



Familias Fuertes

Promotores de salud supporting children coping with cancer

TRAINING GUIDE



KDH
RESEARCH &
COMMUNICATION

730 Peachtree Street NE,
Suite 820
Atlanta, GA 30308
404-968-8008
www.kdhrc.com



GOALS AND OBJECTIVES

Familias Fuertes is for use by facilitators who wish to train promotores de salud to work with children who are coping with cancer. Children who are coping with cancer fall into two categories: 1) children who have pediatric cancer, and 2) children who have a close family member (e.g., parent, sibling) with cancer. From this point forward, we refer to promotores de salud as “promotoras,” but we recognize that there are male and female promotores.

The overall goal of *Familias Fuertes* is to provide promotoras with the knowledge and skills necessary to support and meet the needs of children coping with cancer throughout diagnosis, treatment, and remission. Specifically, by the end of *Familias Fuertes* promotoras will be able to counsel clients about their options relating to treatment, choosing a healthcare facility, continuing education, and locating counseling services. Additionally, promotoras will be able to connect their clients with the appropriate people, organizations, and information as needed for their care.

Latino children coping with cancer are an underserved and vulnerable population. It is often the opinion of parents and other concerned adults that children are too young or developmentally not ready to be told a great deal about cancer. However, all children, no matter how young, pick up on verbal and nonverbal cues from the people close to them and without accurate information, children can and do create their own explanations for what they see happening around them. These explanations may involve blaming themselves or having negative thoughts. *Familias Fuertes* seeks to change the perception that children should not be communicated with about cancer, and equips promotoras with the tools they need to be able to replace a child’s confusion with understanding and social support.

The number of Latino children in the US coping with cancer is high. Approximately 2.5 percent of total cancer cases in the US Latino population occur in children and adolescents, compared with 1 percent of cancer cases in the total US youth population¹. Compared with Caucasian children, Latino children are more often diagnosed with leukemia, bone tumors, and germ cell tumors (cancer of the cells that form the sperm or eggs). Further, because cancer is the second leading cause of death for Latino adults, healthy children in Latino families may be faced with having to deal with a parent or other family member’s illness.

Promotoras are lay health workers who are trained to reach out to and support members of their community by providing health information, health navigation, and social support. Promotoras fall under the broader title of community health worker (CHW). However, promotoras specifically work with the Latino population.

This training program is based on two broad assumptions:

- 1) Promotoras will be working in the Latino community, and
- 2) Promotoras will already have basic promotoras training, which will give them the skills to deliver *Familias Fuertes* effectively (see the resources section for basic promotoras training programs).

Definition of CHWs

CHWs are “community members who work almost exclusively in community settings. They serve as connectors between health care consumers and providers to promote health among groups that have traditionally lacked access to adequate health care.”

—Witmer A. (1995). Community health workers: Integral members of the health care work force. *Am J Public Health*, 85, 1055-1058.

After completing Familias Fuertes, promotoras will have:

the knowledge to...

- Explain cancer in age-specific and culturally-appropriate ways.
- Identify and explain available treatment options for cancer.
- Explain possible treatment side-effects.
- Understand the mental, physical, emotional, and cognitive abilities and issues of children coping with cancer.

and the skills to...

- Talk to children about what they are experiencing in an age-specific and culturally-appropriate manner.
- Conduct a needs assessment of a child coping with cancer to determine the resources and support needed.
- Research available resources to support the child coping with cancer throughout diagnosis, treatment, and remission.
- Liaise with the child's school and related professionals (e.g., social worker) to arrange for continuing education in the event of absences from school.
- Help parents and children talk openly and effectively about their feelings.
- Discuss end-of-life or palliative care choices.
- Help children resume their former lives after treatment.

After reading through Familias Fuertes, a facilitator will be prepared to lead a training for promotoras on the topic of children coping with cancer. At the end of the training, promotoras will be equipped with accurate information about cancer and the resources needed by children coping with cancer, and the skills to effectively support these children's emotional, mental, physical, and social needs.

HOW TO USE THIS GUIDE

The Sessions:

Session 1: *Introductions*

Session 2: *Cancer and Its Impact on Children*

Session 3: *Overcoming Barriers and Understanding Client Needs*

Session 4: *Resources for Children Coping With Cancer*

Session 5: *Communicating With Children, Families, and Schools*

Session 6: *Assistance During Treatment*

Session 7: *Remission and Beyond*

Familias Fuertes is self-contained with almost all the materials you will need to deliver the training (with the exception of items such as a flipchart and pens). Facilitators should ideally have experience training promotoras, however, we provide tips throughout Familias Fuertes to help with facilitation. Templates of all the handouts you will need are included at the end of each session and on the CD contained in this guide for you to duplicate as needed.

The session handouts provide useful information that promotoras can refer to when they start working with a client. For this reason, promotoras should keep all handouts from Familias Fuertes together as an information packet. If resources permit, provide promotoras with a folder or binder in which to keep the handouts and any other notes they make from the sessions. Or, you can ask promotoras to bring a folder with them.

About the sessions

The training program consists of 7 one-hour sessions. Each session will cover a different topic about working with children coping with cancer. Sessions contain multiple activities that tackle specific information and skills. Most activities are participatory. Instead of the facilitator providing information through lectures, participatory learning uses tools like role-play, discussion, and games to impart knowledge. This is a fun way to learn and creates a feeling of community between promotoras and between the facilitator and promotoras.

At the beginning of each session we provide an introduction, a list of objectives, materials you will need, and an estimate of how long each activity should take to keep you within the session time limit of one hour.

Preparation

Promotoras are more likely to be successful if you, the facilitator, are prepared. Here are the steps to getting prepared:

Step 1: Master the material

Read through the entire guide several times, from start to finish, paying particular attention to the “facilitator notes” that accompany each activity. These notes will provide you with any background information you need to know about the activity topic. Promotoras will be looking to you as the expert on the material, so carefully review all the session information. We recommend reviewing the list of additional resources provided at the end of this guide, and looking up information on topics with which you are less familiar.

Step 2: Schedule the training

Once you feel you have mastered the content of each session, the next step is to schedule the training. If you are preparing promotoras for an outreach campaign to work with children who are coping with cancer, schedule the training so that it ends one to two weeks before the outreach begins. This will ensure promotoras are fully equipped and all the information is fresh in their minds.

We provide an information flyer in the *Additional Resources* section, which you can use to advertise the training program. Think carefully about what day and time will work best—you can ask potential promotoras what is better for them. But, if you take this approach, you will have to follow up with the specific date, time, and location. Also, think about whether you want to implement the training in one day, or have one or more sessions per week. If you plan to implement multiple sessions at once, we recommend you schedule in appropriate breaks.

The scheduling of the training program will likely be dependent on the availability of an appropriate space at the organization where you work. We recommend a bright room with plenty of wall space to post information. The room should have tables and chairs that can be arranged in a circle or square with space to break out into small working groups.

Step 3: Prepare your materials

At least one week before the training begins, gather together all the materials you will need for all seven sessions. Make enough copies of handouts for all promotoras, and a few extras if you can. Keep yourself organized by using a binder to store all your duplicated handouts and notes, preferably sectioned by session tabs (similar to this binder). Make sure you have enough spare paper and pens for the group.

Flipcharts are an integral tool in teaching the content of Familias Fuertes. Familias Fuertes uses flipcharts to write down answers from group activities or to present additional information (e.g., definitions of words or phrases). Create all the flipcharts ahead of class using the templates we provide at the end of each session. (We do not provide templates if the only preparation needed is write a title on the flipchart.) Once you have finished the flipchart activity, display the flipchart on the wall as visual aids to help with future activities.

We list the materials you need at the start of each session. Here are the items you will need to secure that are not included in this guide:

- ✓ Flipchart and paper
- ✓ Pens
- ✓ Spare paper
- ✓ Computer, LCD projector, and screen for the PowerPoint presentations (Note: You can also use an overhead projector or present from the slide handouts if other technology is unavailable.)
- ✓ Tape

You can also find a session-by-session checklist of materials needed for the entire training in the *Additional Resources* section.

Step 4: Practice

Practicing a delivery of the material will highlight any information areas or activities you need to spend more time preparing. Practicing also ensures the sessions run smoothly. If possible, practice in the room where you will hold the training sessions. This will enable you to become familiar with the space and ensure all the equipment is working.

Step 5: Remind promotoras

Finally, be sure to give promotoras a reminder call or email a few days to one week before the training program begins. If you are holding multiple sessions, one way to remind promotoras is through a phone chain. The day before the next session begins, call one of the promotoras to remind him or her about the session. This participant will then have a designated participant to call who will in turn call another participant. The last participant in the list calls you so that you know everyone has received a reminder call.

FACILITATION TIPS

Get to know the promotoras: Promotoras may have either professional or personal experience working with children coping with cancer. It is likely that most promotoras will have already been touched by cancer in some way. In the first session, promotoras are asked to introduce themselves and describe their experience with the topic, and this will give you a good understanding of the backgrounds of your promotoras. While drawing on personal experiences can enrich learning moments, be careful they do not derail the activity. Draw salient points from stories that reinforce the activity goal, but keep the discussion focused on the task at hand. You may wish to use segues such as “Thank you for sharing your story. Everybody, what is the lesson we can draw from this experience?”

Provide easy to follow directions to promotoras²: This training guide consists of seven sessions, each with multiple activities. In order to complete all activities in the stated timeframe, directions should be concise, yet easy to follow. Here are some suggestions to help you give easy-to-follow directions:

- **Know the goal:** Prior to starting the activity, you should be familiar with each step and the desired outcome of the activity.
- **Explain the goal:** Explain the purpose of the activity to promotoras before describing the individual steps they must take.
- **Do not make demands:** Directions should be explained as a process, rather than a list of steps promotoras must complete. Invite promotoras to contribute, but do not order them to do so.
- **Make sure everyone can hear:** Ask promotoras to quiet down before explaining directions to ensure that everyone is able to hear.
- **Provide a timeframe:** Be specific about the timeframe so that promotoras can pace themselves throughout the activity.
- **Do not give all directions at once:** Give directions one or two at a time to avoid giving long lists of directions that are difficult to remember.
- **Make directions visible:** Write directions on a flipchart, or provide written directions as a reference.
- **Be specific at all times:** Directions should be specific. Rather than asking groups to brainstorm about questions a child with cancer might ask, ask groups to assign a recorder and brainstorm possible questions that a child with cancer aged two to six years might ask about his or her disease, using age-appropriate language.
- **Check for comprehension:** At each point directions are given throughout an activity, ask if anyone has questions or needs clarification.

Encourage and facilitate teamwork³: In an attempt to avoid lecture-style learning, and make the activities approachable to promotoras, many of the activities presented in this training guide encourage teamwork in the form of small group discussions or games. To get the most out of these activities, the group dynamic must be one of open communication and respect for differing opinions. The following are some tips on how to encourage teamwork and learning:

- **Use active listening:** Show you are listening to promotoras by maintaining eye contact and nodding to indicate understanding.
- **Encourage everyone to participate:** Make an effort to encourage everyone to participate. If someone seems left out of discussion, ask for his or her opinion on the subject and encourage him or her to share.
- **Show that all viewpoints are accepted:** Inform all promotoras that all viewpoints are welcome, and that everyone will respect each other's opinions.
- **Avoid jargon:** Use terms and phrases promotoras are familiar with, and make sure directions are heard and comprehended.
- **Uphold a defined sense of trust and understanding throughout the sessions:** Establish trust by being honest with promotoras. Share some of your own experiences and admit it if you do not know answers to some questions.
- **Avoid being too serious:** Promotoras want to learn in an environment where they are comfortable and feel at ease.

Keep promotoras talking and on-point⁴: As the facilitator, it is your job to stimulate discussion among group promotoras. The following tips may prove helpful in keeping discussions flowing and on-task:

- **Be inquisitive:** Start discussions by posing questions to the promotoras. Indicate you are listening by providing follow-up questions.
- **Connect comments:** Show that participants' ideas and contributions are relevant by linking them to concepts or ideas provided by other promotoras. This will help encourage unity in the group.
- **Keep discussions on track:** During discussions, steer promotoras back on topic by reminding them of the key ideas of the session. Use summary statements to wrap up discussions when time is up or participation begins to wane.

Summary

As facilitator, you have a very important role in helping promotoras master the material contained in Familias Fuertes. By taking the steps outlined above, and incorporating these facilitation tips, you will be well-equipped for the task ahead. Your dedication to preparation can make a lasting impression on the promotoras you train, and the children they help in the future. Latino children coping with cancer are an underserved group and Familias Fuertes will help promotoras meet the needs of these children throughout the country.

Let's now turn to the sessions—good luck!

