Navigating the Healthcare System

A Workshop for People with Cancer
and their Family Caregivers

Trainer's Guide

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Navigating the Healthcare System

A Workshop for People with Cancer and their Family Caregivers

Trainer's Module:

Teaching the "Navigating the Healthcare System" Curriculum

Overall Goals

The skills of understanding and finding one's way through the healthcare system as a patient are sometimes termed "navigation." The National Cancer Institute and American Cancer Society have championed the idea of patient navigation. Some institutions now have an American Cancer Society Patient Navigator who can help people living with cancer and their family caregivers better understand the system and access additional resources. Yet access to patient navigation resources remains far from widespread and there is a growing recognition that navigation needs can extend beyond the healthcare setting.

The **Navigating the Healthcare System** workshop has developed out of the need to place these key navigation skills directly in the hands of people living with cancer and their family caregivers. The overall goal of the workshop is to instruct, equip, and support people living with cancer and their family caregivers with practical skills, strategies and resources to successfully navigate the healthcare system.

The goal of this module is to offer you, as health professionals and educators, a framework for teaching navigation skills to people living with cancer and their family caregivers through the Navigating the Healthcare System workshop.

> **Key Glossary Terms:**
>
> **Train the Trainer Model:** A model to disseminate knowledge by training people (*trainers*) to teach others.
>
> **Navigating the Healthcare System Trainer:** A healthcare professional or other educator trained to teach people living with cancer and their family caregivers using this curriculum.
>
> **Person living with cancer:** A general term for anyone living with any cancer at any stage of diagnosis or treatment. This term is sometimes used synonymously with "survivor" or "patient."
>
> **Family caregiver:** Someone who provides assistance and support to a person living with cancer. Although a *family caregiver* is often a close family member to the person living with cancer, he or she may also be a close friend.
>
> **Module**: A workshop session consisting of text, slides, exercises and resources for people living with cancer and their family caregivers.

Background and Introduction to the Workshop

The **Navigating the Healthcare System Workshop** was developed by The EPEC (Education in Palliative and End-of-Life Care) Project, a train-the-trainer educational program whose mission is to educate all healthcare professionals on clinical competencies in palliative care and the Lance Armstrong Foundation (LAF). This partnership couples the EPEC Project's educational approach and experience in palliative

care with the LAF philosophy that unity is strength, knowledge is power and attitude is everything. This workshop seeks to prepare people living with cancer and their family caregivers to navigate a complex healthcare system in order to receive the best care possible throughout their cancer experience.

Palliative care is care that is focused on improving quality of life for people living with cancer and their family caregivers at any stage of illness. Although it is sometimes associated with "end-of-life care," the approach and goals of palliative care are ones that can be applied to people living with cancer and their family caregivers at any stage of illness. These approaches include: a focus on quality of life, recognition of the importance of setting goals for care and an emphasis on clear communication between patients, families and providers. The Navigating the Healthcare System workshop is intended to develop many of these skills. It is not intended to focus on patients at the end-of-life but instead on skills for people living with cancer and their family caregivers at all stages of illness.

Materials for the **Navigating the Healthcare System Workshop** include the **Participant's Handbook** consisting of 4 modules of content for people living with cancer and their family caregivers and a **Trainer's Guide** for workshop instructors**.**

The Participant's Handbook is divided into four sessions, or modules, with text, slides, exercises and resources for people living with cancer and their family caregivers.

> **Module 1**: Introduction to Navigating the Healthcare System
>
> Module one introduces the concept of *healthcare navigation.* This module introduces the different members of the healthcare team, treatment settings, common treatments, and basic insurance information.
>
> **Module 2**: How families live with cancer
>
> This module offers techniques for building a team of care and identifying areas where people living with cancer and their family caregivers may need help or support. The module provides strategies for tapping into the existing talent, resourcefulness and energy of existing support networks and identifies available sources of information and support.
>
> **Module 3**: Recognizing and Communicating Needs at Home
>
> Module 3 discusses common signs, symptoms and needs that people living with cancer and their family caregivers may be facing. The focus is largely on several health communication tools that can help identify and track needs to be communicated to family caregivers and healthcare providers.
>
> **Module 4**: Recognizing and Communicating Needs with Healthcare providers
>
> In Module 4 people with cancer and their family caregivers will learn important steps to take before, during and after a healthcare visit and have the chance to view these navigation techniques demonstrated in a short video.

The Trainer's Guide provides a framework to help nurses, social workers, patient educators and others who will teach people living with cancer and their family caregivers. The Trainer's Guide begins with this module, highlighting important educational principles and strategies for teaching the Navigating the Healthcare System workshop. It also includes Trainer's Notes for each module of the Participant's Handbook covering practical planning, timing, teaching, and evaluation tips specific to each module.

Educational and Facilitation Principles Important for Trainers

As a Navigating the Healthcare System Trainer, your goal will be to teach new knowledge and skills to people living with cancer and family caregivers. It is important for the Trainer to consider, in delivering this curriculum to people living with cancer and their family caregivers, some concepts related to effective teaching and facilitating. As the Trainer, you have important information to communicate during the session. Additionally, you want participants to learn about certain skills. The impact will be greatest if you are able to foster participation, draw upon the experiences and wisdom of participants', and establish a non-threatening and non-judgmental learning environment. This requires you to play a major role in facilitating the process, and the group's interactions. Hence key elements in teaching this curriculum to people living with cancer and their family caregivers are adult learning principles as well as principles of psychoeducation. In the two sections below, we outline these areas and their relevance for Trainers.

Principles of Adult Education

Humans appear to derive pleasure from learning, and engage enormous energy in the process from their earliest days. Young people learn most rapidly and naturally from emulation and from play. Apparently, people are 'hard wired' to gather contextual learning most effectively through these two forms of engagement.

Therefore, Navigating the Healthcare System Trainers need to use adult education methods to ensure that the most effective teaching methods. Until recently, too much emphasis has been placed on education methods that are often minimally effective for producing change, such as information-rich, minimally-interactive, didactic lectures.

In the EPEC Project, educational methods such as case studies, narratives, role plays, and small group discussions are used to provide the natural and effective. As a Navigating the Healthcare System Trainer, you will want to use methods that are as interactive as possible.

How adults create memory and retain information

When an adult learns something new, the new fact first goes to short-term memory. Short-term memory must be converted into intermediate and then long-term memory for the new information to be retained. This process takes time and has a limited capacity. An adult can put about three major facts per hour into long-term memory.

In order for new information to be taken in, the person must be alert and paying attention. Keep in mind that a person will generally be able to attend to new information for only about 10 minutes. Then, he or she will need two minutes or so of mental rest to process it before attempting to learn a new piece of information. Overall attention declines after 45 minutes unless there is a significant change to reengage the learner.

Barriers to learning

As a Navigating the Healthcare System Trainer, you will be teaching people living with cancer and their family caregivers. As adults who have come through many learning experiences, they may have certain barriers to learning. Adult learners, for instance, are independent and often resist the student role. They come to learning situations with a variety of motivations. For them, some learning is re-learning rather than new learning. Prior learning may have been accomplished with different teaching methods as well. Attitudes may be more established and difficult to shift than with a younger person.

The learner may:

- feel he or she is at least as competent in the subject matter as the teacher,

- resent authority figures (e.g., teachers, healthcare professionals),

- be anxious that he or she will be seen as inferior or will be embarrassed during the session,

- have had bad learning experiences in the past which he or she has generalized to all learning experiences,

- have come to the session with other problems on his or her mind and be unable to focus,

- be interested in the material but be constrained by time pressures and focused on other priorities, or

- have personal barriers to learning the topic (e.g., a fear of cancer; having difficulty coping.

Although a Trainer should try to meet as many needs of the participants as possible, it is unrealistic to try to be everything to everyone. If possible, the Trainer should attempt to assess the participants' needs and issues by asking what types of barriers they have had in the past.

While some issues may be beyond the scope of a teacher's responsibilities, some factors that affect learners may be dealt with by establishing the value and relevance of the material.

Overall, respect helps to overcome barriers a good deal. This includes:

- Respecting the adult learner's independence, maturity, and previous knowledge and experience.

- Respecting them as co-learners. Although you as the teacher have the materials and possibly more content and teaching expertise, but they also bring valuable knowledge and perspectives.

- Respecting and inquiring about participants' motivations to learn.

- Respecting resistance to change. There is likely an understandable reason. Once you do understand it, it (or you) may yield.

Knowing your learners and engaging different learning styles

The two most common teaching and learning styles are referred to as "passive" and "active."

Passive learning

Passive learning occurs when the participant does not take an active role in the process. Examples are: reading, watching, listening to a lecture, or observing an interaction between the teacher and another student. This type of learning can lead to information transfer, reflection, evaluation, assessment, and analysis.

One major advantage of passive learning is that a large amount of information can be presented. A major disadvantage is that recall of the material is limited. Passive learning correlates with memorization and simple fact recall. The learner may know the facts, but not be able to apply the information to solve practical problems. This is why it is important to link passive learning to active learning.

Most participants probably have had many learning experiences grounded in a passive teaching style. This characterizes what many of us received in grade school and beyond. Consequently, when providing education to others, we all may be inclined to teach using this same style. The passive style can be characterized by:

- The teacher deciding what the learners should learn.

- The teacher teaching the learner in a unidirectional fashion.

- There is no role for the learner's own experiences.

Active learning

Active learning occurs when the information provided is analyzed, discussed, debated, processed, linked to relevant activities, or incorporated into current decision-making processes. Participants may be challenged with a problem or activity that involves debate and resolution. Small groups may be convened to negotiate a solution or identify how the issue being discussed is relevant to their current situation.

