with doctors, are able to provide a wealth of information from many sources. Many hospitals, clinics and physician offices also have resource rooms or information areas where pamphlets, videos and computerized information can be found. One simple telephone call to the right person – a doctor, social worker, nurse, librarian, health educator, or pharmacist who specializes in cancer, or to an experienced cancer survivor, can quickly lead you to helpful sources of information. Local resources combined with the information available through national organizations and the Internet are extremely helpful.

Cancer Organizations

There are a large number of organizations and associations, both locally and nationwide which are excellent sources of information about cancer and treatment. You don't have to go it alone. The CST Resource Book lists valuable telephone numbers. In addition, some cities and regions have private cancer resource centers such as **The Wellness Community** and **CancerCare**.

The American Cancer Society, also called the ACS, has offices located in most medium-sized and big cities throughout the United States. The listing in the telephone book is under "A" for American Cancer Society. The toll-free number for the National Headquarters of ACS is 1-800-ACS-2345

The National Cancer Institute – or NCI -- through its Cancer Information Service provides access to many types of information resources. The NCI has many printed materials that are widely available from treatment facilities' resource libraries, doctors offices and regional offices of the Cancer Information Service. The NCI's toll-free telephone number -- 1-800-4-C-A-N-C-E-R (1-800-422-6237)

The Internet

The Internet offers what seems like endless information -- from research articles, to treatment information, to emotional support. On the Internet, cancer survivors can get information from anywhere in the world, all with the touch of a few keys on a computer at home, in public libraries, health-resource centers, or community centers. Trained librarians and information specialists can help you use these tools if you don't already know how. The information available through the Internet is growing every day.

A word of caution: There is a great deal of very good and helpful information available on the Internet. But, there is a lot of false information, too. The Internet reflects real life, and it is

Session II: Finding Information

important to question your sources. Remember that the most reliable medical information will come from non-profit cancer organizations, research facilities, hospitals, libraries, and government agencies.

For cancer survivors who do not or cannot use the Internet, it is recommended that they ask a friend with Internet access to help out. When it comes to information about medical treatment, anything that is more than two or three years old is likely to be out of date. Even with information that has been published within the last two or three years, you have to find out if this information is still current today.

Many survivors have found that there is a lot of good information *and* a lot of questionable information available about cancer. It's up to you to question how good and reliable the information is, and figure out how much to trust it. To determine the value of a book, tape or magazine article, look at the author's credentials. Does the author seem to be respected among cancer care professionals? Has the book been reviewed by experts or professional groups? Does the book, tape, or article tell you its source of information? Are there conflicts of interest in the publication or sales of the book, tape, or magazine?

4. Experiential Exercises

Using Computers

Identify a site

A public library, elementary school or hospital computer lab, or a local college can all offer computers on which survivors and their family members can learn to use the internet. (If you use a site other than an oncology setting, please leave some extra copies of the Cancer Survival Toolbox brochures for distribution.)

Enlist assistance from Computer or Library Experts

Professionals such as local librarians, computer lab instructors or hospital/community resource personnel can help you teach participants computer search skills effectively. Many of these professionals may be willing to help, as they have a vested interest in learning or sharing the cancer resources of the internet and the Cancer Survival Toolbox.

Practice locating information on the Internet

The Booklet enclosed with the Cancer Survival Toolbox audio programs provides a guide to finding information on the internet as well as some popular web sites for finding information on page 10.

These sites include:

National Coalition for Cancer Survivorship (NCCS) - <http://www.canceradvocacy.org>

American Cancer Society - <http://www.cancer.org>

American Society of Clinical Oncology - <http://www.cancer.net>

The NCCS web site is an excellent first site to visit for survivors. When they navigate to this site they can find information about survivorship programs, read and even listen to the Cancer Survival Toolbox audio transcripts, and link to other sites. We suggest you use this as a starting point in teaching group participants about finding information on the internet.

Session II: Finding Information

5. Evaluating the Session

Once again, it is important to gather data from the group participants about what they learned from the group session. Before closing, ask participants to complete the evaluation form.

6. Closing

It is important to allow time for the group members to gather back together to end the session. People may briefly want to share one source of information they learned about that they have found helpful or that they think they might use in the future. The group can then adjourn.

Session II: Finding Information

Evaluation

Instructions to Participants:

Please circle the response that best represents what you have gained as a result of this program:

1. Has your awareness of the importance of finding good information for increased?

1	2	3	4	5
not at all	a little	somewhat	quite a bit	a great deal

2. Has your knowledge about sources of information increased?

1	2	3	4	5
not at all	a little	somewhat	quite a bit	a great deal

3. Has your confidence about your ability to find information increased?

1	2	3	4	5
not at all	a little	somewhat	quite a bit	a great deal

4. Has this training session been helpful to you?

1	2	3	4	5
not at all	a little	somewhat	quite a bit	a great deal

Additional Comments: Please tell us anything else you would like about what you thought of this training session or how you might use what you learned.

Session III: Making Decisions

AGENDA

1. Welcome and introductions
2. The importance of decision-making for survivors
3. Experiential exercises
 - Identifying your decision-making style
 - Weighing the pros and cons
4. Completing evaluation forms
5. Closing

OVERVIEW

Key Messages

- Each person is an individual, NOT a cancer statistic.
- Different individuals have different decision-making styles.
- A second opinion can be helpful in making decisions.

Objectives

After completing this session, participants will be able to:

- Identify how they prefer to make decisions
- Find out the benefits of getting a second opinion to help make decisions
- Recognize that they may need some time to make decisions;
- Weigh the PROS and CONS in making a decision
 - Understand that every person is an individual, not a cancer statistic.

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session III
- An audiocassette or CD player
- A few sheets of 9x11 paper and pencil for each participant

Handouts

- What is your decision-making style?

Exercises

1. Identify Your Decision-Making Style
2. Weighing the Pros and Cons

Session III: Making Decisions

1. Welcome and Introductions

Greet participants as they enter. Briefly ask returning participants to reintroduce themselves and introduce any new participants. Review the agenda and the learning objectives for this session.

2. The Importance of Decision-making skills

Several survivor voices describe the importance of decision-making to them in the very beginning of the Cancer Survival Toolbox audio program for Session III.

- ✓ We recommend that you play this section of the audio program as a way of introducing the topic of decision-making skills. Or you may choose to introduce the topic yourselves, using points the narrator makes.

[Jim]

The urologist explained my treatment options: surgery to take out the entire prostate or limited surgery with radiation. My wife and I felt like we had to decide on the treatment right away.

I'm used to being in control of my life, taking charge at work and at home. I'm really upset that my cancer has returned, especially because my current treatment options don't seem like they will help me much.

You know, it was kind of tough, but I asked Bob about his cancer. I was so relieved that he wanted to talk about it. And, once I heard how similar his experiences were to mine, I started feeling better.

I recently heard some of my friends talking about the healing effects of what they called complementary and alternative therapies. I searched the Internet for more information, to see if I should give any of these therapies a try.

You may continue the audio program or begin making these points yourself.

[Narrator]

Each day, we all make decisions about our lives. Some of these decisions are fairly easy to make, like what time to get up and what clothing to wear. It takes more time to make other, more important decisions -- about school, marriage, children, finances, and death. These decisions involve other people, either because they will be affected by the decision or because their opinion is important. Sometimes, our freedom to make important life decisions is limited by forces beyond our control, perhaps by health insurance.

And, we all have different abilities for making decisions about our lives. Some people feel they hold the power to decide. Others feel that life is beyond their control and that they have little ability to make any decisions for themselves.

Our ways of making decisions are often shaped by whether we are male or female, our family background, our culture, our education, and our role or station in life. These patterns are powerful

Session III: Making Decisions

shaping forces that influence why and how we make decisions when a crisis or serious illness occurs. For cancer survivors, which means anyone who is living with a diagnosis of cancer, many factors affect the decision-making processes. Let's listen to what Joan, an oncology nurse, has observed in working with many cancer survivors over the years.

[Joan]

When people are faced with a diagnosis of cancer, their abilities to make decisions about even the simplest daily events may be shaken by the very word "cancer." Too often the word "cancer" is wrongly linked with death. For example, think about a time when a family member or friend had to have medical tests. Think about their relief when the tests came back and showed no cancer. Their response might well have been, "Thank goodness it wasn't cancer."

A diagnosis of cancer can paralyze your usual ability to make decisions about your life and health temporarily or even for a long period of time. You may feel overwhelmed, anxious, angry, or at a loss to make any decision. These feelings are common. When faced with decisions about life, health, or death, many people become uncomfortable because of their emotions or fears. You may want to hide from them or you may choose to face them head on.

As you know, making decisions is very hard during an emotional crisis, such as a cancer diagnosis. First there is a new language -- the language of cancer -- to learn and understand. Think for a moment about going to sleep in your own home and waking up in another country where people speak a language very different from your own. Now, think about being in that other country and being faced with decisions about cancer what kind of treatment you need, what you will feel and look like, whether you can go to work, and when you can do the things you used to do. Imagine how frightened and helpless you would feel to wake up in this strange place, having to speak a language you don't know, and needing to make decisions that will affect the rest of your life. Is it any wonder that our emotions and the strange new language of cancer can interfere with making decisions?

If you find yourself in this situation, you don't have to feel out of control. There are skills you can learn to help you make decisions. While these skills will help you make a decision, they will not tell you which decision to make. No one but you can make the best decision for you. In this session, we will go through some skills that can help you make better decisions about your life and your cancer.

Stop the audio program here.

- ✓ Following this introduction, it may be helpful to ask participants whether they have experienced anything like what has been described in relation to decision-making.