1 American Cancer Society. (2006). Cancer Facts & Figures for Hispanics/Latinos 2006-2008. Retrieved from <http://ww2.cancer.org/downloads/STT/CAFF2006HispPWSecured.pdf>

2, 3, 4 These facilitation tips are recommended by Callejas, L., Mayo, J., Monsalve-Serna, M., & Hernandez, M. (2006). Linking Community Helpers & Services With Schools Serving Latino Families: An orientation to the RAICES/Promotoras model and associated training curriculum (FMHI pub. no. 246). Tampa, FL: University of South Florida, Louis de la Parte Florida Mental Health Institute. Retrieved from <http://raices.fmhi.usf.edu/files/RAICES-trainee.pdf>

SESSION 1: INTRODUCTIONS

INTRODUCTION

Working with children who are coping with cancer can be an emotionally draining process. Learning about how to work with children coping with cancer touches on very sensitive issues and it is likely that promotoras will have some personal experience of being affected by cancer. In order to facilitate frank discussions about difficult topics in later sessions, the promotoras must feel comfortable with one another and understand that they are each working toward the same goal. It is very important, therefore, to create an atmosphere of trust in the training group. Session 1 will help you do that by setting respectful ground rules for the Familias Fuertes training. Before you get started with the activities, review the overall goals of Familias Fuertes with the promotoras (see the *Goals and Objectives*). Clearly define what promotoras will learn and how the course will be run. Pin up the flipchart page *Ground Rules for Participation* and read through the rules. Pass out and review the handout, *Overview of Sessions*, which will serve as a syllabus for the promotoras so they know what topics will be covered each week.

The first activity will help promotoras get to know each other, and for you to get to know them, which will help everyone feel more comfortable. This activity also encourages promotoras to share any of their past experiences on the topic. Throughout Familias Fuertes, promotoras will learn from each other's real life examples and wisdom gained through previous hands-on experience.

Through two activities, Session 1 also provides an introduction to the topics of cancer and working with children coping with cancer. Promotoras may feel nervous if they have little experience with the topic. By giving background information in this first session on cancer and how to work with children, the group will feel more at ease. Additionally, these two activities set the scene for the rest of the course by providing information about why it is so critically important for promotoras to work with this population group. Promotoras will also learn about child developmental stages and the information they will need to successfully learn how to communicate with children on an age- and developmentally-appropriate level.

Finally, Session 1 wraps up by reviewing key promotoras attributes. While Familias Fuertes assumes promotoras will already have basic promotoras training, it is important in this Session to remind them about their commitment to the communities they serve.

Session Learning Objectives

After completing this Session, promotoras will have:

the knowledge to...

- State the main cancers affecting the Latino population in the US
- Relate a child's developmental stage to his or her reaction to coping with cancer

and the skills to...

- Identify a child's developmental stage

MATERIALS NEEDED

- ✓ A small, soft ball such as a Nerf ball or styrofoam ball
- ✓ Three sheets of paper of different colors
- ✓ Pens/Markers
- ✓ Computer, LCD projector and screen (optional)
- ✓ *Children's Developmental Milestones* PowerPoint presentation
- ✓ Flip chart pages
 - *Ground Rules for Participation*
 - *Cancer in the Latino Community*
 - *Promotoras de Salud Pledge*

HANDOUTS

- ✓ *Overview of Sessions*
- ✓ *Latinos and Cancer Fact Sheet*
- ✓ *Children's Developmental Milestones (presentation slides)*
- ✓ *Developmental Milestones Matching Worksheet*
- ✓ *Developmental Milestones Matching Answer Key*
- ✓ *Key Principles for Working With Children Coping With Cancer*
- ✓ *Key Attributes of Promotoras de Salud*

ACTIVITY 1: My experience and goals

Time: 20 minutes

Activity goal: This activity helps promotoras introduce themselves and discuss any relevant previous experience(s).

Activity Description:

1. Write one of the following experience areas on each of three different sheets of colored paper:
 - a. Knowledge about cancer
 - b. Working with children
 - c. Promotoras skills and experience
2. Place each sheet of paper on a different table.
3. Explain to the promotoras that each table represents one of three main topic areas the training program covers: knowledge about cancer, working with children, and promotoras' skills and experience. Ask the promotoras to sit at or near the table that reflects the area in which they have the most knowledge or experience.
4. Toss a ball to a promotora and ask her to introduce herself and describe any experiences related to the topic area listed on the chosen table. Ask the promotora to state the topic area that she would like to know more about.
5. Ask the promotora to toss the ball to another promotora who is sitting at a different table.
6. Continue until all promotoras have introduced themselves and discussed the topic area they know the most about, and the area about which they want to learn more.

7. At the end of the introductions, promotoras should be familiar with each other's experience and goals for the training program.
8. After the promotoras have shared their backgrounds and the areas they would like to know more about, tell the group that the next activity will provide them with background information on cancer in the Latino population in the US. Inform them that cancer affects Latino children disproportionately in both direct (i.e., the child has cancer) and indirect ways (i.e., through a family member with cancer) and that the next activity will provide an overview of cancer statistics for Latino adults and children in the US.

ACTIVITY 2: Cancer prevalence in the Latino population

Time: 10 minutes

Activity goal: This activity teaches promotoras the cancer prevalence rates among Latino adults and children in the US.

Facilitator notes: Review the main types of cancer afflicting Latinos on the *Latinos and Cancer Fact Sheet*. For more information about cancer prevalence and mortality in the US, see the additional resources section.

Activity Description:

1. Display the flipchart page *Cancer in the Latino Community* and ask promotoras to call out what they think are the most common types of cancer in the Latino community for adults and write down suggestions. Repeat for pediatric cancer among Latinos.
2. Using a different color marker, label the top five most common cancers for children and adults as stated on the *Latinos and Cancer Fact Sheet* (you can use numbers, stars, or symbols). If promotoras did not call out all the correct types of cancers, add those to the flip chart.
3. Handout the *Latinos and Cancer Fact Sheet* and ask promotoras to read over it briefly. Tell them to keep the handout as a reference for when they are talking to clients.
4. As you move to the next activity, recap that this activity shows many Latino children are directly or indirectly touched by cancer. However, explain that these children are an underserved group for promotoras programs because adults usually think children are too young to communicate or learn about cancer. Also explain that children of all ages can perceive when something is wrong. Only open communication with children will prevent them from interpreting what they see and hear in a negative way. The next activity will give promotoras the foundational skills needed to work and communicate with children coping with cancer.

ACTIVITY 3: Working with children coping with cancer

Time: 20 minutes

Activity goal: This activity teaches promotoras about child developmental stages and how a child's stage of development affects his or her understanding of cancer and illness.

Facilitator notes: To work with children coping with cancer, promotoras will need basic understanding about children's developmental stages and the related milestones for each stage. This knowledge will help promotoras understand what a child is capable of understanding at every age, what he or she feels

emotionally, and what communication methods are age-appropriate. Be sure you are comfortable with the information presented in this activity before beginning this activity.

Activity Description:

1. Begin the activity by presenting the *Children's developmental milestones* PowerPoint presentation which gives an overview of developmental milestones at different ages. Be sure to give promotoras the presentation handout *Children's developmental milestones* so they can follow and make notes. Since most of the slides are tables, simply review the information given in each column. For example, for slide three you might say, "This slide presents the physical, intellectual, social, emotional, and moral milestones for infants through two year olds. The physical milestones for this group are ... [then list the milestones in the physical column]. The intellectual milestones are ... [then list the milestones in the intellectual column]" and so on. Point out that the age groups overlap because children develop at different paces.
2. Ask promotoras to work with the person on their left. Pass out copies of the *Developmental Milestones Matching Worksheet*. Explain that the worksheet describes how children at different ages understand the world, cancer, and death; however, the descriptions of the developmental characteristics do not match the age group. Ask pairs to match the description of developmental characteristics with the appropriate age using an arrow.
3. Give the pairs five minutes to complete the worksheet then pass out the answer key and review the correct answers.
4. Wrap up the activity by emphasizing that understanding how children differ physically, cognitively, socially/emotionally, and morally will help promotoras work with children of different ages. In particular, knowing this information will help promotoras communicate with children about cancer and death and provide them with appropriate coping resources. Finally, give promotoras the handout titled *Key Principles for Working with Children*, and ask them to review it in their own time.
5. Explain to participants that the sessions that follow will dig deeper into these topics but, before proceeding, it is important that the group review the core attributes of promotoras so that they can maintain the promotora standard when working with children coping with cancer.

ACTIVITY 4: Promotoras de salud pledge

Time: 10 minutes

Activity goal: This activity reviews the key attributes of promotoras de salud and asks them to commit to upholding the promotoras de salud standard.

Activity Description:

1. Place the promotoras into groups of three.
2. Give each group a piece of flipchart paper with "A Promotora is ..." written across the top.
3. Ask each group to draw a representation of what a promotora means to them. This can be an image of what a promotora looks like or words or images that represent a promotora. Give groups three minutes to complete their drawing. The drawing should be what immediately comes to mind.
4. Go around the class and ask each group to explain what their drawing represents.

As a promotora, I pledge to use the knowledge and skills I learn here to help maintain the physical and mental wellbeing of the people in my community. I pledge to serve my community by connecting people to resources and services and giving them the support they need.

5. Next, handout the fact sheet titled *Key Attributes of Promotoras de Salud*.
6. Go around the room and ask each promotora to read an attribute aloud until all attributes have been read.
7. Ask promotoras if there are any additional attributes that should be added and have the promotoras add them to the sheet.
8. Next tell the promotoras that they are going to say out loud a pledge to uphold these key attributes in their work. Display the flipchart titled *Promotoras de Salud Pledge* and read it out aloud together.

CONCLUSION

After completing this session, promotoras will be equipped with basic facts about cancer prevalence among Latino adults and children and understand why it is important that they work with children coping with cancer. Promotoras will also have knowledge about children's developmental stages which is critical to understanding how to communicate and work with children coping with cancer. Now that the promotoras feel comfortable with each other you are ready to ease them into a participatory discussion about cancer and its impacts on children, as discussed in Session 2.

FLIPCHART PAGE: Ground Rules for Participation**Activity 1**

(Note: This list is not exhaustive; add your own ground rules to it)

- Respect each other's opinions and suggestions.
- All ideas and suggestions are good.
- We can respectfully disagree but do not criticize what someone says.
- Provide constructive feedback.
- When a person speaks, everybody should listen.
- Everyone will have a chance to speak. This may mean limiting questions and comments to allow everyone to participate.
- We will follow the session outline and stay on time.
- Everything we talk about in the session will be confidential. Do not share with others outside the group.

FLIPCHART PAGE: Cancer in the Latino Community**Activity 3**

Main types of cancer affecting Latino adults and children

Adults	Children

FLIPCHART PAGE: Promotoras de Salud Pledge**Activity 4**

As a promotora, I pledge to use the knowledge and skills I learn here to help maintain the physical and mental wellbeing of the people in my community. I pledge to serve my community by connecting people to resources and services and giving them the support they need.

HANDOUT: Overview of Sessions

Keep this handout as a reference about upcoming or past sessions.

SESSION 1: INTRODUCTIONS

- Activity 1: My experience and goals
- Activity 2: Cancer prevalence in the Latino population
- Activity 3: Working with children coping with cancer
- Activity 4: Promotoras de salud pledge

SESSION 2: CANCER AND ITS IMPACT ON CHILDREN

- Activity 1: The body
- Activity 2: What is cancer?
- Activity 3: Impact of cancer on children

SESSION 3: OVERCOMING BARRIERS AND UNDERSTANDING CLIENT NEEDS

- Activity 1: Barriers to care
- Activity 2: Understanding cultural beliefs about cancer as barriers to care
- Activity 3: Outreach methods for reaching children coping with cancer
- Activity 4: How to conduct a child needs assessment

SESSION 4: NEEDED RESOURCES FOR CHILDREN COPING WITH CANCER

- Activity 1: Types of resources needed by children coping with cancer
- Activity 2: How to locate needed resources
- Activity 3: How to research information about cancer and determine its validity

SESSION 5: COMMUNICATING WITH CHILDREN, FAMILIES, AND SCHOOLS

- Activity 1: How to communicate with children about cancer
- Activity 2: Improving family communication
- Activity 3: Working with the school

SESSION 6: ASSISTANCE DURING TREATMENT

- Activity 1: Understanding clinical trials
- Activity 2: Navigating the treatment center
- Activity 3: Stress and coping
- Activity 4: Death, dying, and spiritual support

SESSION 7: REMISSION AND BEYOND

- Activity 1: Reintegration into society during remission
- Activity 2: Course wrap up, evaluation, and certificate ceremony

HANDOUT: Latinos and Cancer Fact Sheet

Hispanics comprise the largest and fastest growing minority group in the US and unfortunately they are the fastest growing group of cancer service consumers in the US (Stevenson-Perez, 1998). Cancer is the second leading cause of death for Latino adults and children in the US, causing 20 percent of all deaths in this population (American Cancer Society, 2006). In 2006, approximately 82,000 cancer cases were diagnosed among Latino adults. The table below lists the ten most prevalent cancers among Latino adults and children in the United States (US Department of Health and Human Services, 2010).