Involving participants actively in the learning process is key because adult learners process and recall information better if they can:

- do something with the information.

- discuss it with others.

- ask questions about it.

- compare and contrast it to other things in their experience.

- reflect on it.

- try using the information and evaluate the results.

Adults have a variety of preferred learning styles (e.g., visual, auditory, kinesthetic). An active learning process involving interactions that take advantage of these different styles is more likely to reach all participants.

Active teaching

An active teaching style is characterized by:

- The teacher and learner negotiating what is to be learned.

- Education that is based on give and take.

- Valuing the learner's past experiences.

- Information sharing between the teacher and the learner.

Hank Slotnick and other educational theorists have expanded on these observations in the context of medical education.[1] Although Slotnick's observations originally applied to physicians, we believe that these observations are applicable to adult learners of all types.

1. Make the learning practical. Ensure what you teach relates to a problem the learner already has.

2. Encourage participation. Involve learners in the material to be learned and in the learning process.

3. Understand that multiple demands exist on the time and attention of adult learners. Acknowledge that adult learners have other priorities besides educational ones.

Carefully addressing these principles when constructing any educational session is vital for effective educational events.

Principles of Psychoeducation

When coping with a diagnosis of cancer, both individuals and those close to them experience a number of challenges that can affect learning and communication.

They must understand complex information about the disease and its treatments in the face of great stress. Receiving fragmented information, or feeling overwhelmed by the information received, and having difficulty knowing what to expect is a common concern for people living with cancer as well as their family caregivers.

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[1] Slotnick HB. How doctors learn: education and learning across the medical-school-to-practice trajectory. Academic Medicine. 76(10):1013-26, 2001.

The concept of **psychoeducation** in cancer care is based on the premise that fear and anxiety are a result of a lack of understanding and information. Psychoeducation therefore is an approach that combines education and psychosocial interventions. This approach is valuable in both providing practical information about cancer and its treatment, but also teaching about coping skills and strategies for optimally managing issues such as communication (within the family, with healthcare professionals, with others in their social system).

The goal is to help the person living with cancer and/or their family caregiver to learn coping mechanisms for future needs. When provided in a group format, psychoeducation incorporates techniques used in health education with those used in facilitating support groups (e.g. venting of emotions and considering behavior techniques to deal with the illness, considering other perspectives on problems). The session leader acts as a facilitator to guide the participants in this kind of learning by moderating discussion, providing reflections and summarizing key points of learning.

Some psychoeducational interventions are single-sessions. Others are ongoing groups. Principles that are critical when providing such a curriculum in a group format- where individuals will be sharing their own thoughts, reactions and personal information - include the following considerations:

1. **Understand the concerns and worries that participants may have about sharing personal information.**

   The facilitator should establish the "sharing rules" at the beginning of the session and address the expectations for confidentiality for example using first names only. Individuals may worry that what they share might be discussed by those in attendance outside of the session, and this is a valid concern. In this session, strategies such as providing examples of how "some people living with cancer respond to X with anger/sadness/etc." or "other people living with cancer might have problems with Y" can be a safer way to have members explore reactions to common challenges and permit them to reflect on common circumstances in a non-personal way.

   The facilitator should establish any other "ground rules" that will be key to creating an open learning environment. This can include demonstrating respect for idea sharing, remembering not to interrupt each other. Facilitators should be prepared to revisit these ground rules if issues arise during the session.

2. **Use group leadership skills, as described by Herman[2] , including**:

   - promoting a sense of cohesion,
   - developing a safe environment,
   - keeping interpretations focused on the group (vs. individuals),
   - helping members to support each other,

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[2] Hermann J. Cancer Support Groups: A Guide for Facilitators. American Cancer Society. 2002

- reinforcing the positive,

- providing structure, and

- providing information.

Group dynamics

When a structured learning experience brings together people for a period of time around a common issue, even if only for a few hours, it is possible to observe group characteristics and dynamics. You may compare this to experiences that you have had in your own training, where you interacted with others in a class setting over several hours. Many groups or classes, even in the limited time that they are together, will move through what are known as the beginning, middle and end phases of a group's development phases[2].

In the *beginning phase*, participants may initially be very quiet as they form impressions of the facilitator, evaluate the initial introductory remarks and the relevance of the session to their needs. They may also be looking to identify common ground with the other participants. This can be particular profound for those living with cancer (as participants may be thinking "Am I better off or worse off than others here today? Will I hear about things that I don't really want to think about? Will others be upset by what I might want to talk about?") As was discussed earlier, consider the different learning styles of those in attendance.

In the *middle phase*, some participants will become more actively engaged, offering comments and questions, and perhaps even challenging ideas presented or describing personal experiences This is typically indicative of members finding relevance in the content and discussion and a desire to give and receive feedback. How individuals interact within this session often is closely linked to their own coping and learning style.

In the *end phase*, as a session comes to a close, participants who may be ambivalent about the experience may even leave before the final closing, while those who have been particularly engaged may openly acknowledge the value of the experience and the impact of others on their own learning. Some participants may linger to talk further and to express feedback or thanks, or seek addition information from the facilitator.

The Navigating the Healthcare System Trainer will want to bear all of this in mind, as well as principles for adult education discussed earlier.

How is this different from other types of education?

Teaching people living with cancer and their family caregivers is something that you likely do every day. It is important to think how it might be different than other types of education. Some of these differences include:

Setting

Many traditional educational activities happen at a specific time and place. The teaching described in this curriculum may be scheduled as a session or sessions, or it may occur when people have come to a clinic or support group for other reasons.

Timing

Depending on the setting you may need to think of brief snapshots of the material. You may for example, have only 15 minutes at the end of an appointment with the person living with cancer or their family caregiver.

Who is being taught

This material is much different than material for colleagues. The major difference between teaching healthcare professionals and teaching people living with cancer and their family caregivers is that teaching involves what they are personally going through. This means that a Trainer will need to be sensitive to possible emotional associations with the material. This can be done by acknowledging that participants have a very personal connection with the material being taught and being able to monitor participant's emotional reactions during the class and respond appropriately.

Physical limitations

It is important to consider that participants may also be struggling with fatigue or other symptoms, and their ability to take in large amounts of information may be impacted by their physical discomfort or their distress level. The pace of the session and the planning of adequate breaks need careful attention.

Implementing the Navigating the Healthcare System Curriculum

Educational session design

Most well-designed educational programs mix both passive and active learning styles. Typically, some information needs to be transferred that is best presented using a relatively passive presentation style. On the other hand, information that is only shared in a passive learning format may become boring or irrelevant to the participant. The key to learning for adults is to provide new, relevant information that is usable within a relatively short time.

For trainers who are comfortable with a lecture-only teaching style and for participants who are comfortable with passive learning, group involvement and active participation may be viewed as problems. Trainers may feel they lose control of the group when turning the session over to the group members to grapple with exercises. Participants may think they could be learning more (e.g., quantity) if they could get the information through lecture or reading. Remember that participants are capable of cognitively understanding a great deal of information, but they can only retain so much of it per unit

time. It is important to consider that participants may also be struggling with fatigue or other symptoms, or their ability to take in large amounts of information may be impacted by their stress level.

This curriculum is designed to be offered as a half day (4-hours including lunch and breaks) workshop or as individual hour-long sessions. The following sections offer Trainers specific considerations for teaching the curriculum as well as some ideas about alternate formats.

Needs assessment

Before teaching, a needs assessment can help Trainers focus their content. A needs assessment is the process of understanding the needs of your audience. Sometimes, this is fairly formal, such as through a survey of participants before coming to a teaching session. This survey might ask what topics participants want to learn about or could ask knowledge questions about a topic in order to assess areas where knowledge might be lacking. When this is done in advance of a teaching session, the trainer can focus the session on the specific needs identified. Examples of questions include:

"What did you come today hoping to learn more about?"

"What are you hoping to learn to become more skilled at in terms of navigating the healthcare system?"

A needs assessment can also be conducted informally, by asking a few relevant questions to the audience at the beginning of a presentation: these questions might include asking the participants' familiarity with the topic or which specific parts of the topic they would most like to learn about. Since this type of needs assessment is done right before a session, it means that the Trainer needs to be flexible with what he or she is planning to teach.

Timing

If you have a half-day session with people living with cancer and their family caregivers, consider offering the workshop during that time. This has the advantage of allowing participants to experience the entire curriculum. Keep in mind that it requires more significant time from facilitators.

More commonly, Trainers give one module at a time as part of ongoing educational efforts for people living with cancer and their family caregivers. This has the advantage of requiring less of a time commitment from people living with cancer, their family caregivers and Trainers. It also means that people are free to choose which topics they want to learn about.

Audience

A range of learning styles and preferences exist. Those who receive information in a way compatible to their coping style (e.g. "information-seekers" vs. "information-avoiders"),

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will benefit most. This needs to be considered when determining a) who will benefit from the Navigating the Healthcare System curriculum and b) who will benefit from learning experiences that are in a group vs. one-to-one.

Psychosocial distress can be a factor that limits the individual's ability to gain from and participate in a group educational experience (especially a one-time workshop). Anxiety is a common experience for people living with cancer and family caregivers, particularly early in their experience with cancer and its treatment, although can be experienced at any point of the cancer trajectory. Severe levels of anxiety can interfere with the effectiveness of patient education efforts.