3. Experiential Exercises

Exercise 1: Identifying your decision making style

Instructions to group participants:

To help you identify how you make decisions about cancer, review each of the following statements and then choose one that best suits your style:

Session III: Making Decisions

1. I prefer to leave all decisions about my cancer treatment to my doctor.
2. I prefer that my doctor make the final decision about which cancer treatment will be used, but he or she first seriously considers my opinion.
3. I prefer that my doctor and I share responsibility for deciding which cancer treatment is best for me.
4. I prefer to make the final selection of my cancer treatment after seriously considering my doctor's opinion. Or,
5. I prefer to make the final selection about which cancer treatment I will receive.

If you chose statements number 1 or number 2, you prefer that your doctor make decisions for you.

If you chose statement number 3, you prefer a shared style of making decisions with your doctor.

If you chose either statement number 4 or number 5, you prefer to make the decision yourself.

Each of these decision-making styles is neither better nor worse than the others. There are advantages and disadvantages to each. But it can be helpful for you and those who care for you to be aware of your decision-making style and preferences.

- ✓ Discussion Questions: Can you think of any advantages or disadvantages for each style?

Exercise 2: Weighing the Pros and Cons

Instructions for group participants:

In cancer treatment, there may be many decisions to make; like deciding whether to enter a clinical trial or using complementary approaches. It is helpful to start with weighing the pros and cons, that is, the benefits and drawbacks

This is a simple exercise and one that can help you with your decisions. Here's what to do:

1. **Take a sheet of paper and a pencil.**
2. **At the top of the paper, jot down the most important things in your life.**
(They might include your family, your job, your goals, your hopes, or your dreams for the future.)
3. **Now, draw a line down the middle of the sheet of paper.**
4. **Label one side PROS and the other CONS**
5. **On one side, write down the pros (or benefits) of treatment, and on the other side; write down the cons (or disadvantages).**
6. **Look at each of the pros and cons and how they relate to the important things in your life or the dreams that you have yet to fulfill.**

Session III: Making Decisions

7. **Now put the sheet of paper away in a drawer and leave it there for at least a day. In a day or two, take out the sheet of paper, reread it, and think about what you wrote.**
8. **Make any changes in the pros and cons that you feel are needed.**
9. **Finally, think about the decisions you must make in light of your list of pros and cons.**

- ✓ Discussion Questions: Have you successfully used this decision-making strategy for any other situations in your life? If yes, how helpful was it and why? Do you think this might be helpful to you in any decisions you may be making about your cancer?

4. Evaluating the Session

- ✓ Distribute the Evaluation for Session III and ask participants to complete them before the closing. (optional)

5. Closing

Review what has been learned about decision-making skills once again and suggest that participants keep these in mind as they go through the next week. Ask them to feel free to share any examples next week of times they used any of these skills.

Session III: Making Decisions

Evaluation

Instructions to Participants:

Please circle the response that best represents what you have gained as a result of this program:

1. Has your awareness of the importance of decision-making for cancer survivors increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

2. Has your understanding of your decision-making preference increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

3. Has your confidence in your ability to use decision-making skills increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

4. Has this training session been helpful to you?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

Additional Comments: Please tell us anything else you would like about what you thought of this training session or how you might use what you learned.

Session IV: Problem-Solving

**Session IV: Problem-Solving
AGENDA**

1. Welcome and introductions
2. Introduction to problem-solving
3. Steps to problem-solving
4. Managing discouragement
5. Completing evaluation forms
6. Closing

OVERVIEW

Key Messages

- Problem solving involves 5 steps.
- Every problem-solving plan can be modified.
- Get support for your plan from everyone you can.

Objectives

After completing this session, participants will be able to:

- Understand the importance of problem solving in surviving cancer;
- Identify problem solving skills you need when faced with a cancer diagnosis
- Learn the steps for making a problem-solving plan.

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session IV
- An audiocassette or CD player

Handouts:

- The Five Steps of Problem-Solving
- Assessing Depression

Exercises

1. Practicing the steps of problem solving
2. Applying problem solving skills

1. Welcome and Introductions

As the facilitator, greet participants as they arrive and distribute name tags again. If the group is composed of all the same members, first name re-introductions are all that will be needed. However, if anyone new has joined the group, reintroduction of everyone with their names and why they came to the series will be helpful.

2. Introduction to Problem-Solving

You may want to play the introduction to the audio program for session 4 of the Cancer Survival Toolbox. If not, you may want to make the points included in the introduction as follows.

[Tom]

Just when I think I have one problem beat, another problem jumps up at me. So, I tell my doctor that I'm going to need some time to think about this.

[Ellen]

The one problem I had right away was, how to tell my family, friends, and co-workers about my cancer? But, my bigger problem was figuring out how I would be able to take care of my girls if I have to stop working or work less during my chemotherapy.

[Evelina]

After my diagnosis, I wanted to go home to the Philippines and start my faith healing, not this chemotherapy.

[Tom]

We considered each option on its own and talked about how it could affect us and our families, and the other parts of our plan.

[Ellen]

I wrote down a whole list of questions for my doctor, like:

How would chemotherapy help me?

What would happen if I decided not to have it?

How often would my treatments be scheduled?

Where would I have to go to get my treatments?

[Evelina]

Over the next few weeks, I realized that I wasn't going to die from my cancer soon. I started to feel less afraid of chemotherapy. I was ready to talk about the best treatments for me.

Session IV: Problem-Solving

[Narrator]

Today we have more -- and better -- treatments for cancer than ever before. These treatments often result in cure or longer life. At the same time, cancer care has become more complicated, and therefore more confusing for the people who are living with cancer, whom we call cancer survivors. Cancer treatment can put a lot of physical, emotional, and social demands on the survivor. That means that cancer survivors must develop and use their problem solving skills.

Almost every study of cancer survivors shows that people who have the tools to solve their unique problems report more feelings of success, better quality of life, and more sense of control over their lives and treatment. The problems they face include coping with therapy, managing home, work, and treatment, maintaining a good outlook on life, planning for the future, and so forth. To move forward with your life after cancer requires you to solve these kinds of problems. In order to do that, you must have the tools to perform your tasks and reach your goals.

3. Steps of Problem Solving

1. Identify the problem
2. Get the facts
3. Plan your action
4. Carry out your plan
5. Evaluate your plan and make necessary changes

Instructions to Facilitators:

- ✓ Take the time to describe each of the steps and make them understandable to the participants. Let them know that we will take them more slowly with an example.

Using the example of Tom from the audio program, go through each of the problem solving steps. You may play the program now or read the example from the transcript

Tom is 27 years old and comes from Georgia. He has just been diagnosed with testicular cancer. He has been married for two years.

[Tom]

Before my diagnosis, my wife, Mary, and I were making plans to begin our family. After I got my diagnosis, I went to my doctor's office to choose the date for my treatment. As we were talking, he mentioned that, after the treatment, I will probably be sterile -- that I would not be able to have children. This is the first time I heard anything about this. I can't believe it -- just when I think I have one problem beat, another problem jumps up at me. So, I tell my doctor that I'm going to need some time to think about this. I've got to talk this over with Mary.

[Narrator]

As he follows the five steps for problem solving, let's see how Tom handles the problem.

Step 1 – Identify the Problem

He has said what the problem is: treatment for his cancer will probably make it impossible to have children. This completely changes the plans they made to start a family. When Tom goes home and discusses it with Mary, they are careful not to take any action before they really think it through. They ask themselves a number of questions to look at this problem from several different angles: How does Tom see the problem? How does Mary see it? What are their goals? Do they each have different goals? How important are the issues related to the problem and/or their goals? Are there other circumstances, like expectations from each of their families or aspects of their religious beliefs, that could affect the way they see the problem and their goal?

Stop the audio program now and ask the group to discuss the first step of problem solving. Next, play the section of the program that addresses step 2. -Getting the Facts

Step 2 – Getting the Facts

Let's look at Step 2. Get the Facts. After feeling that they have talked about what the problem is, Tom and Mary meet with the doctor to find out about their options and other treatments. They go prepared with a list of questions and take notes during the visit. Tom brings a small tape recorder and tapes what the doctor says. Tom and Mary also look for other experts and sources for information. Tom gets on the Internet. Mary goes to the bookstore and to the Patient Education Department at the hospital. They ask to speak with a social worker who is able to provide resources. The social worker also tells them about a support group that might be helpful. Do you know of any other sources of information for Tom and Mary? They now have a lot of information on several options, including sperm banking, adoption, and treatment alternatives, so they are ready for Step 3 – create a plan and think it through carefully

Stop the audio program now- Have the group discuss the gathering of information. What would they want to know and how would they get it if they were Tom.

Step 3- Make a Plan

You may want to play the section of the audio program in which Tom follows step 3 or read the transcript

[Tom]

We decided to write down our options with the pros and cons for each one. Then, we could choose the one that we think would be best to meet our goal of starting a family. We were also careful to think about the steps we would need to take for each option, the resources we would need, and problems we could face. We considered each option on its own and talked about how it could affect us and our families, and the other parts of our plan. Like the idea of sperm banking, where sperm are stored so that they would be available for in vitro fertilization later on, in case I am sterile after treatment. We asked a lot of questions, like: what steps would we have to take to store sperm and then do in vitro fertilization? Where would we have it done? What would Mary and I have to do to make this work? How successful is this approach? How do each of us feel about it? What does it cost? And, will our insurance cover it?

Stop the audio program.

Session IV: Problem-Solving

Q. What is Tom's plan? Encourage discussion about using some of the decision making skills in step 3.

Resume playing the audio program.