Ten Most Common Cancers Affecting Latinos in the US

Adult Males*	Adult Females*	Children*†
<ol style="list-style-type: none"> 1. Prostate 2. Colon and rectum 3. Lung and bronchus 4. Kidney and renal pelvis 5. Urinary bladder 6. Non-Hodgkin lymphoma (various cancers of blood cells, other than white blood cells) 7. Liver and inter-hepatic bile duct 8. Stomach 9. Leukemias (various cancers of the bone marrow) 10. Pancreas 	<ol style="list-style-type: none"> 1. Breast 2. Colon and rectum 3. Lung and bronchus 4. Endometrium and uterus 5. Thyroid 6. Non-Hodgkin lymphoma (various cancers of blood cells, other than white blood cells) 7. Cervix 8. Kidney and renal pelvis 9. Ovarian 10. Pancreas 	<ol style="list-style-type: none"> 1. Acute lymphocytic leukemia (cancer of the bone marrow) 2. Brain and other nervous system 3. Hodgkin lymphoma (cancer of the white blood cells) 4. Non-Hodgkin lymphoma (various cancers of blood cells, other than white blood cells) 5. Soft tissue 6. Bones and joints 7. Acute myeloid leukemia (cancer of the bone marrow) 8. Kidney and renal pelvis 9. Germ cell (cancer of the cells that form the sperm or eggs) 10. Unspecified

*Age-adjusted †Male and female combined.

Cancer rates in Latino children are particularly high. Roughly 2.5 percent of total cancer cases in the US Latino population occur in children and adolescents, compared with one percent of cancer cases in the total US youth population (American Cancer Society, 2006). Leukemia, lymphoma, and cancers of the brain and central nervous system are the most common cancer diagnoses among Latino children. Compared with Caucasian children, Latino children are more often diagnosed with leukemia, bone tumors, and germ cell tumors.

HANDOUT: Latinos and Cancer Fact Sheet (continued)

This fact sheet is based on the following references:

American Cancer Society. (2006). Cancer Facts & Figures for Hispanics/Latinos 2006-2008.
Retrieved from <http://ww2.cancer.org/downloads/STT/CAFF2006HispPWSecured.pdf>

Stevenson-Perez, H. (1998). America's cancer prevention, treatment, research, and education programs must include Hispanic Americans. *Cancer*, 83, 1872-76.

US Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute (2010). United States Cancer Statistics: 1999–2007 *Incidence and Mortality Web-based Report*. Retrieved from <http://apps.nccd.cdc.gov/uscs/>

HANDOUT: Children's Developmental Milestones (Presentation Slides)

Overview

- This presentation discusses children's developmental milestones.
- As children grow, they reach certain physical, intellectual, social, emotional, and moral milestones.
- Developmental milestones represent the age-specific skills that each child should have when they reach a certain age range.
 - Keep in mind that each child is different and will develop at their own pace.
- Information about children's developmental milestones can help promotoras understand at every age what a child is capable of understanding, what he or she feels emotionally, and what communication methods are age appropriate.

Infant to 2-Year-Old

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Grows rapidly •Develops motor skills (tracks people with eyes, grabs things, rolls over, sits, stands, feeds self, puts on/takes off clothing) •Puts things in their mouths •Teething •Can stack blocks •Cannot control bowels 	<ul style="list-style-type: none"> •Spontaneously makes noises and coos •Learns through the senses (responds to sounds, likes to taste things) •Enjoys hearing the names of things and begins to speak •Repeats behaviors that they see •Understands simple spoken directions •Starts to enjoy songs and rhymes 	<ul style="list-style-type: none"> •Is able to recognize the primary caregiver and finds this person extremely important •Holds gazes and smiles •Enjoys being played with, held, and tickled •Waves goodbye •Becomes possessive and independent 	<ul style="list-style-type: none"> •Can convey excitement and pleasure •Fears the unexpected (loud noises, sudden movements) •Needs to feel loved (held, cuddled) •Has a temper •Sucks thumb •May be clingy or fussy or seem to revert back to earlier stages of development •May react to emotions and distress displayed by you or the other children in your family 	<ul style="list-style-type: none"> •Understands adult approval and disapproval 	<ul style="list-style-type: none"> •Cannot understand explanations of cancer •May understand that mommy or daddy does not feel well

2 to 6-Year-Old

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Enjoys playing, rough-housing •Is active •Develops manual dexterity (can manipulate small objects) •Can control bowels, bladder •Muscles grow quickly •May not be an adventurous eater; prefers bland foods 	<ul style="list-style-type: none"> •Has a short attention span •Continues to develop vocabulary •Learns mostly through senses •Uses imagination often; may have imaginary friends •Is curious and asks a lot of questions •Begins to understand cause and effect •Understands letters, numbers, currency •Picks up on nonverbal communication 	<ul style="list-style-type: none"> •Clings to primary caregiver •Imitates adult behaviors (trying on clothes, make-up) •Recognizes differences between men and women •Curious about where babies come from •Enjoys being around others; but prefers the same sex •Starts to understand rules and sharing 	<ul style="list-style-type: none"> •Likes being praised •Wants to do things on their own •Shows a lot of emotion •Says “No” often and tests boundaries •Generally less fearful •Becomes boastful, bossy, may name call •Can be easily embarrassed •Family is the center of child’s world; child is confident family will care for his or her needs 	<ul style="list-style-type: none"> •Wants approval •Tries to be good and knows right from wrong •May lie or blame others if they do something wrong •Values other people’s opinions of self •May use verbal threats/wishes without understanding what they mean (such as “I wish you were dead”) 	<ul style="list-style-type: none"> •Understands the idea of germs, may believe that cancer is contagious •May believe that they said or did something to cause the cancer •Will not understand what is going on inside the body; focuses on outward symptoms (such as hair loss, weight changes) •Knows the basics of what a doctor does •No understanding of time or death

6 to 9-Year-Old

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Is energetic, restless •Has growth spurts •May get ill often as a result of being in school •Develops hand-eye coordination and enjoys drawing and writing •Has a good appetite and may be more adventurous with food 	<ul style="list-style-type: none"> •Indecisive •Can read and write •May stutter when upset •Begins to have clear memories •Is capable of logical thought •Has a longer attention span •Develops hobbies and retreats to fantasy less •Wants to know why things happen •Begins to exaggerate •Has greater interest in birth and babies 	<ul style="list-style-type: none"> •Begins to identify with other adults (teachers, neighbors) •May be disloyal to friends, have unstable relationships then gradually become more social •Becomes concerned with the reactions of others •May still use aggression to problem-solve •Enjoys school 	<ul style="list-style-type: none"> •Feels insecure and does not take criticism or blame well •May be negative and act out •Has a very self-centered attitude •Complains often •Tries to develop a sense of self •Is easily distracted •May be secretive •Becomes helpful and outgoing •Is curious •May be affectionate and act silly 	<ul style="list-style-type: none"> •Seeks approval from others; may blame others for something they did •Feels guilt and shame 	<ul style="list-style-type: none"> •May understand the basics of human anatomy •Understands cause and effect •Fears that cancer is something contagious •Has an interest in the causes of cancer •May ask for specific details about cancer •Starts to understand that cancer can lead to death •Personifies death as a person or monster who takes you away

9 to 12-Year-Old

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Rough-houses and enjoys team sports •Has coordination and body control •Females begin developing quicker than males •Becomes aware of the body and sexuality 	<ul style="list-style-type: none"> •Develops strong interests in activities, hobbies, collecting things •Capable of thinking abstractly •Enjoys books and writing •Capable of arguing logically and may challenge others •May become critical of adults •Shows an interest in national and international events •Asks more about “what happened” 	<ul style="list-style-type: none"> •Enjoys group activities, but still hangs out with the same sex •Is competitive •Thinks highly of parents and shows affection toward them •Becomes selective when choosing friends and may have a best friend •Wants to be accepted by peers •Enjoys being part of a community 	<ul style="list-style-type: none"> •Becoming independent, but may develop behavior problems if not accepted by others •Enjoys privacy •Mostly concerned with school and friends •May become rebellious, dramatic, and moody 	<ul style="list-style-type: none"> •Understands the concept of being fair •Begins to take responsibility for mistakes •Has a conscience and set of morals, but strives to please the group and be accepted 	<ul style="list-style-type: none"> •Understands what cells are and that cancer cells act differently than normal cells •Will likely be familiar with cancer and some forms of treatment •Understands that illness can lead to death •May see cancer as punishment for poor behavior •Questions relationship and life changes caused by cancer

Teenager

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Rapidly gets taller, gains weight, and develops strength •Reaches sexual maturity and is more likely to act on sexual desires •May develop acne and be concerned with physical appearance 	<ul style="list-style-type: none"> •Enjoys engaging in arguments and discussions •Begins to think and plan for the future •Capable of introspection •Enjoys reading •May develop interest in religion, faith •Lacks confidence in personal abilities 	<ul style="list-style-type: none"> •May withdraw from parents and siblings as a means of rebellion •Has an established group of friends of both sexes •May date and have serious relationships •May confide in someone outside the family 	<ul style="list-style-type: none"> •Needs to feel special •Worries about school, friends, appearance, failure •May talk back to teachers and authority figures •Is ego-centric and lonely at times •Is conflicted about being oneself versus fitting in •Needs someone to listen; to talk with •Not sure how to handle own emotions [public and private] 	<ul style="list-style-type: none"> •Weighs costs and benefits of decisions •Tries to avoid doing wrong by thinking of alternative solutions •Is generally truthful and concerned about fairness of others •May be frustrated or confused when family or friends don't abide by right and wrong 	<ul style="list-style-type: none"> •Understands human anatomy •Understands the basics of the immune system •Understands what cancer is, is familiar with some treatment options, and understands remission •May feel guilt, anger, even some responsibility for cancer •It is likely teenagers will think about the implications cancer might have on them and their family

References

- The milestones presented here come from The Child Development Guide, part of the Foster Parents Cope curriculum.
 - SUNY Research Foundation/Center for Development of Human Services New York State Child Welfare Training Institute. (1993). The Child Development Guide. Retrieved from <http://www.dshs.wa.gov/ca/fosterparents/training/chidev/cd06.htm>
- The knowledge of death and disease comes from:
 - UBM Medica LLC. (2010). Talking with your child about cancer. Retrieved from <http://www.healthieryou.com/canctalk.html>
 - Worden. (2010). Talking to your child about the loss of a loved one. In PsychCentral. Retrieved from http://psychcentral.com/library/child_death9.htm



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Overview

- This presentation discusses children's developmental milestones.
- As children grow, they reach certain physical, intellectual, social, emotional, and moral milestones.
- Developmental milestones represent the age-specific skills that each child should have when they reach a certain age range.
 - Keep in mind that each child is different and will develop at their own pace.
- Information about children's developmental milestones can help promotoras understand at every age what a child is capable of understanding, what he or she feels emotionally, and what communication methods are age appropriate.

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Children's Developmental Stages

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Infant to 2-Year-Old

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Grows rapidly •Develops motor skills (tracks people with eyes, grabs things, rolls over, sits, stands, feeds self, puts on/takes off clothing) •Puts things in their mouths •Teething •Can stack blocks •Cannot control bowels 	<ul style="list-style-type: none"> •Spontaneously makes noises and coos •Learns through the senses (responds to sounds, likes to taste things) •Enjoys hearing the names of things and begins to speak •Repeats behaviors that they see •Understands simple spoken directions •Starts to enjoy songs and rhymes 	<ul style="list-style-type: none"> •Is able to recognize the primary caregiver and finds this person extremely important •Holds gazes and smiles •Enjoys being played with, held, and tickled •Waves goodbye •Becomes possessive and independent 	<ul style="list-style-type: none"> •Can convey excitement and pleasure •Fears the unexpected (loud noises, sudden movements) •Needs to feel loved (held, cuddled) •Has a temper •Sucks thumb •May be clingy or fussy or seem to revert back to earlier stages of development •May react to emotions and distress displayed by you or the other children in your family 	<ul style="list-style-type: none"> •Understands adult approval and disapproval 	<ul style="list-style-type: none"> •Cannot understand explanations of cancer •May understand that mommy or daddy does not feel well

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2 to 6-Year-Old

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Enjoys playing, rough-housing •Is active •Develops manual dexterity (can manipulate small objects) •Can control bowels, bladder •Muscles grow quickly •May not be an adventurous eater; prefers bland foods 	<ul style="list-style-type: none"> •Has a short attention span •Continues to develop vocabulary •Learns mostly through senses •Uses imagination often; may have imaginary friends •Is curious and asks a lot of questions •Begins to understand cause and effect •Understands letters, numbers, currency •Picks up on nonverbal communication 	<ul style="list-style-type: none"> •Clings to primary caregiver •Imitates adult behaviors (trying on clothes, make-up) •Recognizes differences between men and women •Curious about where babies come from •Enjoys being around others; but prefers the same sex •Starts to understand rules and sharing 	<ul style="list-style-type: none"> •Likes being praised •Wants to do things on their own •Shows a lot of emotion •Says "No" often and tests boundaries •Generally less fearful •Becomes boastful, bossy, may name call •Can be easily embarrassed •Family is the center of child's world; child is confident family will care for his or her needs 	<ul style="list-style-type: none"> •Wants approval •Tries to be good and knows right from wrong •May lie or blame others if they do something wrong •Values other people's opinions of self •May use verbal threats/wishes without understanding what they mean (such as "I wish you were dead") 	<ul style="list-style-type: none"> •Understands the idea of germs, may believe that cancer is contagious •May believe that they said or did something to cause the cancer •Will not understand what is going on inside the body; focuses on outward symptoms (such as hair loss, weight changes) •Knows the basics of what a doctor does •No understanding of time or death