Trainers will want to consider this in light of who they include in such a session – and may find that this is a factor affecting participation rates. People living with cancer should be assessed for anxiety and their willingness to learn before proceeding with education. This is particularly true of group interventions, where witnessing others' anxiety or strong emotions may not be helpful to the individual at that point in time if they are particularly overwhelmed.

Setting and Format

This program, although originally designed to be provided in a group setting, can be adapted by clinicians to use in a number of ways. The following are suggestions:

Stand Alone Session

A single session could be offered in a number of settings as part of the organization's patient education program. If time is limited, specific aspects could be focused on in a "workshop" type of format (e.g. one or more modules from the Navigating the Healthcare System curriculum), based on what the clinician has assessed to be the interests of the intended audience. (Pre-screening of participants should be considered for the reasons noted in under Audience).

One-on-One vs. Group

The Navigating the Healthcare System Trainer may wish to use this in a one-on-one format instead. This will allow for tailoring the information to the specific person living with cancer and/or family caregiver, particularly if this is an intervention to focus on an identified issue (e.g. the person living with cancer has raised concerns about being able to navigate or communicate with a healthcare provider).

Marketing and Publicity

As you plan training sessions, consider how people will be informed about the program happening. Is it part of an ongoing series of education? Will it be marketed by you as the Trainer or by the hospital or clinic? Will you have people sign up in advance?

As a Navigating the Healthcare System Trainer, your goal is to facilitate the learning of people living with cancer and their family caregivers.

Teaching Techniques

There are many approaches to teaching. You are probably familiar with some of these already. Below, we outline three techniques: **interactive lecture**, **small group facilitation**, and **role play**.

Interactive lecture: an interactive lecture is a lecture that presents content, often using slides, and includes interaction with the audience. An interactive lecture can be given to a small group or a large group. The key skill in an interactive lecture is to be able to cover the necessary amount of information while also engaging the learners. Techniques to promote interaction include:

Yes/no or brief survey questions such as:

> *"How many of you have had experiences like this?"*

More open-ended questions allow participants to describe their experiences, such as:

> *"Can someone tell us what happened when they first got their treatment?"*

These types of approaches allow the group to be engaged and allow the facilitator to use the group's experiences to help frame the material.

Small-group facilitation: many teaching sessions happen in small groups of people living with cancer and their family caregivers. A small group may be as few as two people and as many as twenty. The optimum size is often thought to be around eight to ten. The skills that are necessary for small group teaching are the ability to facilitate an interactive exercise (such as video case or a case/story that a person living with cancer or family caregiver brings to the group). Although more informal than an interactive lecture, it is important for a small group to begin with the facilitator establishing an agenda, objectives and timing. This structure can then allow the free flow of ideas to occur.

Role play: Role play is a specific teaching technique in which the facilitator creates clinical interaction for the participants to act out. For example, participants could "play" a doctor and a patient in an interaction about discussing a new diagnosis. The facilitator then debriefs participants about the process.

Co-Facilitator Approach

Sometimes, using two facilitators for a teaching session is a valuable approach to its delivery. During the workshop, one facilitator can focus on presenting information and keeping the process moving, while the other can be attending to the responses of the participants. This might include watching if anyone is having a particularly difficult time with the topic being discussed, offering observations or addition comments or redirecting.

Using this as an opportunity to introduce team members from two professions (for example, social work and nursing) provides added benefit to the learning experience as participants will learn more about both roles.

Potential Pitfalls and Teaching Challenges

All teachers may face challenges during teaching. In the sections below we highlight some of these.

Too diverse a range of experiences in the room

There is some debate about having individuals with significantly different characteristics such as type of cancer & stage of disease (e.g. people living with cancer with early stage breast along with those living with metastatic lung cancer) in the same support group. This should be considered by the Navigating the Healthcare System Trainer – along with their skill to manage the dynamics related to this that can arise – when planning for the workshop audience.

Too much silence

Silence can happen for a number of reasons. Most commonly, participants may be:

- thinking about what has been said and relating it to their own circumstances, or
- confused about what has been said, and need clarification.

Strategy

Ask the group some prompts to gauge their reaction to …

"What has been most helpful to you from what we have just shared with you?"

"Is there something that you would like to hear more about?"

"Do you feel that this discussion has been relevant to your situation?"

"Is there anything that you disagree with or might see differently?"

Too many slides

Using slides can be challenging for presenters. At the same time, trying to stick strictly to slides rather than allowing for discussion or changes in the presentation, can make a presentation less effective.

Strategy

- You can let participants know that you are going to skip some content that is in their packages in order to stay with a point that seems to be of great interest to them.
- Go with the group's needs and interests instead of trying to cover all the planned content.

- Abandon the slide content in favor of discussion, and then transition back, if and when appropriate, to the structured presentation information.

- "Thanks for the great discussion on this point. A similar topic… or Building on this, I'd like to offer some additional ideas."

Too much talking

a. One or two participants dominating discussion

Strategy:

Say something such as:

"We haven't heard from everyone yet today and I want to make sure that everyone has a chance to share their views. Is there anyone else who would like to offer their thoughts about this topic?"

b. Discussion on one point is preventing covering other points that seem important

Strategy:

Say something such as:

"The amount of discussion on this point has illustrated what an important issue this is for those here today. There are, however, some other concepts in today's content that might be equally as important to you or others in the room. Would it be okay if we moved on to the next topic now?"

Difficult Situations/Group Dynamics

a. Conflict between members or a member who is being disrespectful of others (e.g. judging others' perspectives).

Strategy:

- Revisit the "Ground Rules" established at the beginning of the session.

- Facilitate or make an observation that re-establishes the tone you want for the group.

- *"It is clear that we are all individuals and will have different perspectives and experiences. None are more right or more wrong than others. Let's be sure we have room for all of those views in today's session."*

b. A member's overwhelming expression of emotion, such as uncontrollable crying, which may or may not have been triggered by the material.

Strategy:

- Depending on the severity of the emotion, the session may need to be briefly interrupted to check if the member feels okay to continue with the group.

- It may be appropriate to reinforce to the group that expressing emotions is healthy. However, don't let the incident derail the session.

- If possible, be prepared in advance to have a co-facilitator or other staff person available to gently help the member who cannot continue, to leave the group.

- Always follow up with that member privately after the session to provide any needed help.

Summary

This module introduces Trainers to the Navigating the Healthcare System curriculum design and how it is intended to be taught to people living with cancer and their family caregivers. Topics such as principles of adult education, teaching styles, learning styles, and psychoeducation are presented. Suggestions for how to implement a training program using the Navigating the Healthcare System curriculum are outlined, as well as strategies for avoiding common pitfalls.

Navigating the Healthcare System

A Workshop for People with Cancer and their Family Caregivers

Trainer's Notes

Introduction to Trainer's Notes

In the following sections you will find module-specific planning and teaching tips. For each module in the Participant's Handbook, there is a brief section included here for Trainers called "Trainer's Notes."

Trainer's Notes follow the format below:

- Principle Message

- Module Overview

- Preparing for a Presentation

- Making the Presentation

- Interactive Exercises

These notes are designed to help you effectively prepare, focus and deliver your presentation to people living with cancer and their family caregivers.

Also, included in your conference materials is an electronic version of both the Participant's Handbook and the Trainer's Guide on CD-ROM. This version is helpful for printing extra copies of the curricular materials and participant exercises.

Navigating the Healthcare System

A Workshop for People with Cancer and their Family Caregivers

Trainer's Notes:

Module 1: Introduction to Navigating the Healthcare System

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Module 1: Trainer's Notes

Principal Message

Understanding how the healthcare system works and who the healthcare team is will help get the best and most coordinated healthcare.

Module Overview

"Introduction to Navigating the Healthcare System" introduces the concept of navigation and presents basic information to orient the participants to different aspects of the healthcare system. The module presents information on members of the healthcare team and their roles, healthcare settings, and health insurance coverage options. The material is presented in a practical way to facilitate the participant's ability to understand the components of an increasingly complex healthcare system, and participate in beginning one's own plan for achieving the best care possible.

Preparing for a Presentation

1. Aim to meet the needs of your audience

Try to understand as much as reasonably possible about your participant's backgrounds, stage of cancer and existing level of knowledge about the topic. Choose from the material provided in the module according to the needs of your expected participants. It is better for participants to come away with a few new pieces of well-selected information, well learned, than to come away with a deluge of information, but remembering nothing.

2. Presentation timing

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Presentation	40 minutes
Summary	2-3 minutes
Evaluation	5 minutes
Total	49-51 minutes

3. Number of slides

There are 14 slides for Module 1.

4. Preparing your presentation

The text in the module was not designed to be used as a prepared speech. Instead, the text provides material you may want to use. The slides have been designed to trigger your presentation. Although the slides closely follow the text of the module, they do not contain all of the content. Their use presumes that you have mastered the content.

You may want to make notes on the slide summary pages to help you prepare your talk in more detail and provide you with notes to follow during your presentation.

Remember that you can adjust the slides to suit your presentation content, your style, and to make it feel fully familiar and your own.

Practice your presentation using the slides you have chosen, and speaking to yourself in the kind of language you expect to use, until it is smooth and interesting and takes the right amount of time. The most accomplished presenters and teachers still practice prior to a presentation.

5. Equipment needs

- Laptop computer, LCD projector and screen. Note: Some LCD projectors will allow use of a USB (thumb) drive. In this case the USB can be loaded with the slides in advance, making the laptop unnecessary.

- Preprinted slide handouts for each participant. This helps participants take notes. (Also, if no LCD equipment is available for slides, or malfunctions, the presentation can be given from the slide handouts).