Step 4 - Carrying Out the Plan

Now, Tom and Mary are ready for Step 4 -- carrying out the plan. Feeling confident with their plan and with the support of their doctor, family, friends, and new-found support group, Tom and Mary set out on the plan they have chosen. As they do so, they will need to take Step 5, as well -- that's checking the plan along the way. Tom, Mary, and their doctor track their progress as they move forward.

Step 5 - Evaluating the plan

What questions might they ask themselves to measure their progress? Here are several possible questions to consider:

Q. Did this particular step in the plan go as they thought it would?

Q. Are there issues and factors they did not anticipate?

Q. Do they need to change the plan?

Q. Should they change their goals?

Q. Do they need more information?

Q. Do they need more resources?

After asking any or all of these questions, they may need to make some changes in their plan. They might need to take other steps, either together or individually. As you can see, this approach to solving their problems could create a better outcome. Tom and Mary feel involved throughout the process. They feel they have regained some control. In the end, Tom and Mary are happy with their results.

Stop the audio program here. Now the members of the group can discuss how they feel about steps 4 and 5.

As a facilitator, you need to evaluate whether the group is open to discussing the problem solving, using their own personal examples or, if you should use an additional example from the tape. By taking the steps one at a time, members may feel more comfortable sharing their own personal examples for a certain step only.

It is at this time that a member may bring up a personal example that he/she would like to share for the group's input and direction. Recognize and appreciate the group members for their willingness "to risk" and "to share". As the group discusses, look for opportunities to focus on the steps of problem solving.

The audio program gives two additional examples that you can use to practice and reinforce the steps of problem solving. These are optional for you to use based upon your individual group's needs.

Session IV: Problem-Solving

You may want to give the participants more than one opportunity to practice the steps in the group, using examples from the audio program or those which the participants offer.

4. Dealing with Discouragement

If time permits, this session is a good time to talk about feelings of depression, discouragement or sadness. During the actual carrying out of a plan or treatment, survivors may experience these feelings. This is a time to educate and provide them with some simple warning signs that may indicate a need for more professional assistance.

- ✓ Distribute the handout that has been provided or you may want to distribute other published materials that could be helpful on this subject

Encourage group participants to discuss how they handle feelings. Encourage them to share how they maintain hope and continue normal daily activities.

5. Evaluating the session

Just as in the other group sessions, it is important to distribute the evaluations and ask the participants to complete them before the closing. It is important to express appreciation to the participants for their assistance in completing these forms each week and reinforce how their input will help to insure the helpfulness of future programs.

6. Closing

Summarize the steps of problem solving. Ask for and listen for comments seeking further clarification and understanding. Encourage participants to incorporate the skills they learned in this session. Handouts should include Steps of Problem Solving and Depression handouts. End by reviewing date, time, and location for session 5.

Session IV: Problem-Solving

Evaluation

Instructions to Participants:

Please circle the response that best represents what you have gained as a result of this program:

1. Has your awareness of the importance of problem-solving skills for cancer survivors increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

2. Has your understanding of problem- solving skills increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

3. Has your confidence in using problem-solving skills increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

4. Has this training session been helpful to you?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

Additional Comments: Please tell us anything else you would like about what you thought of this training session or how you might use what you learned.

Session V: Negotiating

Session V: Negotiating

AGENDA

1. Welcome and introductions
2. Introduction to negotiating
3. Negotiation skills
4. Insurance benefits and employee rights
5. Completing evaluation forms
5. Closing

OVERVIEW

Key Messages

- It is important to identify what your needs are after your cancer diagnosis.
- When negotiating anything, it is important to believe that you are an equal to the person you are negotiating with no matter what your background.
- You must be sure that everyone in the negotiation clearly understands what you want to say.
- You must be able to identify and express your values, the principles and standards you live by.
- You must be able to set your personal limits – the boundaries of behavior you will not cross.
- You must be able to recognize and set aside your emotions when negotiating.
- You must be willing to look for more than one solution to any problem.

Objectives

After completing this session, participants will be able to:

- Listen and communicate effectively
- Identify the values that are the principles and standards by which you live
- Set your personal limits-the boundaries of behavior that you will not cross
- Learn to set your emotions aside when negotiating
- Visualize more than one solution to any one problem

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session IV
- An audiocassette or CD player
- Hand held mirrors for each participant

Handouts

- Negotiating skills
- Laws Pertaining to Health Insurance (located in the CST Resource Booklet)

Exercises

1. Therapy Decisions
2. Insurance Benefits and Employee Rights
3. Separating from Emotions
4. Visualizing more than one solution to a problem

1. Introduction to Negotiation

The audio program for session 5 contains the voices of survivors talking about issues that required negotiation skills. You may want to play the introduction of the audio program or describe the scenarios as a way of introducing this session. Another suggestion would be to ask participants to imagine they are Anna, Anthony and Nancy as each part of the tape is played. Have them write down their feelings as they listen imagining that the scenario is happening to them. Use this information when you talk about becoming aware of your feelings and setting aside emotions while negotiating.

[Anna]

I trust my doctor to look out for my best interests. But, I couldn't help feeling disappointed that he didn't think much of a new biologic therapy -- even though he said that he didn't know a lot about it.

Stop the audio program here and allow participants to write down their feelings.

[Anthony]

My doctor's office contacted my insurance company to get approval for the surgery and chemotherapy treatments we talked about. But, the insurance company told him that they will only pay for the surgery. Now what?

Stop the audio program here and allow participants to write down their feelings.

[Nancy]

Before I got cancer, I worked Tuesday through Saturday from 8 in the morning to 4 in the afternoon. After my diagnosis, my cancer doctor said he could give me the drugs as an outpatient in his office -- but that the best time to do so was on Fridays.

Stop the audio program here and allow participants to write down their feelings.

[Narrator]

Cancer survivors, which includes anyone diagnosed with cancer, will need to negotiate about many things with a number of people. Welcome to Program 5 in the Cancer Survival Toolbox, about negotiating. A negotiation is a meeting with two or more people in which they discuss an issue and try to reach an agreement. In this program you will learn basic negotiation skills to help you ask for what you need after your cancer diagnosis. For example, you may have to make new arrangements with your family to handle household chores during treatment. You may need to negotiate a change in your work schedule with your boss. The place or type of treatment may have to be negotiated with your insurance company. Or, you may even negotiate your treatment plan with doctors, a radiation therapy department, or a chemotherapy clinic.

When negotiating anything, it is important to believe that you are an equal to the person you are negotiating with no matter what your background. As Americans, we are proud of our different

Session V: Negotiating

religious, ethnic, and cultural backgrounds. You should be proud of your background and not be embarrassed to openly share these important personal facts about yourself with your health care team. If you feel that your doctors and nurses are not dealing with you in the way that you would like, politely let them know what you expect. Their job is to help you and to make you comfortable. By sharing your wishes, you can help them accomplish those goals.

Several skills will help you be a good negotiator. You must have good communication skills. That means that you need to listen to the information provided to you by other people and then take this information and use it to make your decisions. It also means that you must be sure that everyone in the negotiation clearly understands what you want to tell them. Part of this is identifying and expressing your values, the principles and standards you live by. You must be able to set your personal limits -- the boundaries of behavior you will not cross. And, you must be able to set your emotions aside when negotiating and be willing to look for more than one solution to any problem.

This would be a good time to distribute the handout on negotiation skills. Encourage participants to use the handout to take notes during the session

1. Negotiation Skills

Resume playing the audio program.

[Narrator]

There are five specific action steps you can take to prepare for any negotiation. First, gather the information you think you will need; and, second, use that information to plan an agenda for your negotiation discussions. Third, set limits as to the minimum you would accept as a solution to your needs and what trade-offs you would be willing to make. You need to decide on these before you actually get to the negotiating process. Fourth, listen to your inner voice. And, finally, try to create win-win situations in which you and the people you are negotiating with are satisfied with the outcome. Let's hear how Joan, an oncology nurse, finds these actions valuable in working with cancer survivors.

Stop the audio program here.

Many people find it extremely difficult to negotiate within the context of a cancer diagnosis. The key messages cited above may be new concepts for cancer survivors. Cancer survivors may have difficulty believing they are an equal to their cancer specialist. Yet it is crucial that they believe they are an **equal partner** in the health care team.

Once you have reviewed the key messages with the group, ask each person to briefly state how they feel about these statements. Do they believe they are an equal in any negotiation? Have they ever purchased a new car? Did they feel equal to the car salesman in that negotiation? Are they able to recognize their emotional response to a given situation while they are having that emotion? Can they name one of their core values? Can they identify a personal limit – something they would not agree to do under any circumstances?

Play the audio program now.

Negotiation Exercise 1: Therapy Decisions

Let's use the example of Anna in the tape to illustrate the steps in the negotiation process. Anna has read about a new therapy that she feels would be of benefit in treating her lymphoma. Her doctor is reluctant to try this therapy. Let's listen to the tape and see Anna uses the negotiation skills on the handout.

[Anna]

I read a lot about a new treatment, called biologic therapy, that seems like a good option for my type of cancer, non-Hodgkin's lymphoma. So, at my next appointment with my cancer doctor, I asked him about the treatment. He said that he didn't know a lot about biologic therapy. But, from what he did know, he didn't think that it might help me. And besides, he said he doesn't feel comfortable with new treatments until doctors have been using them for some time. I trust my doctor to look out for my best interests, but I couldn't help feeling disappointed with his response. I thought this new treatment might be worth a try.

Stop the audio program here.