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6 to 9-Year-Old

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Is energetic, restless •Has growth spurts •May get ill often as a result of being in school •Develops hand-eye coordination and enjoys drawing and writing •Has a good appetite and may be more adventurous with food 	<ul style="list-style-type: none"> •Indecisive •Can read and write •May stutter when upset •Begins to have clear memories •Is capable of logical thought •Has a longer attention span •Develops hobbies and retreats to fantasy less •Wants to know why things happen •Begins to exaggerate •Has greater interest in birth and babies 	<ul style="list-style-type: none"> •Begins to identify with other adults (teachers, neighbors) •May be disloyal to friends, have unstable relationships then gradually become more social •Becomes concerned with the reactions of others •May still use aggression to problem-solve •Enjoys school 	<ul style="list-style-type: none"> •Feels insecure and does not take criticism or blame well •May be negative and act out •Has a very self-centered attitude •Complains often •Tries to develop a sense of self •Is easily distracted •May be secretive •Becomes helpful and outgoing •Is curious •May be affectionate and act silly 	<ul style="list-style-type: none"> •Seeks approval from others; may blame others for something they did •Feels guilt and shame 	<ul style="list-style-type: none"> •May understand the basics of human anatomy •Understands cause and effect •Fears that cancer is something contagious •Has an interest in the causes of cancer •May ask for specific details about cancer •Starts to understand that cancer can lead to death •Personifies death as a person or monster who takes you away

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9 to 12-Year-Old

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Rough-houses and enjoys team sports •Has coordination and body control •Females begin developing quicker than males •Becomes aware of the body and sexuality 	<ul style="list-style-type: none"> •Develops strong interests in activities, hobbies, collecting things •Capable of thinking abstractly •Enjoys books and writing •Capable of arguing logically and may challenge others •May become critical of adults •Shows an interest in national and international events •Asks more about "what happened" 	<ul style="list-style-type: none"> •Enjoys group activities, but still hangs out with the same sex •Is competitive •Thinks highly of parents and shows affection toward them •Becomes selective when choosing friends and may have a best friend •Wants to be accepted by peers •Enjoys being part of a community 	<ul style="list-style-type: none"> •Becoming independent, but may develop behavior problems if not accepted by others •Enjoys privacy •Mostly concerned with school and friends •May become rebellious, dramatic, and moody 	<ul style="list-style-type: none"> •Understands the concept of being fair •Begins to take responsibility for mistakes •Has a conscience and set of morals, but strives to please the group and be accepted 	<ul style="list-style-type: none"> •Understands what cells are and that cancer cells act differently than normal cells •Will likely be familiar with cancer and some forms of treatment •Understands that illness can lead to death •May see cancer as punishment for poor behavior •Questions relationship and life changes caused by cancer

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Teenager

Physical Milestones	Intellectual Milestones	Social Milestones	Emotional Milestones	Moral Milestones	Knowledge of Death and Disease
<ul style="list-style-type: none"> •Rapidly gets taller, gains weight, and develops strength •Reaches sexual maturity and is more likely to act on sexual desires •May develop acne and be concerned with physical appearance 	<ul style="list-style-type: none"> •Enjoys engaging in arguments and discussions •Begins to think and plan for the future •Capable of introspection •Enjoys reading •May develop interest in religion, faith •Lacks confidence in personal abilities 	<ul style="list-style-type: none"> •May withdraw from parents and siblings as a means of rebellion •Has an established group of friends of both sexes •May date and have serious relationships •May confide in someone outside the family 	<ul style="list-style-type: none"> •Needs to feel special •Worries about school, friends, appearance, failure •May talk back to teachers and authority figures •Is ego-centric and lonely at times •Is conflicted about being oneself versus fitting in •Needs someone to listen; to talk with •Not sure how to handle own emotions [public and private] 	<ul style="list-style-type: none"> •Weighs costs and benefits of decisions •Tries to avoid doing wrong by thinking of alternative solutions •Is generally truthful and concerned about fairness of others •May be frustrated or confused when family or friends don't abide by right and wrong 	<ul style="list-style-type: none"> •Understands human anatomy •Understands the basics of the immune system •Understands what cancer is, is familiar with some treatment options, and understands remission •May feel guilt, anger, even some responsibility for cancer •It is likely teenagers will think about the implications cancer might have on them and their family

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 - Worden. (2010). Talking to your child about the loss of a loved one. In PsychCentral. Retrieved from http://psychcentral.com/library/child_death9.htm

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HANDOUT: Developmental Milestones Matching Worksheet

How children understand the world, cancer, and death at different developmental stages

Using an arrow, match the list of characteristics with the appropriate age group.

Age Group	Developmental Characteristics
Infant to 2-Year-Old:	<ul style="list-style-type: none"> • May see cancer as punishment for poor behavior • Asks more about “what happened” • Questions relationship and life changes caused by cancer • Understands that illness can lead to death
2 to 6-Year-Old:	<ul style="list-style-type: none"> • Fears that cancer is something contagious • Has an interest in the causes of cancer • May ask for specific details about cancer • Starts to understand that cancer can lead to death • Personifies death as a person or monster who takes you away
6 to 9-Year-Old:	<ul style="list-style-type: none"> • Needs someone to listen; to talk with • May feel guilt, anger, even some responsibility for cancer • Not sure how to handle own emotions [public and private] • May confide in someone outside the family • It is likely they will think about the implications cancer might have on them and their family
9 to 12-Year-Old:	<ul style="list-style-type: none"> • May understand that mommy or daddy does not feel well • May react to emotions and distress displayed by you or the other children in your family • Cannot understand explanations of cancer • May become clingy or fussy or seem to revert back to earlier stages of development
Teenager	<ul style="list-style-type: none"> • Family is center of the child’s world; child is confident family will care for his or her needs • No understanding of time or death • Picks up on nonverbal communication • Will not understand what is going on inside the body, and will likely focus on outward symptoms that they can see

HANDOUT: Developmental Milestones Matching Answer Key

How children understand the world, cancer, and death at different developmental stages

Using an arrow, match the list of characteristics with the appropriate age group.

Age Group	Developmental Characteristics
Infant to 2-Year-Old:	<ul style="list-style-type: none"> • May see cancer as punishment for poor behavior • Asks more about “what happened” • Questions relationship and life changes caused by cancer • Understands that illness can lead to death
2 to 6-Year-Old:	<ul style="list-style-type: none"> • Fears that cancer is something contagious • Has an interest in the causes of cancer • May ask for specific details about cancer • Starts to understand that cancer can lead to death • Personifies death as a person or monster who takes you away
6 to 9-Year-Old:	<ul style="list-style-type: none"> • Needs someone to listen; to talk with • May feel guilt, anger, even some responsibility for cancer • Not sure how to handle own emotions [public and private] • May confide in someone outside the family • It is likely they will think about the implications cancer might have on them and their family
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Teenager	<ul style="list-style-type: none"> • Family is center of the child’s world; child is confident family will care for his or her needs • No understanding of time or death • Picks up on nonverbal communication • Will not understand what is going on inside the body, and will likely focus on outward symptoms that they can see

HANDOUT: Key Principles for Working with Children Coping with Cancer

Promotoras should review this handout in their own time. This should serve as a reference about specific skills a promotora must have in order to effectively work with children coping with cancer.

As a promotora working with children, you should:

- Be comfortable with children and use an approach that fits his or her personality. This may be sitting on the floor, playing a game, or coloring while talking.
- Talk to the child in an environment that is comfortable for the child. This may be in his or her room, at a table, or sitting on the floor with no barriers in between you.
- Be able to communicate with language that is appropriate to the child's age, stage of development, and culture.
- Ask the child to repeat or paraphrase important pieces of information you tell him or her to check for understanding. Sometimes it is best to follow the child's lead and not push him or her to talk beyond what they are comfortable talking about.
- Use a friendly and relaxed approach when talking to the child.
- Be patient and understand that it may take time for a child to be comfortable enough with you to talk about serious or upsetting topics.
- Treat children with respect.

HANDOUT: Key Attributes of Promotoras de Salud

A promotora...

... is a member of the community and shares the same culture, customs, and beliefs of the community she serves.

...is a trained, natural helper who offers personalized support to clients.

...helps to remove barriers to healthcare so clients can access the care they need.

...has a strong sense of social responsibility and engages in civic participation.

...serves as a bridge between the community and available services.

...serves as an advocate for individuals to help them meet their individualized healthcare needs.

...teaches community members about important health topics in a culturally sensitive way.

...participates with the community as an informal counselor or group leader.

...directs individuals toward appropriate resources and works to ensure comprehension of documents, materials, and processes.

...works with the community to promote healthy living.

...is able to provide basic emergency assistance, such as first aid.

...is empathetic toward, and has a strong desire to help, the community.

...is knowledgeable and respectful of the beliefs and traditions of others.

...is resourceful and knows where to find relevant information.

SESSION 2: CANCER AND ITS IMPACT ON CHILDREN

INTRODUCTION

Cancer is on the rise. Most people know of someone who has been diagnosed with one form of cancer or another. Yet, despite the fact that cancer is all around us, a solid understanding of cancer among the Latino population is lacking. When working with children coping with cancer, promotoras will need to give explanations about what cancer is, how it develops, what organs in the body it affects, and how it is treated. To be able to communicate accurate information about cancer, they must first learn these facts themselves. This session will equip promotoras with the knowledge to discuss human anatomy, how cancer begins, how it spreads within the body, and how it can be treated. Promotoras should recognize that cancer is not one disease, but rather a host of diseases. Once a promotora knows the biology of cancer she will be better equipped to address the needs and concerns of a child coping with cancer.

The session begins with a basic anatomy lesson, which is foundational knowledge, before you can start discussing cancer with promotoras. Organ names are given in Spanish and English so that promotoras are familiar with terms English-speaking doctors may use in discussing their patient's cancer.

After learning about the main organs in the body, the next activity provides basic facts about cancer, and how it starts from a single abnormal cell. This information will not only help promotoras explain to clients what is happening in the body, but will also enable them to differentiate fact from myth.

Finally, the session concludes by reviewing the emotional, physical, and social impact of cancer on children. Understanding how cancer makes children feel and behave will help promotoras design effective strategies to help them.

Session Learning Objectives

After completing this session, promotoras will have:

the knowledge to...

- Explain main human organs in Spanish and English
- Explain what cancer is and how it is diagnosed and treated
- Understand how cancer affects children directly and indirectly

and the skills to...

- Identify key body parts in the human body
- Identify solutions to common problems experienced by children coping with cancer

MATERIALS NEEDED

- ✓ Pens/Markers
- ✓ Flipchart
- ✓ Computer, LCD projector and screen (optional)
- ✓ *What is Cancer?* PowerPoint presentation
- ✓ Human body poster
- ✓ Flip chart pages
 - *Child With Cancer*
 - *Family Member With Cancer*

HANDOUTS

- ✓ *Human Body Worksheet*
- ✓ *Human Body Answer Key*
- ✓ *Organ Identifier*
- ✓ *What is Cancer? (Presentation slides)*
- ✓ *Problems and Solutions*
- ✓ *Child With Cancer*
- ✓ *Family Member With Cancer*

ACTIVITY 1: The body

Time: 15 minutes

Activity goal: This activity will improve promotoras' knowledge of the human body, where major organs are located, and their primary function.

Facilitator notes: Review the *Human Body* poster before starting the activity so you know the placement of major organs in the body. Also review the *Organ Identifier* handout to become familiar with the function of organs in case of questions. You may also wish to look at the references in the *Additional Resources* section for more information about anatomy.

Activity Description:

1. Divide promotoras into groups of four.
2. Explain that you will be handing out, to each group, a worksheet with a picture of the human body. The picture of the body will be missing several organs that are labeled and shown in a box on the worksheet. Each group should decide where in the body each missing organ goes and then draw it on their *Human Body* worksheet. Explain that the worksheet does not have every single organ, just the major ones.
3. Allow 10 minutes for the groups to complete the worksheet.
4. Hang up the *Human Body* poster and review with the groups where on the body each group drew the missing organ.
5. Ask if promotoras have any questions about any of the organs identified in this activity. To answer questions, refer to the *Organ Identifier* handout.

6. Give each promotora a copy of the *Organ Identifier* handout and a copy of the *Human Body Answer Key*, which has a list of all the organs in the body in Spanish and English.
7. Explain to the group that now they have a basic knowledge of the organs most affected by cancer. The next activity will help them understand what cancer is, how it is treated, and the effects it has on an individual's body and life.

ACTIVITY 2: What is cancer?

Time: 20 minutes

Activity goal: This activity provides a basic understanding of what cancer is, how it is diagnosed, and how it can be treated.

Facilitator notes: Be sure to review the PowerPoint materials, and study the basic concepts of cancer before conducting the activity. You may wish to also view references provided in the additional resources section.

Activity Description:

1. Give promotoras the *What is Cancer?* handout and present the *What is Cancer?* PowerPoint presentation.
2. Once the presentation is complete, ask the promotoras if they can summarize what cancer is. Write their answers on the flipchart.
3. Ask if they can summarize the main ways that cancer is treated. Write their answers on the flipchart.
4. Ask if they can summarize the potential effects of cancer and its treatment. Write their answers on the flipchart.
5. Make sure that the main points from the PowerPoint presentation make it onto the lists.
6. Wrap up the activity by explaining that now they understand the general effect of cancer on the human body. The next activity focuses specifically on how cancer affects children emotionally, socially, and physically.