- Copies of the "Understanding your Healthcare Team" exercise provided in the Trainer's Notes.

- Flipchart and markers for recording discussion points.

Test your equipment beforehand to ensure that it works. Have a back-up plan so that if there is any equipment failure you can move without panic to your back-up plan. For instance, have in mind that you will:

- refer to the hand out slides if the slides can not be shown on the screen.

- have participants list items on their hand outs that you would have written up for all to see if the markers or overhead projector do not work.

Making the Presentation

1. Introduce yourself

If you have not already done so, introduce yourself. Include your name, title, and the organization(s) you work for. You may also wish to include the above information and/or your contact information at the beginning or end of the presentation slides. Briefly describe your clinical experience related to the information you will be presenting.

2. Introduce the topic

Show the title slide for the module. To establish the context for the session, make a few broad statements about the importance of teams in cancer care. Tell participants the format and time you will take to present the session. Identify the teaching styles that you intend to use.

3. Review the session objectives

Show the slide with the session objectives listed. Read each objective and indicate those you are planning to emphasize.

4. Present the material

Recommended style: interactive lecture

An interactive lecture will permit you to engage your audience, yet cover your chosen material within the time. You can use as your interactive components the trigger tape stimulated discussion and an interactive exercise. An example of an exercise is below. To foster discussion, ask participants for examples from their institutions or experiences. Ideally, the examples could be linked to one of the major teaching points. You can also use the case example, "A Cancer Survivor's Story" on page 11 to generate discussion.

Interactive exercise: Understanding your healthcare team

Timing: 15 minutes

Recommended number of participants: any number

Necessary Materials: Print outs of the exercise for participants (found at the end of the Trainer's Notes for this module); Flip chart or white board to record discussion points

The goal of this exercise is to have participants identify the role of healthcare professionals involved in their care. The exercise is in three parts:

1. Person living with cancer/family caregiver pairs brainstorm a memorable situation where many healthcare professionals were involved in their care.

2. Facilitator invites participants to share their experiences.

3. Group discusses the roles of the healthcare professionals involved and additional resources available to address unmet needs.

Ask your participants to work in pairs of person living with cancer and family caregiver. Give each pair a copy of the exercise, which is included at the end of the Trainer's Notes for this module. Have the pair fill in the worksheet with their own experience of an interaction involving many members of the healthcare team. Ask them to consider:

1. How many and what types of healthcare professionals were involved

2. Each person's role in their care

3. How well these different professionals communicated with each other

When the groups have completed the task, invite participants to share the experience they wrote down. Using one experience as an example, have the group try to identify:

- the different types of healthcare professionals involved

- the issues each healthcare professional was trying to address

- additional healthcare professionals who could address any of the pair's unmet needs

- whether understanding the roles of the many kinds of healthcare professionals will help make them a part of the participants' care teams

Record discussion points on a flip chart or white board. The 'Healthcare Professional' tables on pages 16-19 can be used as a reference for participants.

6. Summarize the discussion

Briefly review each part of the presentation. Recap two or three of the most important points that were discussed.

Exercise: Understanding your healthcare team

The goal of this exercise is to identify the role of healthcare professionals involved in your care.

This exercise is in two parts; person living with cancer /family caregiver discussion and a group discussion.

1. Person living with cancer/Family caregiver discussion

Work in pairs to brainstorm a memorable situation where many healthcare professionals were involved in your healthcare.

First, write down all of the different healthcare professionals who were involved – include physicians, nurses, social workers and any others.

Next to each name, write down their role in your care.

Finally, consider how well you perceived them communicating with each other.

Healthcare professional   Role
_____
_____
_____
_____
_____
_____
_____
_____

2. Group Discussion:

Once you have completed this task, the facilitator will ask for volunteers to share the experience they wrote down. Using one experience as an example the group will then work together to:

> Consider:
>
> ⌃ the different types of healthcare professionals involved
>
> ⌃ the issues each healthcare professional was trying to address
>
> ⌃ additional healthcare professionals who could address any of the pair's unmet needs
>
> ⌃ whether understanding the roles of the many kinds of healthcare professionals will help you make them part of your team. If so, in what ways?

Navigating the Healthcare System

A Workshop for People with Cancer and their Family Caregivers

Trainer's Notes:

Module 2: How Families Live with Cancer

Principal message

People living with cancer need to build a team of care at home and in the clinical setting to help them manage everyday responsibilities and challenges.

Module overview

"How Families Live with Cancer" outlines strategies for building a team of care at home and coordinating more efficiently with the medical team. It begins by talking about how to align goals of care for the person with cancer between the clinical and home teams. The module also lists guidelines for team building, discusses how to identify tasks and roles for team members and how to match those roles and tasks to specific members of the team. The module also lists sources of information and support for team members.

Preparing for a presentation

1. Aim to meet the needs of your audience

Try to understand as much as is reasonably possible about your participants' backgrounds, stages of cancer, support networks, and existing levels of knowledge about the topic. Choose from the material provided in the module according to the needs of your expected participants. It is better for participants to come away with a few new pieces of well-selected information, well learned, than to come away with a deluge of information, but remembering nothing.

2. Presentation timing

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Video trigger tape & discussion	10 minutes
Presentation	30 minutes
Summary	2-3 minutes
Evaluation	5 minutes
Total	49-53 minutes

3. Number of slides

There are 10 slides for this module.

4. Preparing your presentation

The text in the module was not designed to be used as a prepared speech. Instead, the text provides material you may want to use. The slides have been designed to trigger your

presentation. Although the slides closely follow the text of the module, they do not contain all of the content. Their use presumes that you have mastered the content.

You may want to make notes on the slide summary pages to help you prepare your talk in more detail and provide you with notes to follow during your presentation. Remember that you can adjust the slides to suit your presentation content, your style, and to make it feel fully familiar and your own.

Practice your presentation using the slides you have chosen, and speaking to yourself in the kind of language you expect to use, until it is smooth and interesting and takes the right amount of time. The most accomplished presenters and teachers still practice prior to a presentation; don't miss this step.

5. Equipment needs

- Laptop computer, LCD projector and screen. Note: Some LCD projectors will allow use of a USB (thumb) drive. In this case the USB can be loaded with the slides in advance, making the laptop unnecessary

- DVD player and monitor or projector

- Preprinted slide handouts for each participant. This helps participants take notes. (Also, if no LCD equipment is available for slides, or malfunctions, the presentation can be given from the slide handouts)

- Copies of the "Making a Team-O-Gram" exercise.

- Flipchart and markers for recording discussion points

Test your equipment beforehand to ensure that it works. Review your DVD segments to assess which trigger videos or portions you would like to use. Cue your video to the start of the segment you will use for the session.

Have a back-up plan so that if there is any equipment failure you can move without panic to your back-up plan. For instance, have in mind that you will:

- if the DVD fails, read the vignette of the trigger tape story

- if the slides cannot be shown, refer to the hand out slides

- if the markers or overhead projector do not work, have participants list items on their hand outs that you would have written up for all to see

Making the presentation

1. Introduce yourself

If you have not already done so, introduce yourself. Include your name, title, and the organization(s) you work for. Briefly describe your clinical experience related to the information you will be presenting.

2. Introduce the topic

Show the title slide for the module. To establish the context for the session, make a few broad statements about the importance of teams in cancer care. Tell participants the format and time you will take to present the session. Identify the teaching styles that you intend to use.

3. Review the session objectives

Show the slide with the session objectives listed. Read each objective and indicate those that you are planning to emphasize.

4. Show the DVD trigger tape

After reviewing the objectives for the session, show the DVD trigger tape. It has been designed to engage the audience and provide an appropriate context for the session. It was not designed to demonstrate an ideal interaction, but to "trigger" discussion.

Trigger tape content

Karen, a breast and lung cancer survivor, and her husband, Jim, discuss how Karen has been feeling tired lately and how different family members and friends may be able to help.

Discussion

After the trigger tape, ask the participants for their comments about the issues and the interaction they have just seen. To affirm what they contribute, consider recording the important points on a flipchart or overhead projector.

If the discussion is slow to start, you may want to ask more direct questions, like:

- What are some of the challenges that you imagine Karen might face now (consider physical, emotional and other challenges)?

- What issues did Karen and Jim identify?

- What resources in the family does she have draw on to meet the challenges?

- What would a home care team look like for Karen and Jim?

- How is this situation similar to or different from your own?

Use the discussion to set the stage for the material to follow. Don't let the discussion focus on a critique of the technical quality of the DVD or how "real" the players seemed. If the participants don't like something that was said or done in the DVD, acknowledge that there is always room for improvement and ask them how they would do it themselves.

Setting limits to discussion time

It is usually best to limit discussion of the DVD to no more than 5 minutes, then move on to the presentation. To help move on if the discussion is very engaged, try saying something like:

- Let's hear two last points before we move on.

- Now that you have raised many of the tough questions, let's see how many practical answers we can find.

For the more advanced facilitator who is very confident of both the material and his or her pedagogic skills, it is possible to use the trigger tape as a form of case-based teaching and to facilitate the discussion to draw out the teaching points of the module. The hazard of this approach is that the discussion will not yield the desired teaching points. Feel free to return to the slides if this happens. If this approach is used, it is essential to write up the points on a flip chart as they arise, in order to fill in any gaps and to summarize at the end. Again, use this method with caution and only if you are really ready.

5. Present the material

Recommended style: interactive lecture

An interactive lecture will permit you to engage your audience, yet cover your chosen material within the time. You can use as your interactive components the trigger tape stimulated discussion and an interactive exercise. To foster discussion, ask participants for examples from their institutions or experiences. Ideally, the examples could be linked to one of the major teaching points.