From this part of the tape we can see that **the issue for negotiation** is going to be the type of treatment Anna will receive. We know that she is ***feeling disappointed*** with her doctor's response, although she also ***feels trust*** that her doctor has her best interests in mind. Her doctor does not ***feel comfortable with new treatments*** until they have been used for some time. We also know that her doctor does not know a lot about biologic therapy. These are all important pieces of information to keep in mind when Anna is planning the negotiation.

Resume the audio program.

[Anna]

I decided to get more information about biologic therapy on my own and then see if I could convince my doctor to consider it. I went to the library and read through current magazines and health sections of newspapers. I found out which company makes the drug used in the treatment. I even got the names of research doctors who have used this drug and think it is worthwhile. I also found an article about a doctor who works in a hospital in a nearby city who has used the treatment for my type of cancer. I copied the story and made an appointment with my own cancer doctor to see if he could refer me to this other doctor.

Stop the audio program here.

Anna has **gathered information from current sources** to use in her negotiation with her doctor. Using the fact that her doctor does not feel comfortable with new treatments until they have been used for some time, she obtained the names of doctors who used the drug and found it worthwhile. She found out about a local doctor who has used the treatment for her type of cancer. Her **agenda** for her next meeting with her doctor is to get a referral from him to see the local doctor who is using the treatment for her type of cancer.

Resume the audio program.

[Anna]

My cancer doctor was surprised and impressed by my ability to find good information. But, he was still skeptical. He also asked an important question; would my insurance company pay for a second opinion that involves biologic therapy? So, I left his office this time feeling disappointed, and somewhat discouraged.

But, that wasn't going to stop me. The next day, I called my insurance company. I found out that the other doctor is part of my company's plan. But, I would have to get a referral from my own cancer doctor in order for the insurance to cover a visit to the other doctor.

I felt like I was going around in circles. I brought my problem up at my next support group meeting to see what other people said. A man in the group, who had a similar experience, suggested that I ask the doctors to arrange a telephone meeting. He also recommended that I collect all the information I can from the most reliable and up-to-date sources possible that support biologic therapy and give it to my cancer doctor before he talks with the other doctor.

Stop the audio program.

Sometimes, in the negotiation process, you have to go back to the beginning before you can get to the end. Anna goes back to her doctor thinking she has enough information to get her doctor to agree to a referral to the doctor who is using biologic therapy for her cancer. Instead, her doctor introduces a new problem into the negotiation process. Will Anna's insurance pay for the second opinion about biologic therapy? Now, Anna must go back to step one. She must gather the information from her insurance company about coverage for the second opinion she wants. When she contacts the insurance company, she can make use of the information she has already obtained for her meeting with her own doctor. She has information from current sources about the use of biologic therapy for her type of cancer. If needed, she can give this information to the insurance company.

When she calls the insurance company, Anna obtains the information that the insurance will pay for the second opinion if her own doctor makes the referral.

Anna is also aware of her feelings. She is disappointed, discouraged and frustrated, feeling like she is going around in circles. She asks her support group for their help and gains some additional information from a man in the group. He suggests giving her doctor copies of all the information about biologic therapy she collects from reliable, up-to-date sources. He also suggests that the two doctors talk on the telephone.

The **agenda** for Anna's next meeting with her doctor might look something like this:

- Remind her doctor of her interest in biologic therapy and what they talked about at her last appointment.
- Tell her doctor that she called the insurance company and they will pay for the second opinion if he will make the referral.

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- Give her doctor the information that she has collected about biologic therapy.
- Give her doctor the name and phone number of the doctor she wants to see for a second opinion and ask him if he would be willing to talk to this doctor on the telephone.
- Ask her doctor to give her a referral for the second opinion.

The items on the agenda are set up in the order of Anna's comfort in discussing them. She is very comfortable reminding her doctor of what they talked about at her last appointment. If her doctor remembers something they talked about that Anna has not mentioned, he might remind her about it. Telling her doctor about her successful call to the insurance company will boost her confidence so that she can then move on to the next step. After giving her doctor the information she collected, Anna will ask her doctor to do two things for her: talk to the second doctor on the telephone, and give her a referral for a second opinion with the second doctor.

Anna has few **limits in this negotiation**. If her doctor is still not willing to give her a referral and is also not willing to talk to the second doctor on the telephone, there are some things Anna can do. Remember that there is always more than one way to solve a problem.

Anna can tell the doctor that she feels he has her best interest in mind, and needs to know why he is still not willing to find out more information about biologic therapy for her cancer. She can ask him if he thinks it will be harmful for her to take this treatment. These questions will help Anna to **understand her doctor's feelings and thoughts about the issue they are negotiating**. It is important to ask these questions calmly, **without letting anger, frustration or disappointment enter the discussion**. Be aware of your emotions, your inner voice, but don't let it enter the discussion.

Resume the audio program.

[Anna]

I took his advice and it worked. My cancer doctor knew some of the names I collected of research doctors who support biologic therapy. In fact, they are people he really respects. So, he called the other doctor to get a sense of how he would handle my treatment. The next day, my cancer doctor called me to say, that though he's still somewhat skeptical, he would give me a referral to see the other doctor.

Stop the audio program.

Anna has completed a successful negotiation. She asked her cancer doctor about a new treatment. Her cancer doctor did not want to use this treatment for Anna's type of cancer. Anna gathered information to help convince her doctor that this treatment might help her. She planned an agenda for a second meeting with her doctor, gathered more information about the new treatment and was aware of her feelings about what her own doctor said to her in their first meeting. She contacted her insurance company and found out that they would pay for a second opinion about the new treatment if her own doctor made the referral. She noted her limits and planned what she would say if her doctor still refused to make the referral. Her questions in response to a second refusal were planned so that she could learn about her doctor's values and needs in refusing to refer her to the second doctor.

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Negotiation Exercise 2: Insurance Benefits and Employee Rights

This exercise will use the example of Anthony in the audio program. Anthony is a 55 year old man with colon cancer. Anthony's brother died from colon cancer that had been treated, but came back and attacked his liver two years after his cancer surgery. Anthony must negotiate with his insurance company to get the company to pay for a specific type of treatment for his cancer.

When you negotiate with an insurance company, it is important to talk to someone who has the authority to make decisions. You can ask directly, for example, "Who can authorize payment for a bone marrow transplant in my case?" Be sure to get the person's name, job title and direct phone number. Write this information down in a notebook where you keep all your insurance information. Don't give up. If your insurance company still rejects your claim, you can get help from a social worker, cancer support group, a state or federal agency or an attorney.

Start the audio program (refer to the CST transcript for the exact location).

[Anthony]

My cancer doctor told me that I had a large tumor in my colon, and that it could be treated in more than one way. One option is surgery to remove the tumor and the part of the colon near the tumor. If I chose that, I would have a permanent colostomy, or opening in my side, for the discharge of stool. Another option, to reduce the size of the tumor, is radiation treatments before having surgery. This might give the surgeon a way to prevent a permanent colostomy by making a temporary colostomy and then later reattaching the parts of the colon that remain.

A third option is to have either of those two surgeries followed by a period of chemotherapy. Since my brother had colon cancer that came back after two years, my doctor felt surgery followed by chemotherapy would give me a better chance of remaining cancer-free after the surgery. He explained that this is a fairly new way of treating colon cancer where there is a risk of the cancer returning. There is now way to know for sure whether my colon cancer would return if I did not have the chemotherapy. My doctor told me that many cancer survivors do live without their cancer coming back after having surgery and no other treatment. But, he thought this approach made sense for me, because my brother's cancer had come back, so might mine.

So I collected a lot of information on my three treatment options and talked to my family about them. When I met with my cancer doctor again, we both agreed that surgery and chemotherapy would be best for me. We needed to do everything possible to remove any trace of colon cancer from my body.

My doctor's office contacted my insurance company to get approval for the surgery and chemotherapy treatments. But, the insurance company told him that they will only pay for the surgery. They didn't feel chemotherapy was needed and they wouldn't pay for it. My doctor's office staff suggested that I talk with my employer, since they pay for my insurance policy.

My supervisor at work sent me to talk to someone called a benefits manager in the personnel office. The benefits manager gave me a copy of the insurance policy, which is much larger than the benefits book they gave me before. Together, we looked for anything that would help. The benefits

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manager also told me to write a letter to the insurance company and ask for the reason why they will not pay for chemotherapy. He said that knowing why a claim is rejected can help when negotiating to get it covered. The insurance company wrote back that the standard treatment for colon cancer is surgery alone. They said that they do not pay for experimental treatments, like the chemotherapy after surgery.

So now I needed help from my cancer doctor to convince the insurance company that chemotherapy for colon cancer in cases like mine is not experimental. I also needed to find out what I had to do to appeal the decision of the insurance company.

Stop the audio program.

Let's talk about the issues raised by Anthony's situation. Anthony clearly believes that he and his doctor are equal partners in deciding what treatment he will receive for his colon cancer. He takes the information his doctor has given him, collects more information on the three treatment options, and then has a family meeting to talk about the treatment options. After talking with his family, he meets with his doctor again, and they both decide surgery and chemotherapy would be the best treatment for Anthony's colon cancer.

When Anthony's doctor contacted the insurance company to arrange for his treatment, the insurance company refused to pay for the chemotherapy. Now Anthony had to negotiate with his insurance company.

Anthony first gathered information from his employer about the terms of the insurance policy. He wrote to the insurance company to find out the reason they would not pay for chemotherapy. The answer to this letter would give Anthony the information he needed to try to convince the insurance company to pay for chemotherapy after surgery.