ACTIVITY 3: Impact of cancer on children

Time: 25 minutes

Activity goal This activity will provide promotoras with an understanding of the impact that cancer has on children.

Facilitator notes: The background information for this activity is provided on the two handouts *Child With Cancer* and *Family Member With Cancer*. These two handouts provide examples of problems experienced by children coping with cancer, and potential solutions. Thoroughly review the problems and solutions on these handouts, but also think of additional problems and solutions—these lists are not exhaustive and each child that your promotoras work with will be unique.

Activity Description:

1. Divide the group of promotoras in half and give each group a blank *Problems and Solutions Worksheet* and a pen or pencil.
2. Tell each group to assign a recorder—someone who will write down all of the ideas the group generates.
3. Tell the first group they will be brainstorming problems they think children with cancer will encounter. This can include emotional, social, physical, and anything else they think is relevant. Tell the group that they also need to provide a possible solution to the problem.
4. Tell the second group they will be brainstorming problems they think children who have a family member with cancer will encounter. As with the first group, ask them to provide possible solutions to the problems.
5. Give the groups 10 minutes to brainstorm.
6. Display the two flipcharts *Child With Cancer* and *Family Member With Cancer*. Ask the recorder from each group to read aloud their group's list of problems/difficulties, and write these down under the correct subheading.
7. Ask if anyone has anything to add before moving on.
8. Next, ask the recorder from each group to read aloud their group's list of solutions, and write these down under the appropriate flipchart heading.
9. Ask if anyone has anything to add to the lists.
10. With the lists side by side, ask the promotoras what problems and solutions the two groups share. Circle these on both flipcharts to show that many of their problem-solving strategies will be the same for both groups.
11. Provide the *Child With Cancer* and *Family Member With Cancer* handouts to all promotoras and ask them to spend a couple of minutes reading them.
12. Facilitate discussion to see if anyone has anything to add to your lists based on the handouts.
13. Let promotoras know that there is space on the handouts for them to add other ideas they came up with during the activity and that the handouts are not exhaustive—every child's situation will be unique. Also point out that problems and solutions will depend on the age of the child.

CONCLUSION

The biological toll of cancer on the body is not always clear. Without clear explanations, children may not be able to comprehend what is happening inside their bodies or the body of their family member. This session provided promotoras with the knowledge to provide clear explanations about the biology of cancer and the physical symptoms a child or their family member may be experiencing. Further, this session has provided promotoras with a fundamental understanding of the many fears and anxieties that accompany a cancer diagnosis, and potential solutions they can implement to help children. With this information in hand, promotoras are well situated for the next session on identifying and addressing client needs.

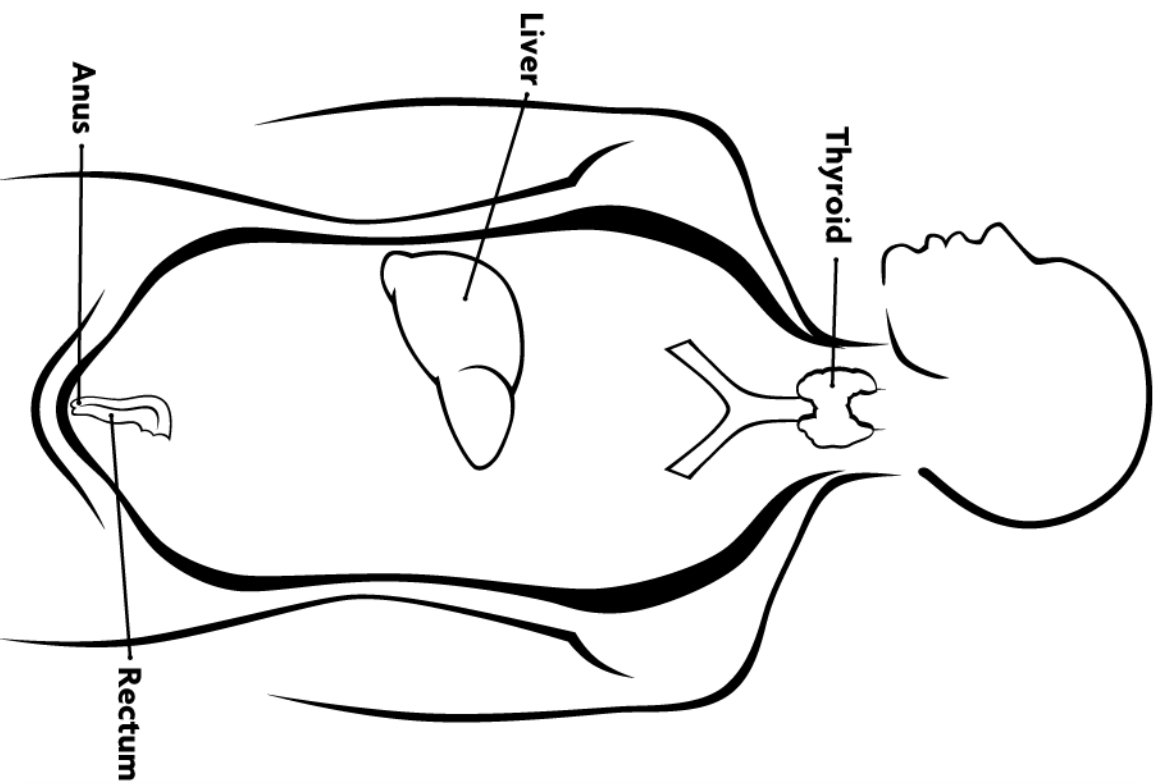
Activity 3

FLIPCHART PAGE: Child With Cancer

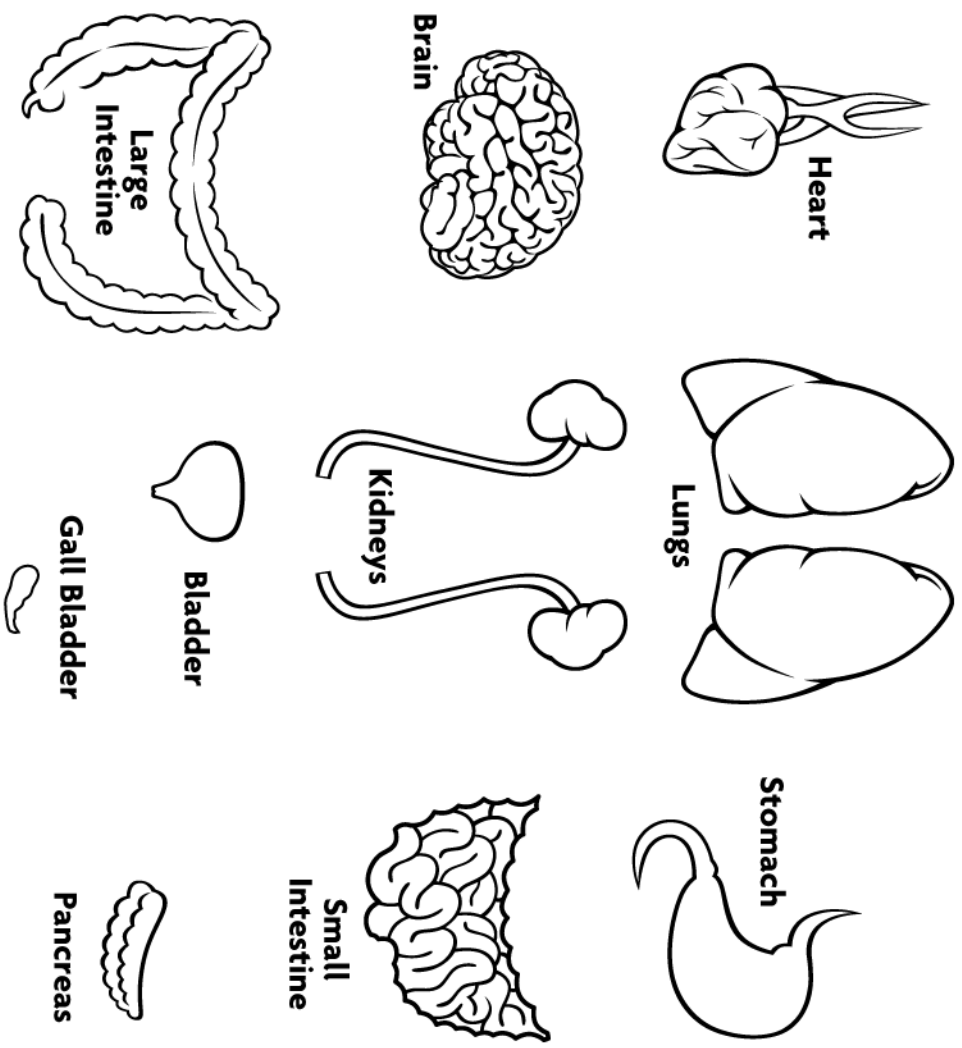
Problems	Solutions

FLIPCHART PAGE: Family Member With Cancer

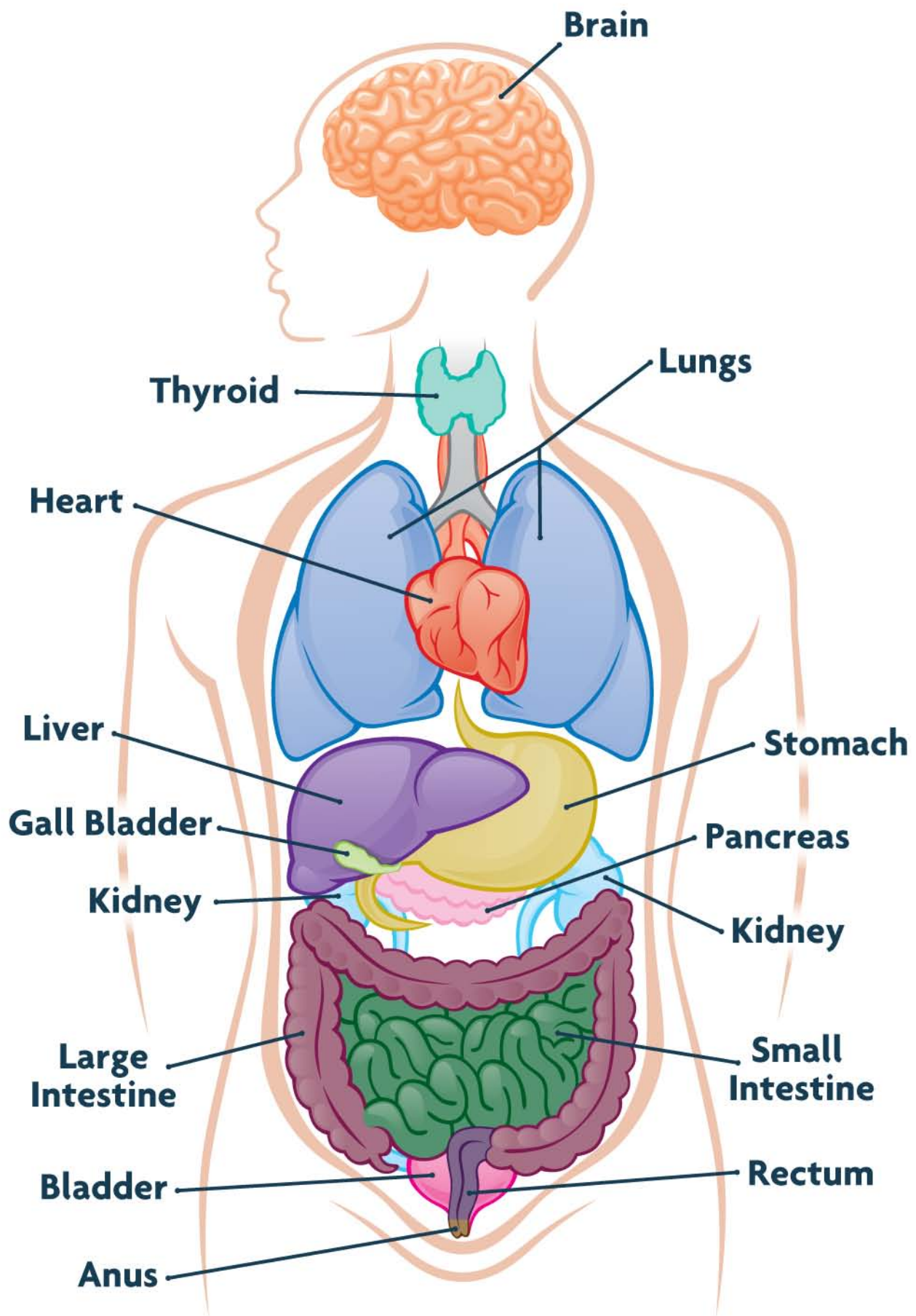
Problems	Solutions



Missing Organs to Place



Human body answer key



HANDOUT: Organ Identifier

This handout describes the most common areas of the human body, listed in alphabetical order, where cancer develops.

Anus: The anus is in charge of getting rid of feces from the body, and is an opening located at the end of the digestive tract.

Bladder: The bladder collects urine that is filtered by the kidneys, and is located in the pelvis.