Interactive exercise: Making a Team-O-Gram

Timing: 20-25 minutes

Recommended number of participants: any number- recommended for smaller groups

Necessary Materials: Print outs of the exercise for participants (found at the end of the Trainer's Notes for this module); Flip chart or white board to record discussion points

The Team-o-gram helps participants identify potential team members.

Ask participants to work in pairs of person living with cancer and family caregiver. Give each pair a copy of the Team-o-gram, which is included at the end of the Trainer's Notes for this module. Have each group brainstorm lists of tasks they need help with, as well as potential team members. This can be done among the whole group or just in pairs. Then each pair should try to match team members to specific tasks. Another possibility is to use the trigger tape example to develop a Team-o-gram for Karen and Jim in front of the whole group before splitting into pairs so that participants have a better idea of how to use the Team-o-gram. You can also refer to the example Team-o-gram on page 55.

When the groups have completed the task, invite them to comment on:

- What they liked and disliked about the exercise.

- How they could use this tool at home and/or how it could be improved.

- Other possible ways to identify and track your home care team.

6. Summarize the discussion

Briefly review each part of the presentation. Recap two or three of the most important points that were discussed.

Exercise: Making a Team-O-Gram

The goal of this exercise is to practice building a team.

Part of building a strong team to help you at home is identifying:

- What needs to be done?

- Who is available to help?

- What role fits each team member best?

Step 1: What needs to be done?

List some things that need to be done at home in the chart below. You can use the chart on page 54 in your workbook as an example. Be as specific or general as you like. Then mark whether you are able to do the item or if you think you might need help.

Things I need	I can do that	I need help

Step 2: Who is available to help?

Next, identify some people (or organizations) in your life that you think might be willing or able to help. Next to their name, list some things they might be good at or what they might enjoy helping with.

Name	How can they help?

Step 3: What role fits each team member best?

Finally, look at each person or group above and think about what roles they could play in your team. Don't forget to think about your role, too. Try to think about the things you need in terms of categories. For example, you might have categories for Transportation, Doctor Visits, Researching Treatment Options, etc. You can assign a manager for each category and then team members to help out. List your categories below and then identify a head person for each category and helpers.

Category	Manager	Helpers

Step 4: Make your Team-O-Gram

Now that you have the categories, we can make an organization chart. Refer to page 55 in your workbook for a sample team-o-gram. First, identify the CEO of your team. Most of the time, this will either be the person with cancer or the family caregiver. Put that person at the top of the diagram. Underneath the CEO, you can list the category managers and the helpers. (It is OK if the CEO also manages a department or is a helper.) Use the sample as a guide and ask your group leader for help if you are having trouble.

CEO

Navigating the Healthcare System

A Workshop for People with Cancer and their Family Caregivers

Trainer's Notes:

Module 3: Recognizing and Communicating Needs at Home

Principal Message

Know how to recognize, track, and communicate symptoms and needs.

Module Overview

"Recognizing and Communicating Needs at Home" provides strategies to prepare for future healthcare appointments at home. The module describes the skills needed to be an effective patient navigator and the tasks involved. It also provides an introduction to different types of communication styles that participants may have. The primary focus of the module deals with recognizing signs, symptoms and needs of people living with cancer. Tools such as the *LAF Health Journal* and the *NEST*[3] tool are introduced as ways for people living with cancer and their family caregivers to organize, record, and track information. Goals of care and advance care planning are also discussed as examples of important communication.

Preparing for a Presentation

1. Aim to meet the needs of your audience

Try to understand as much as possible about your participants' backgrounds, stage of cancer and existing level of knowledge about the topic. Choose from the material provided in the module according to the needs of your expected participants. It is better for participants to come away with a few new pieces of well-selected information, well learned, than to come away with a deluge of information, but remembering nothing.

2. Presentation timing

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Presentation	40 minutes
Summary	2-3 minutes
Evaluation	5 minutes
Total	49-51 minutes

3. Number of slides

There are 13 slides for this module.

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[3] Emanuel LL, Alpert HR, Emanuel EE. Concise screening questions for clinical assessments of terminal care: the needs near the end-of-life care screening tool. *J Palliat Med.* 2001;4(4): 465-74.

4. Preparing your presentation

The text in the module was not designed to be used as a prepared speech. Instead, the text provides material you may want to use. The slides have been designed to trigger your presentation. Although the slides follow the text of the module, they do not contain all of the content. Their use presumes that you have mastered the content.

You may want to make notes on the slide summary pages to help you prepare your talk in more detail and provide you with notes to follow during your presentation.

Remember that you can adjust the slides to suit your presentation content, your style, and to make it feel fully familiar and your own.

Practice your presentation using the slides you have chosen, and speaking to yourself in the kind of language you expect to use, until it is smooth and interesting and takes the right amount of time. The most accomplished presenters and teachers still practice prior to a presentation.

5. Equipment needs

- Laptop computer, LCD projector and screen. Note: Some LCD projectors will allow use of a USB (thumb) drive. In this case the USB can be loaded with the slides in advance, making the laptop unnecessary.

- Preprinted slide handouts for each participant. This helps participants take notes. (Also, if no LCD equipment is available for slides, or malfunctions, the presentation can be given from the slide handouts).

- Copies of the "Identifying Communication Styles," "Filling out NEST," and "Advance Care Planning" exercises, and the NEST worksheet.

- Flipchart and markers for recording discussion points.

Test your equipment beforehand to ensure that it works. Have a back-up plan so that if there is any equipment failure you can move without panic to your back-up plan. For instance, have in mind what you will do if:

- if the slides cannot be shown, refer to the hand out slides.

- if the markers or overhead projector do not work, have participants list items on their hand outs that you would have written up for all to see.

Making the Presentation

1. Introduce yourself

Include your name, title, and the organization(s) you work for. You may also wish to include the above information and/or your contact information at the beginning or end of the presentation slides. Briefly describe your clinical experience related to the information you will be presenting.

2. Introduce the topic

Show the title slide for the module. To establish the context for the session, make a few broad statements about the importance of recognizing and communicating your needs and symptoms. Tell participants the format and time you will take to present the session. Identify the teaching styles that you intend to use.

3. Review the session objectives

Show the slide with the session objectives listed. Read each objective and indicate those you are planning to emphasize.

4. Present the material

Recommended style: interactive lecture

An interactive lecture will permit you to engage your audience, yet cover your chosen material within the time. You can use as your interactive components the trigger tape stimulated discussion and an interactive exercise. To foster discussion, ask participants for examples from their own experiences. Ideally, the examples could be linked to one of the major teaching points. You can also use the case example on page 74-75 to generate discussion.

You can also print out copies of the *LAF Health Journal* found at www.livestrong.org for participants to illustrate the content on pages 85-87. In addition, the two interactive exercises below can be used to teach the module content.

Interactive exercise #1: Identifying Communication Styles

Timing: 10-15 minutes

Recommended number of participants: any number

Materials: Handouts of the exercise (found at the end of the Trainer's Notes for this module); Flip chart or white board to record discussion points

The goal of this exercise is to help identify communication styles. Have participants work together in pairs. First, they will identify the communication skills for individuals important in their cancer experience. Next, participants will select team members that are well suited for some of the common communication situations people living with cancer and their family caregivers face.

When the participants have completed the task, invite them to share what they wrote down. Using one experience as an example, have the group try to identify:

- When might you need different types of communication skills?

- In which situations would communication be more difficult?

- Were you surprised by anything you wrote down?

Record discussion points on a flip chart or white board.

Interactive exercise #2: Filling out NEST

Timing: 20-25 minutes

Recommended number of participants: any number

Materials: Handouts of the exercise (found at the end of the Trainer's Notes for this module) and the NEST tool for participants (found at the end of Module 3); Flip chart or white board to record discussion points

The goal of this exercise is for people living with cancer and/or their family caregivers to fill out *NEST*. *NEST* is a screening tool to help people living with cancer and their family caregivers identify symptoms and needs that that they can then discuss with their healthcare providers.

Ask participants to split into pairs of person living with cancer and family caregiver. Each person should fill out the NEST form. People living with cancer should fill out the NEST form about themselves. Family caregivers should fill out the NEST form about the person living with cancer. Each person will then discuss the results with one another.

Explain the NEST tool and the exercise steps. Give examples of discussion topics to facilitate partner and group discussions. If you have participants with out partners have them fill out the NEST tool and discuss it in a small group.

When the groups have completed the task, invite participants to share what they wrote down. Using one experience as an example, have the group try to identify:

- What was it like to do this?

- How was it helpful?

- Did it teach you things you did not know?

- Do you think you might use this process to help communicate with your healthcare team? If so, in what ways?

Record discussion points on a flip chart or white board.

Interactive exercise #3: Advance Care Planning

Timing: 10-15 minutes

Number of Participants: any number

Necessary Materials: Print outs of the exercise for participants (found at the end of the Trainer's Notes for this module); Flip chart or white board to record discussion points

Use the Advance Care Planning worksheet as an interactive exercise. This document helps participants think about their values and treatment preferences should their illness worsen.

50

Ask your participants to work in pairs of person living with cancer and family caregiver. Give each pair a copy of the exercise, which is included at the end of the Trainer's Notes for this module. Have the person living with cancer fill in the worksheet with their own wishes and the family caregiver fill in a separate sheet with their perceived knowledge of the person with cancer's wishes. Each question presents a hypothetical scenario and asks participants to rate whether or not they would want treatment under such circumstances.