Anthony was lucky to have more than one partner in his negotiation with the insurance company. His employer was willing to help him and sent him to talk to the company benefits manager. His doctor made suggestions that helped him understand what his choices he had for treating his colon cancer, and then helped him negotiate with his insurance company.

Some employers are not as helpful to cancer survivors as Anthony's employer was. It is important to know your rights as a cancer survivor under federal and state laws. The booklet that comes with The Cancer Survival Toolbox explains the laws that relate to health insurance and employment. You might also want to contact the National Coalition for Cancer Survivorship to obtain copies of ***Working it Out: Your Employment Rights as a Cancer Survivor*** and ***What Cancer Survivors Need to Know About Health Insurance*** for the participants in your group.

Exercise 3: Separating from Emotions

When you are negotiating with anyone, it is important to be aware of your "inner voice." This is your emotional response to what is being said. Many people have a hard time separating their feelings from their words. If a person feels angry about what is being said, they may respond in anger. It takes practice to become aware of your emotional response. There are many ways to practice getting in touch with emotions. A few suggestions are:

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- ***Ask participants for a volunteer to demonstrate how we show our emotions.*** Many times our emotions show through body language and facial expression, as well as through tone of voice when we speak. The person feeling the emotions may be unaware that others can tell what they are feeling simply by looking at their facial expression or body language for clues. A good poker player may be able to hide his emotions, but most of us are not professional poker players.

Give the volunteer a mirror and ask him/her to hold it at their side. Have them face the rest of the group, close their eyes, and think of something that happened in their life that made them feel some emotion strongly – it can be a happy moment, a sad moment, a frustrating moment, a disappointing moment, a thrilling moment – anything at all. Now ask the rest of the group what clues they see in this person’s body language and facial expression. See if the rest of the group can tell what emotions this person is feeling.

Repeat the exercise a second time. The second time, instead of having the rest of the group describe the emotions the person is feeling, have the person hold the mirror up to his/her face and then open his/her eyes. Have the person describe what clues they see in their own reflection in the mirror.

- As a homework assignment, ask the people in your group to keep a paper and pencil with them as they watch TV during the week. Have them make notes about their feelings as they watch a comedy, an adventure show or a sad movie. Ask them to try to remember what words or actions in the TV show came immediately before they felt an emotion.

Becoming aware of emotions takes practice. TV shows and movies are a good place to begin. Other places to practice becoming aware of emotions is in conversations with family members, arguments with a spouse, parent or child, parties or other social events, listening to country music lyrics, listening to different types of music.

Have the group share their feelings from this homework assignment in the next session.

Exercise 4: Visualizing more than one solution to a problem

Review briefly the example of Anthony, who must negotiate with his insurance company for payment of his chemotherapy treatments; or the example of Anna, who must negotiate with her cancer doctor to get a second opinion about a new type of cancer treatment. Ask the group to choose to “be” either Anthony or Anna. Ask them to write down different outcomes for the example.

Sometimes, in planning the agenda for a negotiation, it is helpful to imagine the “worst case scenario”; that is, the worst possible response of the other party in the negotiation. Then, you can plan a response to that possibility ahead of time. You can never know for sure what the other person in a negotiation will do or say. You can plan only for as many possibilities as you can think of ahead of time. You should also be prepared for the fact that the other person’s response may be something you were not able to predict.

If the group has trouble getting started with this exercise, you can have the group start together by asking what Anthony would do if his employer refused to help him negotiate with the insurance

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company. Take a few suggestions from the group and then let them work independently for a few minutes.

Bring the group back together to discuss possible solutions to Anthony's or Anna's negotiations.

Negotiating Under Difficult Circumstances: The Durable Power of Attorney for Health Care.

The Durable Power of Attorney for Health Care, also known as a Living Will or Advance Directive, is a document cancer survivors can sign that will let them decide how they wish to be cared for should they be unable to speak for themselves. It also allows them to name a person who they choose, to make medical decisions for them when they are unable to speak for themselves. This could happen for a number of reasons, which may not be related to their cancer diagnosis. They could be in a serious car accident or have a heart attack or have an accidental fall while hiking in the mountains.

A good example of the use of a document such as the Durable Power of Attorney for Health Care is for people who do not wish to receive blood transfusions or other blood products because of their religious beliefs. A written document that they carry with them and have also given to their doctor for his files, will make sure that they do not receive blood products against their wishes.

It is a good idea for everyone to have a document such as a Living Will, whether they happen to be a cancer survivor or not.

Explain the purpose of the Living Will to the group and hand out copies for them to take home and read. This document is usually available in a stationery store at little cost. Encourage the group to think about what types of medical treatment they would want to have done. Talk about respirators (ventilators), cardiopulmonary resuscitation (CPR), intravenous or gastric tube feedings, kidney dialysis, and organ and tissue donation.

5. Evaluating the session

Just as in the other group sessions, it is important to distribute the evaluations and ask the participants to complete them before the closing. It is important to express appreciation to the participants for their assistance in completing these forms each week and reinforce how their input will help to insure the helpfulness of future programs.

6. Closing

In summary, learning good negotiating skills is an important part of dealing with cancer. These skills can help you to get the medical care you prefer, clear up disagreements with insurers, and protect your legal rights. Those skills include information gathering, effective communication, holding to your values, setting personal limits, controlling your emotions, and a willingness to see more than one solution to any problem. Review this program to sharpen your negotiation skills. These skills will lead to successful negotiations not only with your cancer concerns, but in every area of your life.

Evaluation

Instructions to Participants:

Please circle the response that best represents what you have gained as a result of this program:

1. Has your awareness of the importance of negotiating for cancer survivors increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

2. Has your understanding of negotiating skills increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

3. Has your confidence in your ability to use negotiating skills increased?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

4. Has this training session been helpful to you?

1 2 3 4 5
not at all a little somewhat quite a bit a great deal

Additional Comments: Please tell us anything else you would like about what you thought of this training session or how you might use what you learned.

Session VI: Standing Up for Your Rights

Session VI: Standing Up for Your Rights

AGENDA

1. Welcome and introductions
2. The importance of standing up for your rights
3. Exercises
4. Examples of how survivors have learned to stand up for their rights
5. Completing evaluation forms and post-test
6. Closing

OVERVIEW

Objectives:

After completing this session, participants will be better prepared to:

- Feel more in control of your life
- Build confidence to face challenges that seem too difficult to overcome
- Reach out to others, such as talking to someone who is in a similar situation
- Feel hopeful rather than hopeless or helpless

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session IV
- An audiocassette or CD player

Handouts

- Advocating for Yourself and Others

Experiential Exercises

1. The Power of Words
2. Role Playing

Session VI: Standing Up for Your Rights

1. Welcome and Introductions

As the facilitator, greet participants as they arrive and distribute name tags again. If the group is composed of all the same members, first name re-introductions are all that will be needed. However, if anyone new has joined the group, reintroduction of everyone with their names and why they came to the series will be helpful. Remind participants that this is the final session of the series and let them know there will be time allocated at the closing to review what it has been like for them to participate in the program and to say goodbye.

2. The Importance of Standing Up for Your Rights

The audio program for session 6 contains the voices of survivors talking about issues that required negotiation skills. You may want to play the introduction of the tape or describe the scenarios as a way of introducing this session.

[Narrator]

Cancer survivorship represents the challenges faced by over 8 million people living today who have been diagnosed with cancer. It is about the quality of your life when faced with this frightening disease; about how you can learn to communicate, gather information, and make decisions; and, about how you can negotiate and solve specific problems. It is, indeed, about how you speak up or advocate for yourself from the moment you were diagnosed onward.

The luxury of thinking about cancer along survivorship terms is fairly new. As therapies became available to manage this disease, some cancers became curable. Others changed from brief and severe forms to chronic illnesses. The hopes and expectations for surviving cancer have greatly increased.

Before this decade, doctors planned the course of care for people with cancer. Doctors rarely gave choices about what they felt was best for these people as individuals. Eventually, however, people like you began to take more control over all aspects of care that affected their lives. Many wanted to be partners in their own care and began talking with each other. They developed support groups, hotlines, resource materials, and networks. As people with cancer became more vocal, the idea of survivorship emerged.

Welcome to Program 6 in the Cancer Survival Toolbox, about standing up for your rights. The topic of this program is self-advocacy. Advocacy means giving support to a cause. At the conclusion of this program, you will better understand what cancer survivorship means, and how you can become your own best advocate.

What does survivorship mean? How can it be defined? How do you know if you are a survivor? It is important to understand that cancer survivorship is a continual and ongoing process rather than a stage or outcome of survival. It is NOT just about cure, or long-term survival, or living five years past your diagnosis. Instead, it is the experience or process of living with, through, and beyond cancer. From this perspective, we can say that from the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor. That means you are a cancer survivor no matter how long ago you were diagnosed or what stage of cancer you have.

If you are playing the audio program, stop it here. Encourage the group participants to discuss what they have heard thus far.

✓ Question: What does cancer survivorship mean to them?

3. Experiential Exercises

Exercise 1: The Power of Words

Instructions to Facilitator: Explain to participants the following:

Years ago, the word cancer was linked to the word victim. People with cancer may have been thought of as powerless, and that they could do nothing to help themselves once cancer had struck. This exercise is designed to help you see how you feel about the power of certain words.