Blood cells: There are three types of blood cells: red, white, and platelets. White blood cells help the body fight infection. Red blood cells carry oxygen throughout the body. Platelets help blood to clot. All three are located in blood vessels throughout the body.

Bones: Bones make up the skeleton of the body. Without bones the body would not be able to stand up or move. The human body has 206 bones from the skull to the toes.

Brain: The brain controls the muscles of the body, and it produces chemicals that allow it to respond to outside cues. It also performs functions like self-control, planning, reasoning, and abstract thinking. The brain is located inside the skull.

Breasts: The main function of the breasts is to produce milk. Both males and females have breasts although, during puberty, men do not produce enough of a particular hormone and, therefore, their breasts do not develop. Breasts are located on the upper chest.

Gall bladder: The gall bladder stores a digestive juice called bile, which helps you digest food, and is located under the liver.

Germ cells: Germ cells are cells that make up the ovaries in women or testes in men. Although they are usually found in the ovaries or testes, they can sometimes end up elsewhere in the body.

Heart: The heart pumps blood through blood vessels located in all organs of the body, and is located just behind, and slightly left of the breastbone.

Kidney: The kidneys clean the body's blood, produce hormones, and get rid of wastes by sending them to the bladder as urine. The body has two kidneys that are located along the lower back.

Large intestine (colon): The large intestine, or colon, absorbs water and helps get rid of waste from the body. The large intestine is located in the abdomen and is attached on one end to the small intestine and on the other end to the rectum.

HANDOUT: Organ Identifier (continued)

Liver: The liver filters harmful substances from the blood, keeps levels of certain hormones in the blood consistent, stores vitamins and minerals, produces bile that helps with digestion, and produces chemicals that break down fats. The liver is located on the right side of the abdomen.

Lung: The lungs bring oxygen to, and remove harmful substances from, the blood. The human body has two lungs located in the chest on either side of the heart.

Ovaries: The ovaries produce female hormones that play an important role in puberty and pregnancy. Females have two ovaries. The ovaries are located in the pelvis and are attached to the uterus on either side.

Pancreas: The pancreas produces several important hormones and helps to break down foods during digestion. The pancreas is located behind the stomach in the abdomen.

Prostate: The prostate stores and secretes fluid that keeps sperm healthy. It is located between the bladder and the rectum in men.

Rectum: The rectum acts as a temporary storage area for feces, and is located at the end of the large intestine right before the anus.

Small intestine: The small intestine continues the process of digestion after food has left the stomach. It is also where nutrients, such as vitamins and minerals, are absorbed for use by the body. The small intestine is located in the abdomen and is attached to the stomach on one end and the large intestine on the other end.

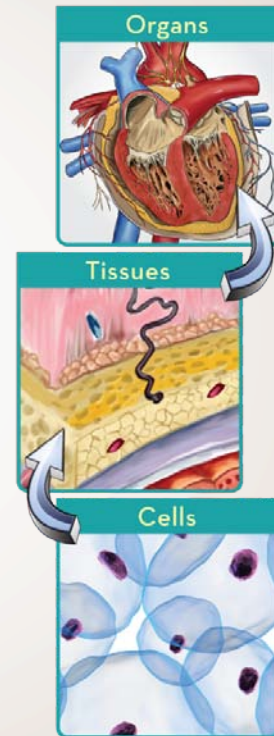
Stomach: The stomach is where food digestion begins, and is located in the upper left portion of the abdomen.

Testes (testicles): The main function of the testes, or testicles, is to make sperm. They also make an important male hormone. The testes are located in the scrotum, a part of the abdomen, near the rectum.

Thyroid: The thyroid is in charge of how quickly the body uses energy, and is located in the neck.

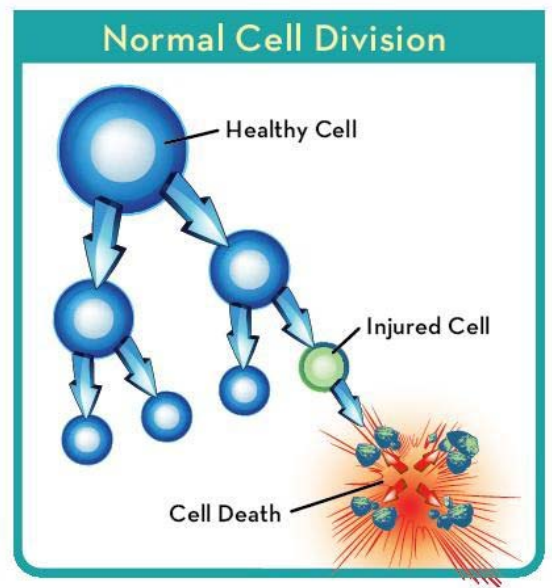
HANDOUT: What Is Cancer? (Presentation Slides)

- The human body is made up of millions of cells.
- Cells are tiny and most can be seen only under a microscope.
- Cells grow, divide, and die regularly.
- Cells can have different jobs.
 - Red blood cells carry oxygen around the body.
 - White blood cells help keep the body from getting sick.
- Cells with the same jobs group together to form tissue.
 - Cells of the heart group form heart muscle tissue.
- Tissues in turn, group together to form organs.
 - Heart muscle tissue makes up the heart, and is the reason the heart beats.



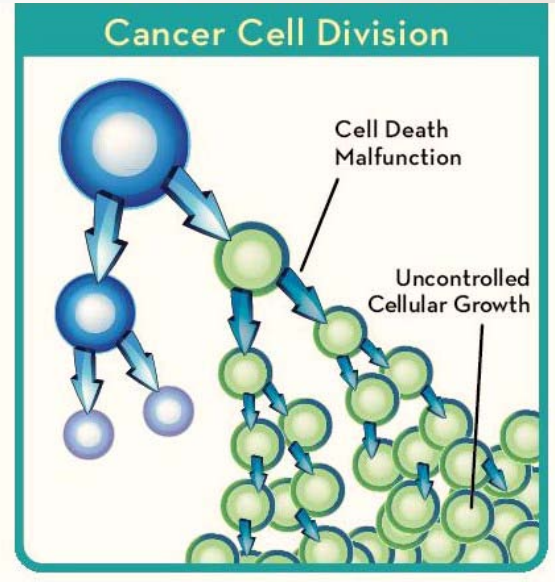
Normal Cell Life Cycle

- Normal, healthy cells grow and split to form two more healthy cells.
- The cells continue to grow and split regularly, until they become unhealthy or injured with age.
- Once a cell is injured, the body kills it so that it does not keep splitting and make other abnormal, unhealthy cells.



Cancer Cell Life Cycle

- Cancer is a general term that refers to a group of over 100 diseases caused by the growth of abnormal cells in the body.
- Cancer starts with a single abnormal cell somewhere in the body.
- This abnormal cell grows quickly and splits into new, abnormal cells that are not found and killed by the body.
- These abnormal cells group together to form a tumor.
- Cancer is the point at which the cells have developed into a tumor.
- These abnormal cells attach to tissues in the body and the body cannot defend itself against them.
- These cells gradually begin to replace healthy cells, and the healthy cells die.



Classification of Cancer

- Cancer is usually classified by its “stage.” The stage refers to how bad the cancer is.
- **Stage 0:**
 - Abnormal cells that remain where they were first found and, at this point, are not cancer.
- **Stage I:**
 - Cancer is limited to the tissue where it was first discovered, and there is evidence of tumor growth.
- **Stage II:**
 - Some spread of cancerous cells in the tissue where the tumor was first discovered.
- **Stage III:**
 - Extensive spread of cancerous cells in the tissue where the tumor was first discovered, and to surrounding tissues.
- **Stage IV:**
 - The cancer has spread throughout the body.

Classification of Cancer

- Some cancers are not classified using the staging system.
 - Brain and spinal cord cancers are classified by the type of cells affected, how normal/abnormal they look under a microscope, and how fast they are likely to spread.
 - Cancers of the cervix, uterus, ovary, vagina, and vulva are classified by a system developed by the International Federation of Gynecology and Obstetrics.
 - There is no clear-cut classification system in place for most cancers of the blood and bone marrow.

How Is Cancer Diagnosed?

- Cancer is detected by a doctor who runs tests. Different types of tests are used to detect different types of cancer. The most common types of tests fall into two categories: imaging and laboratory.
 - Imaging tests (e.g., mammogram, virtual colonoscopy, and ultrasound) make pictures of areas inside the body to see if a person has any suspicious areas or abnormalities that might be cancerous.
 - Laboratory tests use blood, urine, or other substances from the body to find out if someone is sick before symptoms appear.

How Is Cancer Treated?

- Cancer is treated in different ways depending on:
 - The kind of cancer
 - The stage of the cancer
 - The age of the patient
 - How healthy or sick the patient is
- Cancer treatments aim to kill the unhealthy cancer cells, but sometimes also kill the healthy cells in the body.

How Is Cancer Treated? (continued)

- Treatments can be:
 - **Invasive:** when there is a large cut in the skin that needs a lot of healing time (e.g., open heart surgery, brain surgery).
 - **Minimally invasive:** when there is a small cut in the skin that does not need a lot of healing time (e.g., endoscopy, getting a shot).
 - **Noninvasive:** when treatment is provided without breaking the skin or entering a body cavity (e.g., taking blood pressure or checking reflexes).
- The three major treatments for cancer are surgery, radiation, and chemotherapy.

Surgery

- **Surgery:** physically takes out some or all of the tumor. However, this is not always possible, especially when the cancer is in vital organs like the heart or lungs.
 - Most people with cancer will have some type of surgery. If the cancer has not spread to other parts of the body, surgery is the best way to get rid of it.
 - Surgery may be the patient's only treatment if all the cancer can be removed, or it may be used with other treatments (e.g., radiation or chemotherapy).
 - Surgery can be invasive or minimally invasive, depending on how big the tumor is and where in the body it is located.

Chemotherapy

- **Chemotherapy** (or chemo): when the doctor gives the patient drugs that kill any cells in the process of splitting. This includes good cells as well as cancerous ones.
 - Since cancer cells grow and split very fast, they are almost always in the process of splitting.
 - Chemotherapy can be given either by pill (noninvasive) or by injections (minimally invasive) into muscles, veins, arteries, under the skin, or in the abdomen.

Radiation Therapy

- **Radiation:** an invisible form of energy. Radiation therapy uses high-energy radiation to kill the cancer cells or make them smaller. Normal cells may also shrink, though they are generally able to fix themselves.
 - Radiation can be placed directly inside the cancer cells (invasive or minimally invasive) or given by a machine outside of the body (noninvasive).
 - Close to 50% of cancer patients will need radiation therapy.

Other Kinds of Treatments

- **Antiangiogenesis therapy** (or angiogenesis): means “growth of new blood vessels.” Some tumors grow their own blood supply. Some drugs can keep these blood vessels from forming. This treatment does not cure cancer, but can keep the cancer cells from growing and splitting.
 - Not all types of cancer grow their own blood supply, so this treatment is not always useful.
- **Hormone therapy:** hormones are in charge of how fast certain cancers grow (such as breast and prostate cancers). If the doctor stops these hormones from being made, or keeps them from reaching the tumor, the tumor cannot grow or split.

Side Effects of Cancer Treatments

- Surgery side effects:
 - Pain
 - Infection
 - Organ failure
 - Bleeding and clotting problems
 - Changes to bowel and/or bladder function
- Chemotherapy and radiation side effects:
 - Feeling tired
 - Hair loss
 - Nausea and vomiting
 - Pain
 - Changes in appetite, sexual desire, fertility, and bowel and bladder function
 - Bleeding problems
 - Swelling
- It is the death of healthy cells that leads to many of the side effects of chemotherapy and radiation.
- Normal, healthy cells usually get better when treatment is over, and the side effects slowly go away.

Other Effects of Cancer

- School/Work absences
- Stress
- Depression
- Tension between spouses and/or other family members
- Financial problems
- Problems finding someone to look after the patient's children

Where Can I Find More Information?

- In English:
 - The American Cancer Society: <http://www.cancer.org/>
 - The National Cancer Institute: <http://www.cancer.gov/>
- In Spanish:
 - Instituto Nacional del Cáncer:
<http://www.cancer.gov/espanol>
 - Boletín del Instituto Nacional del Cáncer:
<http://www.cancer.gov/boletin>
 - Diccionario de Cáncer:
<http://www.cancer.gov/diccionario/>

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Familias Fuertes

What Is Cancer?

NOTES: _____

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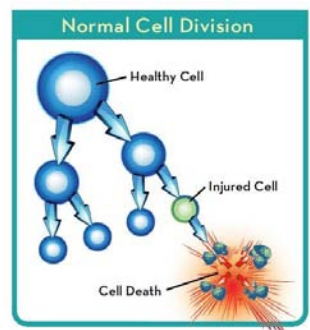
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What Is Cancer?

NOTES: _____

Normal Cell Life Cycle

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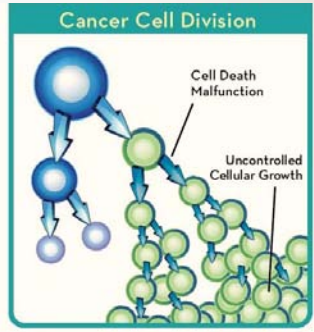
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What Is Cancer?