When the groups have completed the task, invite them to comment on:

- What they liked and disliked about the tool

- Where the person with cancer's and the family caregiver's perception of wishes differed and why that was the case

- How they could use this tool to talk about their preferences

- How they could use this tool to as a starting point for advance care planning or making an advance directive.

6. Summarize the discussion

Briefly review each part of the presentation. Recap two or three of the most important points that were discussed.

Exercise: Identifying communication styles

The goal of this exercise is help identify communication styles.

We all have different ways of communicating with others. This relates to our personal communication style (such as open vs. reserved) and personality (such as some people may be introverted or "quiet" while others are more extroverted or "outgoing"). Think of yourself and the key people in your life. Their specific communication strengths may be valuable in helping you when facing situations requiring particular ways of communicating.

This exercise has two parts. In Part 1, identify the different communication styles that you and people in your life have. In Part 2, identify who can help with different communication tasks.

Part 1: Which of the following communication skills fit with you and the people in your life?

Check the boxes that apply. You may check more than one.

TEAM MEMBER	*Keeps emotions & feelings under control and private*	*Openly talks about feelings and reactions to situations*	*Listens to others; is comfortable when someone expresses concerns to them*	*Gives helpful feedback or advice; Is a good problem-solver and negotiator*	*Is comfortable asking for advice or help from others; can find answers and information*
YOURSELF					
Main family caregiver or friend					
Other family caregivers					
Other:					
Other:					

Part 2: Based on thinking about ways of communicating, who might have the right style to help you?

Type of Situation	Name(s)
1. Communicating about my needs with member(s) of my health care team.	
2. Helping me find information about resources.	
3. Helping me with tasks around the house, taking charge of things I can't manage.	
4. Supporting me if I have had a difficult or upsetting day.	
5. Solving a problem related to my medical coverage or appointments.	
6. Other situations:	
7.	
8.	

Exercise: Filling out NEST

The goal of this exercise is for you as a person living with cancer and/or a family caregiver to fill out *NEST*.

NEST is a screening tool to help people living with cancer and their caregivers identify symptoms and needs that that they can then discuss with their health care providers

This exercise has three steps:

1. Each person (person living with cancer and family caregiver) will fill out one of the NEST forms.

2. Each person will then discuss the results with one another.

3. We will then discuss the results as a group.

Step 1: Filling out *NEST*

NEST has specific questions, with each answered on a 0 to 10 scale, where 0 is none of the time and 10 is all of the time. In general, the more severe or more often you have a need or feel a symptom, the higher a number you should select.

With each question, there are two other sections:

1) A section for "comments"

These comments are for any aspect of the question that might not be captured in the 0 to 10 scale of the main question, such as a specific example of a problem with insurance.

2) A section for possible "resources"

This section includes ideas for people or places to turn to for help with a particular item. As you review *NEST*, some of the questions might seem obvious and some less so. That is all right. These forms were designed to cover the range of experiences of people living with cancer and their family caregivers, and it is very likely that some questions will be more familiar than others.

- If you are the **person living with cancer**, fill out *NEST* **about yourself**.

- If you are the **family caregiver**, fill out *NEST* **about the person living with cancer**

Step 2: Discussing your experiences with each other

After 10 minutes, we will discuss this exercise in pairs. Discuss what needs each of you noticed and what strategies you identified to meet those needs.

> Consider:
>
> ⅄ What were some of the most significant needs that each person noted?
>
> ⅄ What were some of the least significant?
>
> ⅄ Were there any things that surprised either of you?
>
> ⅄ What strategies did you identify to meet these needs?
>
> ⅄ What did you learn about each other by doing this exercise?

Step 3: Discussing the experience as a group

After discussing the *NEST* results in pairs, we will come back together as a large group to discuss the overall experience of filling out these forms.

> Consider:
>
> ⅄ What was it like to do this?
>
> ⅄ How was it helpful?
>
> ⅄ Did it teach you things you did not know?
>
> ⅄ Do you think you might use this process to help communicate with your healthcare team? If so, in what ways?

Each of these tools – the LIVESTRONG Guidebook and the *NEST* Tool – can help you keep track of concerns related to the cancer experience. They can also help you communicate with physicians and other members of your healthcare team.

Exercise: Advance Care Planning

The goal of this exercise is to discuss values that might guide your advance care planning. It is not designed to obligate you to any kind of future treatments, but to explore your values and priorities. Imagine a situation where your illness has gotten much worse. Ask yourself what you would want in the situations described below if the treatment would not reverse or improve your condition.

Directions: Circle the number from 1 to 5 that best indicates the strength and direction of your desire. If you wish, you can add additional thoughts on the *Comment* lines.

1 -- **Definitely want** treatments that might extend your life.
2 -- **Probably would want** treatments that might extend your life.
3 -- **Unsure of what you want.**
4 -- **Probably would NOT want** treatments that might extend your life.
5 -- **Definitely do NOT want** treatments that might extend your life.

What If you…	Definitely Want Treatment			Definitely Do Not Want Treatment	
a. No longer can recognize or interact with family or friends.	1	2	3	4	5

Comment_____

b. No longer can think or talk clearly.	1	2	3	4	5

Comment_____

c. No longer can respond to commands or requests.	1	2	3	4	5

Comment_____

d. No longer can walk but get around in a wheel chair.	1	2	3	4	5

Comment_____

e. No longer can get outside and must spend all day at home.	1	2	3	4	5

Comment_____

f. Are in severe untreatable pain most of the time.	1	2	3	4	5

Comment_____

g. Are in severe discomfort most of the time   1   2   3   4   5
(such as nausea, diarrhea).

*Comment*_____

h. Are on a feeding tube to keep you alive.   1   2   3   4   5

*Comment*_____

i. Are on a kidney dialysis machine to keep you alive.   1   2   3   4   5

*Comment*_____

j. Are on a breathing machine to keep you alive.   1   2   3   4   5

*Comment*_____

k. Need someone to take care of you 24 hours a day.   1   2   3   4   5

*Comment*_____

l. No longer can control your bladder.   1   2   3   4   5

*Comment*_____

m. No longer can control your bowels.   1   2   3   4   5

*Comment*_____

n. Live in a nursing home permanently.   1   2   3   4   5

*Comment*_____

o. Other: 1   2   3   4   5

*Explain*_____

(Adapted from Pearlman, et. al. "Your Life, Your Choices")[4]

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[4] R. Pearlman, et. al., Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will, Veterans Administration Medical Center, Seattle, Washington.

The NEST Tool

The 13 questions below are designed to elicit your experiences during this illness related to all aspects of your care. There are no right or wrong answers. Rather, they are intended to track your experiences. If you answer a higher number than the red highlighted number, it suggests that this is something you should bring up with your healthcare team.

1. How much of a financial hardship is your illness for you or your family?

None   A great deal

0	1	2	**3**	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

Possible Questions to ask your doctor or other healthcare team member:

Can a social worker help me?

Am I eligible for Medicaid?

Can Medicaid cover some of my costs?

Are there any hospital resources that I can access?

Other potential resources:

Hospital financial office

American Cancer Society

Lance Armstrong Foundation

Local churches, synagogues, mosques

Local non-profit cancer organizations

2. How much trouble do you have accessing the medical care you need?

None   A great deal

0	1	2	**3**	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

<u>Possible Questions</u> to ask your doctor or other healthcare team member:

Are there any other hospitals or doctors that are closer to my home?

Can a social worker help me to have better access to my medical appointments?

<u>Other potential resources:</u>

Local non-profit cancer organizations

3. How much help do you need with things like getting meals or getting to the doctor?

None   A great deal

0	1	2	**3**	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

<u>Possible Questions</u> to ask your doctor or other healthcare team member:

Are there any government funded meal programs, such as Meals on Wheels, that I would qualify for?

Are there any government funded nursing programs or home health agencies available?

Does your hospital/office have any transportation programs for patients in need?

Are there any public transportation options for people with medical needs?

Other potential resources:

Family members, friends

Local churches, synagogues, mosques

Local non-profit cancer organizations

American Cancer Society

4. How often do you confide in someone?

Anytime I want   Never

0	1	2	3	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

Possible Questions to ask your doctor or other healthcare team member:

Can you refer me to a mental health professional?

Can you refer me to a support group?

Other potential resources:

Local support groups through American Cancer Society or other local non-profit cancer support organizations

5. How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel or urination problems?

Not at all   A great deal

0	1	2	3	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

Possible Questions to ask your doctor or other healthcare team member:

Is there anything you can do to alleviate my physical symptoms?

Other potential resources:

American Cancer Society

National Cancer Institute

Pain management or palliative care specialist

6. How often do you feel confused, anxious or depressed?

Never   Constantly (always)

0	1	2	**3**	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

<u>Possible Questions</u> to ask your doctor or other healthcare team member:

Can you refer me to a mental health professional?

Can you refer me to a support group?

Can you refer me to a chaplain or other spiritual leader?

<u>Other potential resources</u>:

American Cancer Society

Lance Armstrong Foundation

Local non-profit cancer organizations

7. How much does this illness make life seem senseless and meaningless?

Not at all   A great deal (completely)

0	1	2	3	4	5	**6**	7	8	9	10

Comments:

_____

_____

_____

_____

<u>Possible Questions</u> to ask your doctor or other healthcare team member:

Can you refer me to a mental health professional?

Can you refer me to a support group?

Can you refer me to a chaplain or other spiritual leader?