Instructions to Participants:

Repeat the following statements after me and notice how different they feel:

"I am a cancer victim." (Pause)

"I am a cancer patient." (Pause)

"I am a cancer survivor." (Pause)

Discussion Questions:

Q. How did it feel to say each of these phrases?

Q. Have you heard other terms or phrases used to describe people with cancer? (Other terms that people with cancer use to describe themselves include victor, triumpher, veteran, thriver, activist and warrior)

Q. What are your reactions to these terms?

Many of these words describe someone who has choices and control. They show that you are not powerless, and that you can do much to maintain a high quality of life after cancer. Defining yourself, instead of letting other people label you in a certain way, is an act of self-advocacy. This may seem like a small point, but the words we use to describe ourselves make a big difference in how others see us, how we see ourselves, and how we act. This is also called empowerment.

Resume the audio program.

Session VI: Standing Up for Your Rights

[Narrator]

We often hear the term empowerment. Does it really have any meaning for you as a cancer survivor? Empowerment refers to any process that helps you influence other people and organizations that affect your life. More simply, it is about taking control. As such, empowerment is an important part of cancer survivorship. Empowerment assumes that you usually understand your own needs better than anyone else. It also assumes that it is best for you to have the greatest possible control in shaping your life, and in making your own informed decisions about actions that will affect the quality of your life. Empowerment and self-advocacy go together.

Continue to play the tape until the case example of Mildred. Stop the tape before the Narrator tells Mildred's story.

Exercise 2: Role Play

Ask for volunteers from the group to participate in a role play. Try to get three people who can play a husband, wife and child in a family setting.

Set the following scenario:

Joe, the husband/father in the family, is receiving chemotherapy for lung cancer. The treatments make him very tired for about three weeks after each treatment. He feels better for the next week, and then it is time for the next cycle of chemotherapy. Joe is working part time during his treatments. He feels that he needs to work to support the family and maintain his insurance benefits.

Mary, the wife/mother in the family, works part time for a large computer company. She has excellent insurance benefits through her job and is able to keep a flexible work schedule so that she can go with Joe to his treatments.

Junior (or Sally depending on who volunteers from the group) is the teenager in the family. He/she is involved in school sports, a computer club, a swing dance group and the swim team. Junior/Sally has many friends and often goes out with a group of friends to see a movie, shop at the mall, or practice swing dancing.

Joe has noticed that he is getting more and more tired after his treatments. It seems as if each month, it becomes harder to go to work. He is worried about what this means. Is the cancer getting worse? He does not want to frighten Mary or Junior/Sally, so he does not mention how he is feeling. Mary has noticed that Joe seems to be falling asleep earlier in the evening and that it is harder for him to get up and get ready for work in the morning. He looks tired all the time. He doesn't talk as much at the dinner table and some nights it seems as if he isn't listening to the conversation either. She is also worried.

Junior/Sally has a big dance coming up and two term projects at school. He/she needs a ride to the library after school and a ride to the dance on Saturday. Junior has mentioned the dance and the term projects to his parents at the dinner table. He has not said that he will need a ride to the library and the dance every night that week.

Session VI: Standing Up for Your Rights

Ask members of the group to imagine that each of them is Joe. Ask the following questions and allow the group to brainstorm answers. You might want to write the answers on an easel or whiteboard, if one is available.

What do you need from your family while you are going through your treatment?

What are some options to help you get enough rest?

Who can help you to get what you need?

Is there anyone outside the family who can take Junior to the library?

Can Junior find a ride to the dance with one of his friends?

What questions do you want to ask your doctor?

What do you want your doctor to know about how you are feeling?

Can you take advantage of your rights under the Family Medical Leave Act and take some time off from work?

Can you use the Americans with Disabilities Act to ask your employer to change your work hours while you are being treated for your cancer?

What are the emotions you feel as you think about being Joe?

Now ask the group to imagine that each of them is Mary.

What do you need from Joe? From Junior? From Joe's doctor? From Joe's boss? From your friends? From your relatives?

What are some options you can use through your work?

Can you take some time off from work through the Family Medical Leave Act?

Can someone help you with housework and cooking while Joe is being treated for his cancer?

Can someone help with driving Junior where he needs to go?

What do you want Joe to know about how you are feeling?

What do you want Junior to know about his father's cancer treatment?

What do you want Junior to do to help the family while his father is being treated for cancer?

What information do you think would help Junior understand his father's treatment?

Session VI: Standing Up for Your Rights

Are there any medications or complementary treatments that might help Joe feel better while he is being treated for cancer? Would any of these treatments interfere with Joe's cancer treatment?

What are the emotions you feel as you think about being Mary?

Now, imagine that you are the teenager in this family.

What are you thinking about your father's cancer diagnosis? His treatment?

Do you notice that your father seems more tired now? How does this make you feel?

Are your needs being met? How do you feel about this?

Do your friends know that your father is being treated for cancer? Are you able to talk with them about what is happening in your family?

Do your teachers know that your father is being treated for cancer? Do you feel that you could talk to them about what is happening in your family?

What are the emotions you feel as you think about being Junior?

In order to advocate for yourself, it is important that you know what your needs are. After you identify your needs, think about who can help you meet those needs. Imagine that you can't meet these needs by yourself. Think of at least one person outside the family you could ask to help you. Sometimes, this is a person you hire, such as a cleaning service, a gardener, or a carpool van.

Continue with the tape until the Narrator says:

Try to think of something someone said or did in the past week that increased your hope. Go back even further and try to think of the most helpful thing someone said to you since you were diagnosed with cancer. What made the statement so helpful? Did it have anything to do with your maintaining hope?

Stop the audio program

Allow the group to talk about things that increased their hope. Sometimes hope comes from something other than words. A rainbow on a cloudy, rainy day can bring hope. A bright sun shining in a clear sky. A rose budding on the vine. The happy face of a baby can be a symbol of the continuity of life. A hug from a good friend can bring happiness, warm feelings and hope. Hopeful signs can be found in nature, people, music, poetry, prayer or an encouraging laboratory test result.

Continue with the audio program.

3. Examples of How Survivors Have Learned to Stand Up for Their Rights

This is a good time to remind participants of the many ways that survivors have individually advocate for themselves or joined together in advocacy organizations such as the National Coalition

Session VI: Standing Up for Your Rights

for Cancer Survivorship to advocate for others. The handout for this session lists ways that survivors can advocate for themselves and others. Discuss these with the group.

4. Completing Evaluation Forms

Hand out the Post-test forms. Ask participants to complete these and turn them in before leaving. Emphasize to participants how valuable their feedback is to the design of future programs for survivors.

5. Closing

As noted in Section 4, closing is very important in groups. You will want to have some sort of celebration at the end of the last session. Refreshments could be provided, or you could ask the group if they would like to have a potluck. See other suggestions for closing and certificate distribution in Section 4.

Remind the group that copies of the Cancer Survival Toolbox are available in English and Spanish, free of charge, by calling 1-877-TOOLS -4-U (1-877-866-5748).

Cancer Survival Toolbox® Post-test

Thank you for answering this brief questionnaire. By answering these questions, you'll help us make this program better for people living with cancer. Now that you have completed the self-advocacy training of the Cancer Survival Toolbox, please answer the following questions and return this form to your group facilitator before you leave. Each question is followed by a set of numbers that range from 0 to 5. The number "0" represent "not at all" and the number "5" represents "a great deal." Circle the answer that best fits your response to the question. There are no right or wrong answers. Thank you.

	Not at all			A great deal	
Program 1: Communicating					
Be assertive in telling your doctors about your needs?	0	1	2	4	5
Express your feelings?	0	1	2	4	5
Listen to the "I" messages in conversations with your doctors, nurses and social workers?	0	1	2	4	5
Listen actively to conversations with your doctors, nurses, family members and others?	0	1	2	4	5
Program 2: Finding Information					
Find information about your type of cancer?	0	1	2	4	5
Use information about your type of cancer?	0	1	2	4	5
Find information about your cancer treatment?	0	1	2	4	5
Find information about a clinical trial?	0	1	2	4	5
Learn how to use the Internet to find information on cancer?	0	1	2	4	5
Program 3: Making Decisions					
Identify how you prefer to make your decision?	0	1	2	4	5
Find out the benefits of getting a second opinion to help you make decisions?	0	1	2	4	5
Learn how much time you have to make a decision?	0	1	2	4	5
Understand that you are not a cancer statistic?	0	1	2	4	5
Program 4: Solving Problems					
Understand the importance of solving problems in surviving cancer?	0	1	2	4	5
Identify what problem-solving skills are useful when facing a cancer diagnosis?	0	1	2	4	5
Learn the steps in making a problem-solving plan?					
Program 5: Negotiating					
Identify your values?	0	1	2	4	5
Set your own personal limits?	0	1	2	4	5
Set aside your emotions when you negotiate?	0	1	2	4	5
Identify more than one solution to a problem?	0	1	2	4	5
Program 6: Standing Up for Your Rights					
Stand up for your rights regarding cancer?	0	1	2	4	5
Describe what cancer survivorship means?	0	1	2	4	5
Identify yourself as a cancer survivor?	0	1	2	4	5
Regain some control in your life?	0	1	2	4	5
Become your own best advocate?	0	1	2	4	5

Name _____

Address _____

(Please make sure your mailing address is legible)

Are you a cancer survivor? Yes No If not, are you a family member of a cancer survivor? Yes No

Type of cancer _____ Age of diagnosis _____

Ethnic Origin

- Caucasian
- African American
- Hispanic
- Asian
- Native American
- Other

Education

- Elementary
- Middle School
- High School
- College
- Graduate School

Age

- 18-30
- 31-45
- 46-60
- Older than 60

Evaluating Your Program

Join the ongoing efforts of the Cancer Survival Toolbox Program to evaluate its impact.