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Cancer Cell Life Cycle

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- These abnormal cells group together to form a tumor.
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What Is Cancer?

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What Is Cancer?

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How Is Cancer Diagnosed?

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 - Imaging tests (e.g., mammogram, virtual colonoscopy, and ultrasound) make pictures of areas inside the body to see if a person has any suspicious areas or abnormalities that might be cancerous.
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What Is Cancer?

NOTES: _____

How Is Cancer Treated?

- Cancer is treated in different ways depending on:
 - The kind of cancer
 - The stage of the cancer
 - The age of the patient
 - How healthy or sick the patient is
- Cancer treatments aim to kill the unhealthy cancer cells, but sometimes they also kill the healthy cells in the body.

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What is cancer?

NOTES: _____

How Is Cancer Treated? (continued)

- Treatments can be:
 - **Invasive:** when there is a large cut in the skin that needs a lot of healing time (e.g. open heart surgery, brain surgery).
 - **Minimally invasive:** when there is a small cut in the skin that does not need a lot of healing time (e.g., endoscopy, getting a shot).
 - **Noninvasive:** when treatment is provided without breaking the skin or entering a body cavity (e.g., taking blood pressure or checking reflexes).
- The three major treatments for cancer are surgery, radiation, and chemotherapy.

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What is cancer?

NOTES: _____

Surgery

- **Surgery:** physically takes out some or all of the tumor. However, this is not always possible, especially when the cancer is in vital organs like the heart or lungs.
 - Most people with cancer will have some type of surgery. If the cancer has not spread to other parts of the body surgery is the best way to get rid of it.
 - Surgery may be the patient's only treatment if all the cancer can be removed, or it may be used with other treatments (e.g., radiation or chemotherapy).
 - Surgery can be invasive or minimally invasive, depending on how big the tumor is and where in the body it is located.

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What is cancer?

NOTES: _____

Chemotherapy

- **Chemotherapy** (or chemo): when the doctor gives the patient drugs that kill any cells in the process of splitting. This includes good cells as well as cancerous ones.
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What is cancer?

NOTES: _____

Radiation Therapy

- **Radiation** : an invisible form of energy. Radiation therapy uses high-energy radiation to kill the cancer cells or make them smaller. Normal cells may also shrink, though they are generally able to fix themselves.
 - Radiation can be placed directly inside the cancer cells (invasive or minimally invasive) or given by a machine outside of the body (noninvasive).
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What is cancer?

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Other Kinds of Treatments

- **Antiangiogenesis therapy** (or angiogenesis): means “growth of new blood vessels.” Some tumors grow their own blood supply. Some drugs can keep these blood vessels from forming. This treatment does not cure cancer, but can keep the cancer cells from growing and splitting.
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What is cancer?

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Side Effects of Cancer Treatments

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 - Organ failure
 - Bleeding and clotting problems
 - Changes to bowel and/or bladder function
- Chemotherapy and radiation side effects:
 - Feeling tired
 - Hair loss
 - Nausea and vomiting
 - Pain
 - Changes in appetite, sexual desire, fertility, and bowel and bladder function
 - Bleeding problems
 - Swelling
- It is the death of healthy cells that leads to many of the side effects of chemotherapy and radiation.
- Normal, healthy cells usually get better when treatment is over, and the side effects slowly go away.

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What is cancer?

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Other Effects of Cancer

- School/Work absences
- Stress
- Depression
- Tension between spouses and/or other family members
- Financial problems
- Problems finding someone to look after the patient's children

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What is cancer?

NOTES: _____

Where Can I Find More Information?

- In English:
 - The American Cancer Society: <http://www.cancer.org/>
 - The National Cancer Institute: <http://www.cancer.gov/>
- In Spanish:
 - Instituto Nacional del Cáncer:
<http://www.cancer.gov/espanol>
 - Boletín del Instituto Nacional del Cáncer:
<http://www.cancer.gov/boletin>
 - Diccionario de Cáncer:
<http://www.cancer.gov/diccionario/>

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What is cancer?

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What is cancer?

NOTES: _____

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National Cancer Institute, National Institutes of Health. (2010). *Cancer staging*. Retrieved from <http://www.cancer.gov/cancertopics/factsheet/detection/staging>

National Cancer Institute, National Institutes of Health. (2010). *Radiation therapy for cancer*. Retrieved from <http://www.cancer.gov/cancertopics/factsheet/therapy/radiation>

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What is cancer?

NOTES: _____

HANDOUT: Problems and Solutions Worksheet

With your group, brainstorm potential problems and corresponding solutions that either a child with cancer or a child with a family member with cancer may encounter. (Note: The facilitator will tell you which scenario to brainstorm.)

Problems	Solutions

HANDOUT: Child With Cancer

Note, these may either be problems you as a promotora can solve, or you can make suggestions to the parents about how to solve them.

Problems	Solutions
<ul style="list-style-type: none"> Nutritional: <ul style="list-style-type: none"> Side effects of treatments <ul style="list-style-type: none"> Loss of appetite Mouth sores Nausea/vomiting Diarrhea Social: <ul style="list-style-type: none"> Feeling lonely/isolated from friends Lack of normalcy in life 	<ul style="list-style-type: none"> Nutritional: <ul style="list-style-type: none"> Managing side effects of treatment <ul style="list-style-type: none"> Try smaller, more frequent meals and snacks, but do not force the child to eat. Use soft, easy-to-chew foods in small pieces at room temperature. Try easy-to-digest food (e.g., clear liquids, gelatin, toast, rice, dry cereals, and crackers). Limit high-fiber, fatty, and fried foods, and drink lots of fluids. Social: <ul style="list-style-type: none"> Encourage friends to visit the hospital or your home (if your child is well enough), or ask friends to make a card or video for your child. Try to keep your child involved in normal activities as much as possible. <ul style="list-style-type: none"> Keep up with school work. If the child is home and healthy enough, have him or her help out with regular chores (in moderation). If your child is healthy enough, allow for regular play time (e.g., computer games, video games, etc.).

HANDOUT: Child With Cancer (continued)

Problems	Solutions
<ul style="list-style-type: none"> Emotional: <ul style="list-style-type: none"> Feeling like they have no control over their body Loneliness Depression (especially if the child experiences changes to his or her physical appearance as a side effect of treatment) Feeling Guilty Thinking that cancer means they are going to die 	<ul style="list-style-type: none"> Emotional: <ul style="list-style-type: none"> Allow your child (if old enough) to be in charge of taking his or her medications so that they may feel empowered in fighting the disease. Make sure the child feels supported by family members and friends. <ul style="list-style-type: none"> If possible, have friends/family members come by the hospital or your home Have friends/family members make cards and/or videos. Have friends/family members phone your child if they are unable to visit. It may be helpful to have your child talk to a counselor/therapist. Make sure the child understands that they did not cause the cancer by misbehaving or doing something wrong. Explain that most cancers are treatable with medicine and that having cancer does not mean death.

HANDOUT: Child With Cancer (continued)

Problems	Solutions
<ul style="list-style-type: none"> Communication: <ul style="list-style-type: none"> Not understanding what is happening 	<ul style="list-style-type: none"> Communication : <ul style="list-style-type: none"> Make sure your child understands what cancer is, how it is treated, and any potential side effects of treatment. <ul style="list-style-type: none"> There are books specifically designed to teach children about cancer. Promotoras will also be able to tell you where to find age-appropriate resources. Emphasize that cancer is not contagious.
<ul style="list-style-type: none"> Physical: <ul style="list-style-type: none"> Pain Loss of hair Weight loss 	<ul style="list-style-type: none"> Physical: <ul style="list-style-type: none"> Talk to your child's doctor about how you can manage the pain. Consult an aesthetician about the possibility of getting a wig for your child. See <i>Nutrition Problems and Solutions</i> on the previous page.

HANDOUT: Family Member With Cancer

Note, these may either be problems you as a promotora can solve, or you can make suggestions to the parents about how to solve them.

Problems	Solutions
<ul style="list-style-type: none"> Nutritional: <ul style="list-style-type: none"> No one/not enough time to prepare regular or nutritious meals Social: <ul style="list-style-type: none"> Feeling isolated from friends Feeling isolated from family Lack of normalcy in life 	<ul style="list-style-type: none"> Nutritional: <ul style="list-style-type: none"> Arrange to have a friend or other family member prepare meals for the child. Social: <ul style="list-style-type: none"> If possible, arrange for a friend or relative to provide transportation to/from social activities. Make time for your child each day so that he or she doesn't feel forgotten. For example: <ul style="list-style-type: none"> Have a meal with your child. Read your child a bedtime story. Help your child with homework. Try to keep your child on a regular routine, including: <ul style="list-style-type: none"> Going to school Doing household chores Going to all extracurricular activities (play dates, sports/music practices, etc.) Enforcing all normal household rules

HANDOUT: Family Member With Cancer (continued)

Problems	Solutions
<ul style="list-style-type: none"> Emotional: <ul style="list-style-type: none"> Feeling helpless Depression Feeling Guilty Thinking that having cancer means death Communication: <ul style="list-style-type: none"> Not understanding what is happening 	<ul style="list-style-type: none"> Emotional: <ul style="list-style-type: none"> Make yourself available to answer any questions your child may have; also see if your doctor is willing to answer any of your child's questions. It may be helpful to have your child talk to a counselor/therapist . Make sure your child understands that they did not cause the cancer by misbehaving or doing something wrong. Explain that most cancers are treatable with medicine and that having cancer does not mean death. Communication : <ul style="list-style-type: none"> Make sure your child understands what cancer is, how it is treated, and any potential side effects of treatment. <ul style="list-style-type: none"> There are books specifically designed to teach children about cancer. Promotoras will also be able to tell you where to find age-appropriate resources. Emphasize that cancer is not contagious.

SESSION 3: OVERCOMING BARRIERS AND UNDERSTANDING CLIENT NEEDS

INTRODUCTION

A critical step in working with Latino children coping with cancer is to understand the barriers to healthcare that they face. The first activity in this session will orient promotoras to the types of challenges their clients may experience by presenting a scenario and asking them to brainstorm different barriers to care the child and their family will likely face. An important barrier to recognize is how cultural beliefs affect care-seeking behaviors. The Latino population is incredibly diverse and even within a nationality there are different beliefs about health and sickness. Therefore, the second activity in this session teaches promotoras to think about what cultural beliefs their clients might have that negatively affect their cancer care-seeking behavior.

Clients will not necessarily welcome the promotora into their lives, either because of poor past experiences with the health care system, long held misconceptions about sickness and disease, or a basic lack of understanding about who a promotora is and how they can help the client's family. Activity three of this session asks promotoras to brainstorm ways in which they can establish themselves in the community through referrals from trustworthy people and organizations.

Once a promotora has gained the trust of the community and takes on a new client, the first task she must conduct is a *Child Needs Assessment*. A needs assessment, as described in the final activity of this session, helps a promotora gauge the particular needs of the client in order of priority. This assessment will guide the work of the promotora over the weeks, months, and possibly years during which she will be working with the client.

Session Learning Objectives

After completing this session, promotoras will have:

the knowledge to...

- Identify the barriers to healthcare facing children coping with cancer
- Recognize cancer facts from myths

and the skills to...

- Reach out to children coping with cancer
- Conduct needs assessments for children coping cancer

MATERIALS NEEDED

- ✓ Flip chart
- ✓ Pens and paper
- ✓ Flip chart pages
 - *Barriers to Care*
 - *Connecting to Children Coping with Cancer*

HANDOUTS

- ✓ *Barriers to Care*
- ✓ *Cancer: True or False?*
- ✓ *Official Cancer Myth-Buster Certificate*
- ✓ *Needs Assessment Case Studies*
- ✓ *Child Needs Assessment: Child with Cancer*
- ✓ *Child Needs Assessment: Child with Family Member with Cancer*

ACTIVITY 1: Barriers to care

Time: 15 minutes

Activity goal: This activity will inform promotoras of the barriers to healthcare and resources that their clients will likely face.

Facilitator notes: Latinos may face numerous barriers to care including, but not limited to, language, lack of insurance, lack of transportation, fears or misinformation about the medical system, childcare needs, and difficulty understanding medical terms and treatment descriptions. Thoroughly review the *Barriers to Care* handout before beginning the session. It is important to restate to the promotoras that these children are an overlooked group because promotoras and families alike often believe children should not be told a great deal about cancer. This perception is itself a barrier to care.

Activity Description:

1. Display the flipchart *Barriers to Care* which provides a definition of barriers to healthcare. Explain to the promotoras that this activity will help them to identify barriers to care for children coping with cancer.
2. Explain to the group that you are going to read aloud a scenario about a family with a child coping with cancer and then they will conduct an activity about the scenario. Read aloud the following scenario:

Marito Castillo moved to the US from Mexico 13 years ago with his parents. He is now 15 years old and has two siblings, ages 9 and 4. Marito's mother, Juanita, stays at home with the children. His father, Mario, is a construction worker. Recently, Marito has been incredibly tired, too tired some days to even go to school. His mother noticed how tired and listless he was and that he bruised easily. Even bumping into the corner of a wall would leave a large bruise on his arm. Mario

borrowed a friend's car and drove the family to the local hospital where, after many tests, Marito was diagnosed with leukemia. The parents were given information pamphlets in English describing treatment options for their son. The hospital also gave the parents a lot of registration and payment forms. Marito was included in all of the meetings with the doctors and his parents, however, they all felt scared and overwhelmed by the news and information. They have yet to tell Marito's siblings about the diagnosis. The Castillos have many decisions to make and will face a variety of barriers in the near future.