Other potential resources:

American Cancer Society

Lance Armstrong Foundation

Local non-profit cancer organizations

In the second group of questions, "Zero" indicates "anytime I want," "a great deal" or "completely." "Ten" for these questions is "never" or "not at all." So, the scale is almost the opposite of the questions that you just answered.

8. How much spiritual support do you feel that you need?

A great deal (completely)   Not at all

0	1	2	3	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

Possible Questions to ask your doctor or other healthcare team member:

Can you refer me to a chaplain or other spiritual leader?

Can you refer me to a mental health professional?

Can you refer me to a support group?

Other potential resources:

Local churches, synagogues, mosques

Local non-profit cancer organizations

9. How much have you maintained good relationships with the people close to you?

Completely   Not at all

0	1	2	3	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

Possible Questions to ask your doctor or other healthcare team member:

Can you help me organize a family meeting?

Can you refer me to a chaplain or other spiritual leader?

Can you refer me to a mental health professional?

Other potential resources:

Local churches, synagogues, mosques

Local non-profit cancer organizations

10. How much do you live life with a special sense of purpose?

Completely   Not at all

0	1	2	3	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

Possible Questions to ask your doctor or other healthcare team member:

Can you refer me to a chaplain or other spiritual leader?

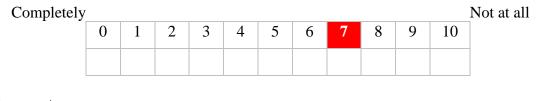Can you refer me to a mental health professional?

Do you know any volunteer organizations that could use my help?

Other potential resources:

Local churches, synagogues, mosques

11. How much do you feel your doctors and nurses respect you as an individual?

Completely   Not at all

0	1	2	3	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

Possible Questions to ask your doctor or other healthcare team member:

Can we discuss my concerns about my treatment?

Other potential resources:

Social Worker

Nurse

12. How clear is the information from the medical team about what to expect regarding your illness?

Completely   Not at all

0	1	2	3	4	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

Possible Questions to ask your doctor or other healthcare team member:

Do you have any additional information or resources about my condition or treatment?

What are the risks and side effects of my treatment?

What is the expected outcome of my current treatment?

Are there any alternative treatments for my condition?

Other potential resources:

Support groups

Cancer-specific networking groups

National cancer-specific organizations

Local non-profit cancer organizations

13. How much do you feel that the medical care you are getting fits with your goals?

Completely   Not at all

0	1	2	3	**4**	5	6	7	8	9	10

Comments:

_____

_____

_____

_____

Possible Questions to ask your doctor or other healthcare team member

What is the expected outcome of my current treatment?

What is my treatment plan?

Can we discuss my treatment plan to make sure it fits with my goals?

Navigating the Healthcare System

A Workshop for People with Cancer and their Family Caregivers

Trainer's Notes:

Module 4: Recognizing and Communicating Needs with Healthcare Providers

70

Principal message

People living with cancer can be greatly aided in navigating the healthcare system in a clinical setting through the use of specific, practiced tools before, during, and after a medical visit.

Module overview

"Recognizing and Communicating Needs with Healthcare Providers" prepares participants by providing appropriate steps to take before, during and after a healthcare visit to ensure better communication between the home and clinical teams. Specifically, participants will practice using the NEST tool and observe a role play of a person living with cancer and their family caregiver interacting with a physician and social worker. This role play allows for the identification of barriers to effective communication as well as developing useful strategies for navigating the healthcare system in a clinical setting.

Preparing for a presentation

1. Aim to meet the needs of your audience

Try to understand as much as possible about your participants' backgrounds, stages of cancer, support networks, and existing levels of knowledge about the topic. Choose from the material provided in the module according to the needs of your expected participants. It is better for participants to come away with a few new pieces of well-selected information, well learned, than to come away with a deluge of information, but remembering nothing.

2. Presentation timing

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Presentation	20 minutes
Video trigger tape & discussion	15-20 minutes
Summary	2-3 minutes
Post-test & Evaluation	5 minutes
Total	44-51 minutes

3. Number of slides:

There are 11 slides for this module.

4. Preparing your presentation

The text in the module was not designed to be used as a prepared speech. Instead, the text provides material you may want to use. The slides have been designed to trigger your presentation. Although the slides closely follow the text of the module, they do not contain all of the content. Their use presumes that you have mastered the content.

You may want to make notes on the slide summary pages to help you prepare your talk in more detail and provide you with notes to follow during your presentation. Remember that you can adjust the slides to suit your presentation content, your style, and to make it feel fully familiar and your own.

Practice your presentation using the slides you have chosen, and speaking to yourself in the kind of language you expect to use, until it is smooth and interesting and takes the right amount of time. The most accomplished presenters and teachers still practice prior to a presentation; don't miss this step.

5. Equipment needs

- Laptop computer, LCD projector and screen. Note: Some LCD projectors will allow use of a USB (thumb) drive. In this case the USB can be loaded with the slides in advance, making the laptop unnecessary

- DVD player and monitor or projector

- Preprinted slide handouts for each participant. This helps participants take notes. (Also, if no LCD equipment is available for slides, or malfunctions, the presentation can be given from the slide handouts)

- Copies of the "Sharing NEST with your Physician" exercise and the NEST worksheet.

- Flipchart and markers for recording discussion points

Test your equipment beforehand to ensure that it works. Review your DVD segments to assess which trigger videos or portions you would like to use. Cue your video to the start of the segment you will use for the session.

Have a back-up plan so that if there is any equipment failure you can move without panic to your back-up plan. For instance, have in mind that you will:

- if the DVD fails, summarize the interaction from the trigger video

- if the slides cannot be shown, refer to the hand out slides

- if the markers or overhead projector do not work, have participants list items on their hand outs that you would have written up for all to see

Making the presentation

1. Introduce yourself

If you have not already done so, introduce yourself. Include your name, title, and the organization(s) you work for. Briefly describe your clinical experience related to the information you will be presenting.

2. Introduce the topic

Show the title slide for the module. To establish the context for the session, make a few broad statements about the importance of communicating your needs and symptoms with your healthcare team. Tell participants the format and time you will take to present the session. Identify the teaching styles that you intend to use.

3. Review the session objectives

Show the slide with the session objectives listed. Read each objective and indicate those that you are planning to emphasize.

4. Present the material

Recommended style: interactive lecture

An interactive lecture will permit you to engage your audience, yet cover your chosen material within the time. You can use as your interactive components the trigger tape stimulated discussion and an interactive exercise. To foster discussion, ask participants for examples from their institutions or experiences. Ideally, the examples could be linked to one of the major take-home points.

Interactive exercise

Timing: 25-30 minutes

Recommended number of participants: any number

Necessary Materials: Completed NEST tool from Module 3 and print outs of the exercise for participants (found at the end of the Trainer's Notes for this module); Flip chart or white board to record group discussion points.

Ask your participants to work in pairs. Have each pair use their completed NEST forms from Module 3 or provide them with a blank one, which is included at the end of Module 3. Have each pair imagine that they are in the physician's office with their completed NEST Tool. One person will "play" him or herself and one person will "play" the physician. The person "playing" him or herself should behave as they would want to in the doctor's office. The person "playing" the physician should imagine themselves hearing about these concerns and how they would react. Participants will spend about five minutes doing the role play.

After completing this role play, play the Demonstration of Navigation trigger tape. The trigger tape consists of a role play with a physician, a social worker, a person living with cancer and her husband and family caregiver. The discussion is about the person living with cancer's health status and needs.

After watching the video, come together as a group to discuss the interaction. Use the provided discussion questions to trigger the group discussion. Additional topics for group discussion can be found on the 'Roundtable Discussion' on the trainer's DVD.

Invite participants to comment on:

- How would you introduce these issues to your physician?

- What do you think some barriers might be?

- How might you overcome barriers?

6. Summarize the discussion

Briefly review each part of the presentation. Recap two or three of the most important points that were discussed.

Exercise: Sharing NEST with your physician

The goal of this exercise is to develop a technique to share NEST with your physician.

NEST is a tool to help people living with cancer identify symptoms and needs. During the last workshop session, we worked on completing this form and saw how it can help identify and discuss concerns. This exercise will be in three parts.

1. Person living with cancer and family caregiver role play

Imagine now that you are in your physician's office and have your *NEST Tool* with you. Using this tool, you have identified a number of needs and symptoms that you have been having.

The task now is to make sure these concerns are addressed when you are with your physician. The objective of this exercise is to practice strategies for introducing these with your physician and healthcare team.

In order to do this, we'd like to do a **role play**: a role play is a way to re-enact an interaction. For this role play, one person will "play" him or herself and one person will "play" the physician. For the person "playing" him or herself, you should behave as you would want to in the physician's office. For the person "playing" the physician, you should imagine yourself hearing about these concerns and how you would react.

Participants will spend about five minutes doing the role play.

After the role play, discuss as a pair what the role play was like.

> Consider:
> - What are the most important needs you identified?
> - What are some that were less important?
> - How would you introduce these with your physician?
> - What do you think some barriers might be?
> - How might you overcome these barriers?

2. Group discussion

After discussing in pairs, we will come back together as a large group to discuss overall strategies.

> Consider:
> - How would you introduce these to your physician?
> - What do you think some barriers might be?

3. Demonstration of Navigation

Since effective communication is important for everyone, including people living with cancer, family caregivers and healthcare professionals, we will now view a video demonstrating how some of the navigation skills and techniques we have discussed can help to provide more effective care.