As noted earlier, evaluating the impact of programs for cancer survivors is increasingly important to insure future funding of such efforts and to measure program efficacy. In providing you with this manual, the Cancer Survival Toolbox development team asks that you join us in gathering empirical data from the participants in your groups. This is a relatively simple process using the forms provided to you. Our team is conducting an ongoing multi-site study and the Pre-and Post-test data you gather will be included in this study. You may also wish to use the data from you group in your own way as well. A form has been included for you to complete and return to us along with copies (or originals) of the Pre- and Post-tests you administer to your group participants. All identifying information from this form will be kept confidential. Only group data will be published.

Distributing and Collecting the Pre- and Post-test.

As noted earlier, most participants in educational programs such as the Cancer Survival Toolbox expect to be asked about the program's effectiveness and are willing to provide you with feedback. Since standard educational methods are being used in this program, it should not be necessary for you to obtain IRB (Investigation Review Board) approval for gathering this type of evaluation data. However, you may want to check with your IRB to be certain.

Pre-test. It is important to distribute copies of the Pre-test to each group member, and ask that they be completed, **before you begin teaching** the content of the Toolbox, just after a brief introduction by the group facilitator(s).

Post-test. It is also important to distribute and collect the Post-test forms **before the closing of final group session (Session 6).**

Pre-test and post-test data are very valuable in promoting the usefulness of this type of self-advocacy training in the future. Also included in this manual are evaluation forms for each of the six sessions. You may want to ask participants to complete these in addition to the Pre-test and Post-test.

The Pre-test and Post-test forms ask for the same information for group participants in order to compare their responses before and after their exposure to the training program.

Facilitator Summary Form

Name _____ Degree _____ Position _____

Organization _____

Address _____

(Co-facilitator)

Name _____ Degree _____ Position _____

Organization _____

Address _____

Session 1 No. of Participants _____ No. of Pre-tests completed _____

Session 6 No. of Participants _____ No. of Pre-tests completed _____

Number of participants in session 2 _____

Number of participants in session 3 _____

Number of participants in session 4 _____

Number of participants in session 5 _____

Did you utilize computers in Session 2? Yes _____ No _____

Did you invite guest speakers? Yes _____ No _____ Whom? _____

Is your setting: Urban _____ Suburban _____ Rural _____

Please share anything you think would be helpful for us to know about your group, methods of instruction, etc.

Please return this form and copies for originals of your pre and post-tests to:

NCCS

c/o Toolbox

1010 Wayne Avenue, Suite 770

Silver Spring, MD 20910

CANCER SURVIVAL TOOLBOX®
TRAINING MATERIALS

AGENDAS

Session I: Communicating

Session II: Finding Information

Session III: Making Decisions

Session IV: Problem-Solving

Session V: Negotiating

Session VI: Standing Up for Your Rights

Session I: Communicating

AGENDA

1. Welcome and introductions
2. Information gathering (pre-test)
3. Introduction to self-advocacy
4. Introduction to the Cancer Survival Toolbox
5. Communication skills:
 - Being assertive
 - Using "I" messages
 - Active listening
 - Checking the message
 - Expressing feelings
6. Exercises
7. Completing evaluation forms
8. Closing

Session I: Communicating

OVERVIEW

Key Messages

- Communication is important for all the other survival skills
- Good communication takes practice
- Using one or all of the five communication skills can improve communication

Objectives

After completing this session, participants will be able to:

- Discuss the importance of good communication in surviving cancer
- Identify basic communication skills
- Demonstrate the ability to use these communication skills

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session I
- CD Player
- Copies of the Cancer Survival Toolbox Audio program for each participant (These can be bulk ordered by calling 1-888-Tools 4 U)
- Small pads (or several sheets) of paper for each participant
- Pencils for each participant

Handouts

- Communication Skills

Exercises

5. What types of communication are challenging for you?
6. Listening for communication skills
7. Role play

Session II: Finding Information

AGENDA

1. Welcome and introductions
2. The importance of information
3. Finding information
4. Computer assisted exercises
5. Completing evaluation forms
6. Closing

Session II: Finding Information

OVERVIEW

Key Messages

- Having and understanding the facts can help you care for yourself better, give you self-confidence, reduce anxiety, and help relieve distressing symptoms.
- The need for good information goes on after treatment starts and even after it ends.
- Sometimes it may feel like too much information is coming at you. It is okay to say, “I have what I need right now.”

Objectives

After completing this session, participants will:

- Know how to find information in their community
- Know about information that is available from other sources
- Judge the quality of the information they find about their cancer and its treatment.

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session II
- An audiocassette or CD player
- The booklet that accompanies the Cancer Survival Toolbox

Handouts

- The Community Resource list from the Cancer Survival Toolbox

Exercises

1. Hands-on experience finding information via computers can be a valuable learning tool in this session. If at all possible you may want to schedule this Information-Seeking session at a site that enables learners to actually sit at a personal computer and learn to navigate the Internet. Such sites include the computer lab or patient resource room of your hospital or agency, your local library, or a high school or college computer lab in your community. If you are using one of these locations, be sure to schedule it with the appropriate staff. Other options include bringing a laptop computer to the group (if the group is not too large) or bringing handouts with instructions for computer use.

Session III: Making Decisions

AGENDA

1. Welcome and introductions
2. The importance of decision-making for survivors
3. Experiential exercises
 - Identifying your decision-making style
 - Weighing the pros and cons
4. Completing evaluation forms
6. Closing

Session III: Making Decisions

OVERVIEW

Key Messages

- Each person is an individual, NOT a cancer statistic.
- Different individuals have different decision-making styles.
- A second opinion can be helpful in making decisions.

Objectives

After completing this session, participants will be able to:

- Identify how they prefer to make decisions
- Find out the benefits of getting a second opinion to help make decisions
- Recognize that they may need some time to make decisions;
- Weigh the PROS and CONS in making a decision
 - Understand that every person is an individual, not a cancer statistic.

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session III
- An audiocassette or CD player
- A few sheets of 9x11 paper and pencil for each participant

Handouts

- What is your decision-making style?

Exercises

1. Identify Your Decision-Making Style
2. Weighing the Pros and Cons

Session IV: Problem-Solving
AGENDA

1. Welcome and introductions
2. Introduction to problem-solving
3. Steps to problem-solving
4. Managing discouragement
5. Completing evaluation forms
6. Closing

Session IV: Problem-Solving

OVERVIEW

Key Messages

- Problem solving involves 5 steps.
- Every problem-solving plan can be modified.
- Get support for your plan from everyone you can.

Objectives

After completing this session, participants will be able to:

- Understand the importance of problem solving in surviving cancer;
- Identify problem solving skills you need when faced with a cancer diagnosis
- Learn the steps for making a problem-solving plan.

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session IV
- An audiocassette or CD player

Handouts

- The Five Steps of Problem-Solving
- Assessing Depression

Exercises

1. Practicing the steps of problem solving
2. Applying problem solving skills

Session V: Negotiating

AGENDA

1. Welcome and introductions
2. Introduction to negotiating
3. Negotiation skills
4. Insurance benefits and employee rights
5. Completing evaluation forms
6. Closing

Session V: Negotiating

OVERVIEW

Key Messages

- It is important to identify what your needs are after your cancer diagnosis.
- When negotiating anything, it is important to believe that you are an equal to the person you are negotiating with no matter what your background.
- You must be sure that everyone in the negotiation clearly understands what you want to say.
- You must be able to identify and express your values, the principles and standards you live by.
- You must be able to set your personal limits – the boundaries of behavior you will not cross.
- You must be able to recognize and set aside your emotions when negotiating.
- You must be willing to look for more than one solution to any problem.

Objectives

- Listen and communicate effectively
- Identify the values that are the principles and standards by which you live
- Set your personal limits-the boundaries of behavior that you will not cross
- Learn to set your emotions aside when negotiating
- Visualize more than one solution to any one problem

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session IV
- An audiocassette or CD player
- Hand held mirrors for each participant

Handouts

- Negotiating skills
- Laws Pertaining to Health Insurance (located in the CST Resource Booklet)

Exercises

1. Therapy Decisions
2. Insurance Benefits and Employee Rights
3. Separating from Emotions
4. Visualizing more than one solution to a problem

Session VI: Standing Up for Your Rights

AGENDA

1. Welcome and introductions
2. The importance of standing up for your rights
3. Exercises
6. Examples of how survivors have learned to stand up for their rights
5. Completing evaluation forms and post-test
6. Closing

Session VI: Standing Up for Your Rights

OVERVIEW

Objectives:

After completing this session, participants will be better prepared to:

- Feel more in control of your life
- Build confidence to face challenges that seem too difficult to overcome
- Reach out to others, such as talking to someone who is in a similar situation
- Feel hopeful rather than hopeless or helpless

Supplies

- Nametags for each participant
- A copy of the Cancer Survival Toolbox audio program for Session IV
- An audiocassette or CD player

Handouts

- Advocating for Yourself and Others

Experiential Exercises

1. The Power of Words
2. Role Playing

CANCER SURVIVAL TOOLBOX®
TRAINING MATERIALS HANDOUTS

Communication Skills

Finding Information on the Internet

The Five Steps of Problem Solving

Assessing Depression

Negotiation

Advocating for Yourself and Others

Communication Skills

Assertiveness

Assertiveness shows that you believe your input is really important. Starting positively with what you want and need helps get your message across clearly to others. When it comes to your health, there is no such thing as a silly question.

Examples: "I really want to be involved in my treatment decisions." "I didn't quite get that. Please repeat what you just said."

Using "I" Messages

This means making statements with the word "I" in them such as "I think" or "I feel," rather than making statements like "you should." "You should" messages tend to put the other person on the defensive, which slows down communication.

Example: This statement: "I feel as if I need more information" is better than "You should be telling me more."

Listening Actively

This means more than just listening carefully and nodding and looking directly at the person speaking. It also means checking to be sure that the message you heard is what the other person really meant to say. Any time two or more people talk, misunderstandings can happen for many reasons, including the speaker not being clear.

Examples: An active listener might say, "So what I'm hearing is...is that right?" or "It sounds as if you feel...am I on track?"

Matching Words with Non-Verbal Communication

Non-verbal communication includes anything expressed without words: facial expressions, gestures, actions, and posture. As a speaker, you want your words and your non-verbal communication to match; if they don't, the listener won't know which message to believe. As a listener, you want to pay attention to the other person's non-verbal communication as well as to the words they use.

Example: An example of a mismatch is a speaker who says "I'm really interested in this," while sitting slumped back in the chair and checking their watch.

Expressing Feelings

Cancer is not a time for mind reading and listeners need you to tell them what you are feeling, as clearly as you can. Of course, this means being aware of how you are feeling, and knowing that it's the feelings others don't recognize that tend to cause problems.

Example: "I feel angry. It's not fair that I got cancer when I was eating right."

Finding Information on the Internet

Following these Internet search tips could make your search easier.

1. Plan your search and choose your terms with care. Take notes to help you stay organized.
2. Be patient. Although the Internet offers immediate access 24-hours a day the Internet can be a very busy place. You can always try your search another time.
3. Learn how each Internet site functions and what kinds of information it offers.
4. Have reasonable expectations. You may not find everything you are looking for on the Internet.
5. Always read the list of Frequently Asked Questions if a list is there. It gives answers to common questions and could save you a lot of time.
6. If you are part of an on-line discussion or mailing list, keep your questions or comments short. Use common sense when sharing information, and don't post anything that should be kept secret, like credit card numbers or passwords.
7. Check your sources and check information further.

A word of caution: There is a great deal of helpful, reliable information available on the Internet. But there is also a lot of faulty information too. The Internet reflects real life and it is very important to question your sources. Remember that the most reliable medical information will often come from non-profit organizations, research facilities, libraries, hospitals and government agencies.

Mailing lists are ongoing e-mail discussions devoted to specific topics of interest. They can be public or private. Some mailing lists use an expert to guide the discussion -- a moderator -- and some do not. A mailing list manager sends messages to a list of multiple e-mail addresses. When you sign up for or subscribe to a mailing list, or a listserv, you get a separate copy, through e-mail, of each message that is posted. It's not uncommon to receive dozens of messages each day from active mailing lists.

Search engines are software programs that are powerful tools for finding resources on subjects anywhere on the Internet. Most search engines are available on the Web at no charge. They work in many different ways -- some search words, titles or headings of documents, some search the documents themselves and others search indexes or directories.

Electronic mail or e-mail, the most popular feature of the Internet, allows one person to send messages to any other person who has a computer that can receive e-mail. It is the simplest way to communicate with others on the Internet. It was originally designed for one-to-one communication, but e-mail is also needed to join a mailing list so that messages can be sent to several people at the same time. There are e-mail programs that can periodically dial your Internet Service Provider, allow you to pick up or download any mail waiting for you, and log off. This lets you read and respond to your e-mail even when your computer is not "hooked up" to the telephone line.

The Five Steps of Problem Solving

1. Identify and define the problem

Look at the problem from as many angles or perspectives as you can. Restate the problem. Can you state the problem as a goal or objective? Are other people affected by the problem? How do others view the problem? You must be able to define the problem before you can solve it.

2. Get the facts

Get the facts. Identify resources, such as cancer organizations, experts, literature, the Internet, advocacy groups and other survivors. Look at your problem statement and/or goal and ask yourself what is reasonable to achieve given all the information you have. Identify what additional information you may need. You will discover that the gathering of information never stops.

3. Plan your action

Strategize your approach to solving the problem. Consider advantages and disadvantages of each approach. Consider obstacles. Can they be overcome? What might be needed? Enlist your resources gathered in Step 2. How is your plan going to impact your family and those around you? Get support for your plan from everyone you can.

4. Carry out your plan

Do it! Press forward! Be positive! Expect to succeed! Approach your plan with the idea that it will work. This does not mean that you might not be fearful or discouraged at times. This does mean that you can recognize the need to feel grief, but you continue to move forward and participate in normal daily activities as much as physically possible. Seek professional help when needed. (See handout, Assessing Depression for signs that you may need help.)

5. Evaluate your plan and make necessary changes

Set small goals along the way. Keep records of how your plan is going. Assess your progress. Does something need to be adjusted? Have you obtained some new information or additional resources? Have your circumstances changed? Evaluate, adjust, and move forward. Remember to solve the problem one step at a time.

Assessing Depression

Following the steps to problem solving can alleviate feelings of discouragement. This doesn't mean that you might not feel discouraged, or sad at times, but it helps to move forward and do your normal daily activities as much as physically possible. If you cannot do this, if you feel too depressed, seek help and support immediately. Depression is a common problem during cancer, but help is available. Problems are harder to solve when you are struggling with depression. Here are some signs to watch for that may mean you have become depressed:

- Feeling helpless and hopeless
 - Losing interest in your usual activities
 - Being unable to concentrate
 - Feeling very sad
 - Changes in eating and sleeping habits
 - Not wanting to be with family and friends
- ✓ If any of these symptoms last for longer than two weeks, talk with your doctor. If symptoms continue, ask your doctor to refer you to a counselor who works with people facing cancer. And please, don't wait.

Negotiation Defined

Negotiation is a special form of communication in which reaching an agreement is the goal. To negotiate means to settle, accomplish or cope with successfully.

Negotiation Skills

1. Being able to listen to the information provided.
2. Demonstrating good communication skills. Be sure everyone in the negotiation has the same understanding of what is being discussed.
3. Identifying your values. These are the principles and standards you live by.
4. Setting your personal limits. These are the boundaries of behavior you will not cross.
5. Being able to set aside your emotions when negotiating.
6. Being willing to visualize more than one solution to any problem.

Negotiation Steps

1. Gather information
2. Plan an agenda
3. Set limits
4. Be aware of your inner voice
5. Create a win-win situation

Advocating for Yourself and Others

In cancer survivorship, advocacy does not stop with standing up for yourself. While it begins with you, it may broaden to include advocacy on behalf of others. As you become a "veteran" cancer survivor, you may find that you want to give something back, to share some of the wisdom that you have learned from having cancer to help another.

For example, when people find out you have had cancer, they may call you and ask you to speak to a family member or friend who has been diagnosed recently. If you are comfortable speaking on a personal level, talking with a newly diagnosed person can be an act of advocacy.

Other ways that you may want to use your personal experience to help others include:

- Starting a support group in your community
- Speaking about your cancer experience to community groups
- Making sure your library has up-to-date resources on cancer
- Speaking to medical, nursing and social work students and to employers and employees about your cancer experience
- Telling your story publicly to the media or your congressman to help change public opinions and policies about cancer
- Join with others who form an advocacy organization

FOR IMMEDIATE RELEASE

[Name]
[Organization]
[Phone]

**[ORGANIZATION] TO HOST [EVENT] FOR CANCER SURVIVORS TO ACCESS
FREE SELF-ADVOCACY PROGRAM**

[City] [(date)] – [Organization] will host [event] on [date], introducing cancer survivors to the *Cancer Survival Toolbox*, a program designed to develop the skills survivors need to successfully navigate their care.

This self-help tool for cancer survivors and their families contains consists of an audio program and a resource booklet to help cancer survivors develop self-advocacy skills. The audio programs incorporate topics such as communicating, finding information, decision-making, problem-solving, negotiating, and standing up for patient rights.

[Organization] plans to distribute the *Cancer Survival Toolbox* to their [cancer survivor group] at their [event] on [date/time]. By sharing this innovative resource with [group], [organization] helps cancer survivors gain the skills essential for self-advocacy while learning how to deal with relevant issues including treatment, employment, insurance, and life after cancer.

“The *Toolbox* is a breakthrough in self-advocacy. It goes beyond the requisite disease information and actually teaches cancer survivors how to use this information in their own best interests,” states Susan Leigh, RN, *Toolbox* development team member and three-time cancer survivor.

Developed collaboratively by the National Coalition for Cancer Survivorship, the Oncology Nursing Society, the Association of Oncology Social Work, and the National Association of Social Workers, the *Toolboxes* are offered free of charge to cancer survivors, their families and non-profit organizations. The *Cancer Survival Toolbox* is available in English or Spanish by calling (877) TOOLS-4-U or (877) 866-5748 or visiting www.canceradvocacy.org/toolbox.

#



The Cancer Survival Toolbox®:
The First Step to Cancer Survival

A FREE SIX WEEK WORKSHOP FOR CANCER
SURVIVORS

SPONSORED BY:

DATES:

TIMES:

LOCATION:

TOPICS:

SESSION 1: COMMUNICATING

SESSION 2: FINDING INFORMATION

SESSION 3: MAKING DECISIONS

SESSION 4: SOLVING PROBLEMS

SESSION 5: NEGOTIATING

SESSION 6: STANDING UP FOR YOUR RIGHTS

**FOR REGISTRATION INFORMATION,
CONTACT:**

The Cancer Survival Toolbox is a program of the
National Coalition for Cancer Survivorship.

The

First

Step to

Cancer

Survival™

Certificate of Completion

This certifies that

*has successfully completed the Cancer Survival
Toolbox[®]
Self-Advocacy Training Program*

Group Facilitator

Date