Please note, *the scenario depicted in this role play is a fictitious one and the advice given is not meant to replace any medical advice that you may receive from your own physician or other healthcare providers. As always, any concerns about your specific situation should be directed toward your physician or other members of your healthcare team.*

Video Summary

Characters: Amy Clark: Person living with cancer

Nick Clark: Amy's husband/family caregiver

Dr. Joshua Hauser: Physician

Korey Reynolds: Social Worker

Scene: The physician's office where Amy and her husband Nick have an appointment.

Background: Amy was diagnosed and treated for stage II breast cancer three months ago. Recently, she experienced swelling and pain in her lower left arm that seems to be getting worse instead of better. She called her physician, Dr. Hauser, to make an appointment.

The scene is the appointment with Dr. Hauser, Korey Reynolds, a social worker who works with Dr. Hauser, Amy and her husband, Nick.

After seeing this role play, we will discuss the interaction that you just saw.

Consider:

⌃ What went well in this interaction?

⌃ What did not go very well?

⌃ How similar is this to interactions that you've had with physicians or other healthcare professionals?

⌃ What techniques will you take from this to help in future interactions with physicians or other healthcare professionals?

Navigating the Healthcare System

A Workshop for People with Cancer and their Family Caregivers

Appendix 1:

Participant Evaluation Materials

Navigating the Healthcare System

Workshop Evaluation

Please indicate your status by circling one: Person living with cancer   Family caregiver

Workshop Topic (please circle one):

    Introduction to Navigating the Healthcare System

    How Families Live With Cancer

    Recognizing/Communicating Needs at Home

    Recognizing/Communicating Needs with Healthcare Providers

1. How would you rate this workshop overall?

1	2	3	4	5
Excellent	Very good	Good	Fair	Poor

    Please explain:

_____

_____

2. How helpful were each of the following items in contributing to your learning.

	Very helpful			Not at all helpful	
a. Video Cases	NA 1	2	3	4	5
b. NEST Tool	NA 1	2	3	4	5
c. Interactive Exercises	NA 1	2	3	4	5
d. Group discussion	NA 1	2	3	4	5
e. Role Plays	NA 1	2	3	4	5
f. Participant's Handbook	NA 1	2	3	4	5
g. Presentation Slides	NA 1	2	3	4	5

	Strongly Agree			Strongly Disagree	
3. The facilitator teaching was effective.	1	2	3	4	5
4. An adequate amount of material was covered.	1	2	3	4	5
5. I was satisfied with the workshop location.	1	2	3	4	5
6. I am likely to use these materials when I get home.	1	2	3	4	5
7. I would encourage others to attend this workshop	1	2	3	4	5

8. Any other comments on the workshop:

Navigating the Healthcare System

Workshop Evaluation

Thank you for participating in this program. We would like to find out a little bit about what you already know about navigating the healthcare system. We will ask you to take this evaluation twice. Once before and once after you participate in the workshop. Our goal in collecting this data is to evaluate the quality of this workshop. The goal is NOT to evaluate you.

Please circle the BEST answer for each of the following questions.

Module 1

1. Patient navigators:

   A) Can be a family member or friend

   B) Communicate the person with cancer's needs with the healthcare team

   C) Develop a personal strategy to meet the person with cancer's needs

   D) All of the above

2. Doctors may order tests to determine what is going on with your cancer. Before a test you should:

   A) Always be sure someone is with you

   B) Ask what to expect and how to prepare for the test

   C) Arrive for the test well fed because you will not be able to eat for a while after it

   D) Bring a lot of reading material; the waits can be long and boring

3. Case managers:

   A) help coordinate care; they are often trained nurses

   B) are cancer doctors; they order my tests and decide on my treatment

   C) work at the nurses station, getting tests that the doctors ordered and organizing charts

   D) primarily work to reduce unwanted costs for the healthcare system

4. Medical bills can be complex and can make people feel anxious…

   A) Many cancer care settings have a social worker or financial specialist who can explain the bills to me

   B) My bills are my responsibility

   C) My bill shows something called a 'deductible;' I don't have to pay that.

   D) A and B

Navigating the Healthcare System

Workshop Evaluation

Thank you for participating in this program. We would like to find out a little bit about what you already know about navigating the healthcare system. We will ask you to take this evaluation twice. Once before and once after you participate in the workshop. Our goal in collecting this data is to evaluate the quality of this workshop. The goal is NOT to evaluate you.

Please circle the BEST answer for each of the following questions.

Module 2

1. Which of the following statements about building a team of care at home is false?

    a. No one person can help all the time.

    b. Most people want to help, but some will feel uncomfortable with a support role

    c. The home care team should only be made up of family and friends

    d. No one can cope with cancer alone; everyone could use a support team

2. Who is the best person to manage the daily responsibilities for a person living with cancer?

    a. Person living with cancer

    b. Family Caregiver

    c. Physician

    d. It varies based on how the person living with cancer feels

Navigating the Healthcare System

Workshop Evaluation

Thank you for participating in this program. We would like to find out a little bit about what you already know about navigating the healthcare system. We will ask you to take this evaluation twice. Once before and once after you participate in the workshop. Our goal in collecting this data is to evaluate the quality of this workshop. The goal is NOT to evaluate you.

Please circle the BEST answer for each of the following questions.

Module 3

1. Cancer can create concerns that are:
   A) Physical and / or psychological
   B) Emotional and / or social
   C) Practical and / or day-to-day
   D) All of the above

2. Keeping track of your concerns is easier if you:
   A) Use a worksheet that helps you be aware
   B) Keep a health journal
   C) Track everything in detail all the time
   D) A and B

3. When the cancer has caused a need it helps to:
   A) Keep it private
   B) Consider different strategies to meet the need
   C) Get involved in distractions to ease the distress
   D) Get used to it and go on with life

4. Advance Directives are…
   A) Instructions from your healthcare team
   B) Specific papers such as a living will, medical power of attorney and other documents that communicate your wishes to your doctors.
   C) Information about your treatment
   D) None of the above

5. Which of the following statements about Advance Directives is true?
   A) They should be reviewed and updated regularly
   B) You should wait for your doctor to bring up the subject before talking to him/her about Advance Directives
   C) You only need an Advance Directive if you have a terminal illness

D) Your healthcare proxy (medical power of attorney) makes all healthcare decisions for you once the Advance Directive becomes official

Navigating the Healthcare System

Workshop Evaluation

Thank you for participating in this program. We would like to find out a little bit about what you already know about navigating the healthcare system. We will ask you to take this evaluation twice. Once before and once after you participate in the workshop. Our goal in collecting this data is to evaluate the quality of this workshop. The goal is NOT to evaluate you.

Please circle the BEST answer for each of the following questions.

Module 4

1. When meeting with a member of a healthcare team it is important to:

    A) Consider what it feels like to be 'in their shoes'

    B) Ask questions if your doctor invites you to

    C) Bring someone with me for important meetings to help me remember everything and follow through

    D) A and C

2. When talking with someone in the professional healthcare team it is important to:

    A) Feel empowered to ask questions

    B) Come to the meeting with a list of questions and things you need to have attended to

    C) Bring someone with me for important meetings to help me remember everything and follow through

    D) All of the above

3. When cancer has caused a need it helps to:

    A) Get ready with a list of what seems to be happening to me

    B) Bring someone with me for important meetings to help me remember everything and follow through

    C) Know as much as possible about what is available in the healthcare system

    D) All of the above

Workshop Evaluation

CORRECT ANSWERS – FOR TRAINERS

The correct answers for each question are listed below.

Module 1

1. D

2. B

3. A

4. D

Module 2

1. C

2. D

Module 3

1. D

2. D

3. B

4. B

5. A

Module 4

1. C

2. D

3. D

Navigating the Healthcare System

Workshop Evaluation

We would like to find out a little bit about how confident you feel about navigating the healthcare system. Please indicate how confident you feel about each of the following topics. Rating 1 means you are not very confident and rating 5 means you are very confident.

I feel…	Not Very Confident				Very Confident
	1	2	3	4	5
I can recognize my concerns.					
I can talk to my healthcare team about my concerns.					
I understand how to use tools to track my concerns.					
I can work with my healthcare team to create a treatment plan for my concerns.					
I can identify miscommunication and feel confident in my ability to address this with my healthcare team.					
I can identify friends and family members to help me with tasks at home.					

Communication and Attitudinal Self-Efficacy (CASE) Scale – Cancer[5]

We would like to find out a little bit about how comfortable you feel about navigating the healthcare system. Please indicate whether you **agree** or **disagree** with each statement.

	Strongly Disagree	slightly disagree	slightly agree	Strongly Agree
1. It is easy for me to maintain a sense of humor.	1	2	3	4
2. It is easy for me to ask my doctor questions.	1	2	3	4
3. It is easy for me to keep a positive attitude.	1	2	3	4
4. If I don't understand something, it is easy for me to ask for help.	1	2	3	4
5. It is easy for me to ask nurses questions.	1	2	3	4
6. I am confident in my ability to understand cancer materials.	1	2	3	4
7. I am confident in my ability to understand my doctor's instructions.	1	2	3	4
8. I know that I will be able to actively participate in decisions about my treatment.	1	2	3	4
9. I am confident that I am able to deal with any unexpected health problems.	1	2	3	4
10. I won't let cancer get me down.	1	2	3	4
11. It is easy for me to get information about cancer.	1	2	3	4
12. I am confident that I can control my negative feelings about cancer.	1	2	3	4

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[5] Wolf MS, Chang CH, Davis T, Makoul G. Development and validation of the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer). *Patient Education and Counseling*. 2005;57:333-41.