3. Ask the group to call out different barriers and challenges the Castillos will face during Marito's treatment. Ask them to think about their own challenges when accessing healthcare services, from insurance and transportation to childcare. Remind the promotoras about Marito's siblings and the barriers the family may face in tending to their needs at the same time as Marito's.
4. Write the barriers on a flipchart page as the promotoras call them out.

Examples of barriers include:

- Transportation
 - Childcare for siblings
 - Applying for insurance/Making insurance claims
 - Managing work and school schedules
 - Language/Interpretation
 - Limited understanding of medical information provided
 - Fears of the medical system
5. Hand out the *Barriers to Care* fact sheet and ask the promotoras to read through it. Ask if anyone would like to add to the list of barriers on the flip chart.
 6. Wrap up by explaining that cultural beliefs about cancer and illness can be a difficult barrier to overcome. The next activity focuses specifically on this barrier.

ACTIVITY 2: Understanding cultural beliefs about cancer as barriers to care

Time: 15 minutes

Activity goal: This activity will help promotoras identify client's cultural beliefs about cancer and understand cancer myths from fact.

Activity Description:

1. Explain to the promotoras that in order to open up communication channels on cultural beliefs, they have to listen actively and be nonjudgmental. Promotoras have to build trust and not be critical of cultural beliefs about cancer and cancer treatment. As the promotoras become aware of cultural beliefs that present a barrier to care, they must not appear to be telling clients what to do, but rather to negotiate a change in belief and behavior. Explain that cultural beliefs may be more prevalent among parents than children, but parental beliefs will likely filter down to the children as well. The Latino population is diverse, and there are many different cultural beliefs, even within one nationality.
2. Ask the promotoras to call out any cultural beliefs relating to illness and cancer in their communities they have encountered.
3. Next, divide the promotoras into two teams.

4. Explain that you will be playing a game where you, as the host, will read aloud a statement about cancer, and the two teams will have to decide if the statement is true or false.
5. Ask each team to assign someone to go first, and then have the teams form a line behind that person. After each question, the person from the front of the line will move to the back, and the next person in line will have a chance to answer a question. Tell the promotoras to raise their hands to answer and do not shout out the answer.
6. On a flipchart page write down the two team names. For example: Team A/Team B, Team 1/Team 2. If you feel there is time, allow the teams a few minutes to come up with their own team names and write them on the flipchart.
7. Once the teams are in place, read the first statement from the *Cancer: True or False?* Handout. Then ask the teams, “Is this statement true or false”? The first of the initial pair of contestants to raise their hand should be chosen to respond. If that person answers correctly, add a point to their team’s column on the flipchart. If that person is incorrect, allow the other contestant in the pair an opportunity to answer. If they answer correctly, add a point to their team’s column. If no one answers correctly, no points are given.
8. Read the correct answer aloud if not already stated. Then read the short explanation from the *Cancer: True or False?* Handout.
9. Move to the next pair of contestants and ask a new question.
10. After all of the questions on the handout have been answered and discussed, tally up the points to determine which team won. Give everyone on the winning team an *Official Cancer Myth-Buster* certificate. (Fill in each winning promotora’s name on the certificate.)
11. Give each promotora a copy of the *Cancer: True or False?* Handout.
12. Ask the promotoras if they have heard of any other myths about cancer. If they have, they should add them to the list. If the promotoras suggest any additional myths, ask them to write them down on their copy of the handout.
13. Wrap up by telling the promotoras that barriers significantly reduce the ability for some Latino children coping with cancer to access the care and information they need. It is the role of promotoras to assist in overcoming these barriers, but first they must learn how to effectively reach out to children coping with cancer. Explain that the next activity addresses how they can conduct outreach to children coping with cancer.

ACTIVITY 3: Outreach methods for reaching children coping with cancer

Time: 10 minutes

Goal: This activity will review different outreach methods that promotoras de salud can use to reach children coping with cancer.

Facilitator notes: Outreach methods to children coping with cancer include, but are not limited to, the following:

- Asking schools to refer potential clients to you
- Asking doctors/ hospitals/clinics to refer clients
- Connecting to a community-based organization that serves people coping with cancer
- Working with a cancer treatment center
- Word-of-mouth
- Churches

Activity Description:

1. Display the flipchart page with the heading: *Connecting to Children Coping with Cancer*.
2. Ask the promotoras to brainstorm methods of reaching out to families. Tell them to think about their previous experiences and how they have connected to clients in the past. Many of these methods will be relevant.
3. Start with ways to connect to children who have cancer and write the responses in the appropriate column.
4. Next, ask the promotoras to call out ways to reach out to children coping with a family member with cancer. Write those responses in the appropriate column. It is OK for methods to overlap columns. For example, asking the school to refer potential clients may be listed in both columns.
5. Wrap up the activity by explaining that the promotoras must be proactive and reach out to the appropriate person located at different institutions (e.g. the social worker at schools and hospitals). A good way of connecting to the right people is to go to the facility, organization, church, etc. in person and speak to the person who is in contact with children coping with cancer. Explain to that person the services you provide and leave a business card with your contact information.
6. Tell the group that once they are connected with a child coping with cancer, the next step is to identify the child's individual needs. The next activity will teach them how to do this.

ACTIVITY 4: How to conduct a child needs assessment

Time: 20 minutes

Activity goal: This activity will teach promotoras how to conduct a child needs assessment.

Facilitator notes: After reaching out to a family, the first thing a promotora must do is a needs assessment. A needs assessment is a questionnaire that provides information the promotora can use to understand the assistance and resources the family may need help accessing. After completing a needs assessment, they should look at the information gathered and determine what needs the client has and their order of priority. This information will then help the promotora develop a plan for helping the client.

Before starting this activity, make sure you are very well familiarized with both needs assessments: *Child Needs Assessment: Child with Cancer* and *Child Needs Assessment: Child with Family Member with Cancer*, so that you can explain how promotoras should fill them out. (Instructions are provided on each assessment.)

Activity Description:

1. Explain the purpose of a needs assessment and what to do with the information gathered.
2. Review both *Child Needs Assessment* handouts with the promotoras and explain how they should complete them. Note that there are two versions of the *Child Needs Assessment*—one for when the child has cancer and one for when a child has a family member with cancer.
3. Divide the class into pairs and give each pair both of the handouts and two *Needs Assessment Case Studies* cards. Each pair should have a case study and needs assessment for both scenarios: one where the child has cancer and one where the child has a family member with cancer.
4. Instruct the promotoras to take turns acting as the client (based on the details on the case study card) while the other conducts a needs assessment and fills out the form. The promotora who is acting in the promotora role will ask the “client” the questions on the needs assessment. Tell

the promotoras to make up details about the family in the case study in order to answer the questions. To make sure there is enough time to complete the activity, ask the promotoras to switch roles after about seven minutes, even if they have not completed the needs assessment.

5. After completing both needs assessments, the promotoras should review the information in their pairs and decide on the most important needs they should address if these children were their actual clients. Make sure that the promotoras write down their thoughts as they will need these for the next activity.
6. Circulate through the room and spend time with each pair as they work through the exercise.
7. Ask the promotoras to keep their materials (case studies, needs assessments, and notes) for the next activity (Session 4, Activity 1), which will involve addressing the needs of their clients.

CONCLUSION

The job of a promotora is ever changing. Each community has different beliefs about health and disease, and each family varies in their willingness to be assisted. To overcome reluctance, the promotoras must be trustworthy members of their communities and nonjudgmental figures who are there to guide and assist clients based on their individual circumstances. This session has taught the promotoras how to use culturally-appropriate outreach methods to connect with families, and, once connected, how to identify the needs of children coping with cancer in their communities. Now the promotoras are ready for the next step—addressing the needs of their clients.

FLIPCHART PAGE: Barriers to Care**Activity 1**

Barriers are objects, ideas, structures, beliefs, or systems that block a person's ability to obtain healthcare when needed.

FLIPCHART PAGE: Connecting to Children Coping With Cancer**Activity 3**

Children With Cancer	Children With a Family Member With Cancer

HANDOUT: Barriers to Care

Whether adults or children, Latinos experience significant barriers to healthcare that may influence cancer-related health outcomes.

Access to Care

- Latinos are the ethnic group most likely to report no usual source of healthcare (i.e., no primary healthcare location where they go for doctor's appointments and check-ups).
- Limited access to care leads to a lower chance of Latinos obtaining the tests and screenings necessary to diagnose cancer at an early stage.
- Latinos with cancer are more likely to receive a diagnosis at a later stage than non-Hispanic whites.

Insurance

- Latinos of all age groups are more likely than non-Latinos to be uninsured.

Language

- About 50 percent of Hispanics have limited comprehension of English and prefer to discuss important matters, such as healthcare, in Spanish.
- Spanish speakers are more likely than English speakers to report difficulty communicating with health providers in the U.S.
- Interpreters are not always available, or able, to provide an accurate translation of complex medical information.

Transportation

- Not owning a car, or having only one car to coordinate getting to work, taking children to school, and attending doctor's appointments can be problematic. People often turn to public transportation, borrow cars from friends, or ask friends or family members for rides when balancing medical appointments with the family's other commitments.

Fear and Mistrust of the Medical System

- The U.S. medical system is daunting or overwhelming to some Latinos and the scope of the system may create anxiety.
- Immigration reform has created other sources of uncertainty. People may be unsure that they have the appropriate documentation to apply for health insurance or even to attend a doctor's appointment, and may fear deportation.

Cultural Beliefs

- Latinos may hold certain beliefs and myths about cancer that inhibit access to needed care.
- Some people believe that a cancer diagnosis means death is inevitable and will avoid treatment, or not take the proper steps to ensure they are receiving the best treatment options available to them.

HANDOUT: Barriers to Care (continued)

This fact sheet is based on the following references:

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- Huerta, E. E. (2003). Cancer statistics for Hispanics, 2003: Good news, bad news, and the need for a health system paradigm change. *CA Cancer J Clin.* 53, 205-207. doi:10.3322/canjclin.53.4.205
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- Munet-Vilaró, F. (2004). Delivery of culturally competent care to children with cancer and their families—the Latino experience. *J Pediatric Oncology Nursing*, 21(3), 155-159. PMID 15296045.
- National Council of La Raza. *Health insurance and citizenship*. Retrieved from http://www.nclr.org/section/hispanic_health_data_insurance_citizenship/
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HANDOUT: Cancer: True or False?

STATEMENT: Cancer is contagious.

TRUE OR FALSE? False.

EXPLANATION: Cancer **cannot** be transmitted from one person to another by physical contact with someone who has cancer. Cancer is caused by changes to your own cells.

STATEMENT: Eating grilled or pan-fried meats can increase a person's risk of cancer.

TRUE OR FALSE? True.

EXPLANATION: When meat is grilled (to the point where it is well-done or burned), harmful chemicals are created. Experts recommend limiting the amount of grilled meat in a person's diet, and avoiding the burnt parts altogether in order to lower the risk of cancer. They also recommend marinating and precooking meats in a microwave before cooking by other methods. Keep in mind that many grilled foods **are** safe and healthy including grilled vegetables and fruits.

STATEMENT: Cancer is a punishment from God for doing something wrong.

TRUE OR FALSE? False.

EXPLANATION: Cancer is caused by changes to your cells that cause them to divide rapidly and spread. These changes to your cells can be caused by chemicals or mutations, and are unrelated to faith.

STATEMENT: If a person is diagnosed with cancer, he or she will die.

TRUE OR FALSE? False.

EXPLANATION: Cancer is not a death sentence. Many cancers can be completely cured, especially if they are detected early. Surgery, chemotherapy, and hormone therapy are all successful treatments for cancer, depending on how early the cancer is detected and what type of cancer it is.

HANDOUT: Cancer: True or False? (continued)

STATEMENT: Anyone can develop cancer.

TRUE OR FALSE? True

EXPLANATION: Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. These abnormal cells may be caused by environmental factors, such as exposure to certain chemicals. They may be caused by genes passed from parents. They may also occur spontaneously by randomly-occurring mutations that cannot be predicted or avoided. Although there is nothing you can do to guarantee a cancer-free life, it is possible to decrease the chance of developing cancer through a healthy lifestyle.

STATEMENT: You should not tell your doctor if you are going to a traditional healer.

TRUE OR FALSE? False.

EXPLANATION: While it can be OK to see a traditional folk healer while you are undergoing cancer treatments, you should talk to your doctor to ensure that the healer's methods (such as herbs, etc.) do not interfere with the cancer treatments. Some herbs can cause harm on their own or when combined with common cancer treatments, such as chemotherapy.

STATEMENT: You can give yourself cancer by bumping into something and bruising your breast.

TRUE OR FALSE? False.

EXPLANATION: Being hit or bumped on the breast does not cause breast cancer. Cancer is caused by changes to your cells that cause them to divide rapidly and spread. These changes to your cells can be caused by chemicals or mutations, and are unrelated to accidents.

STATEMENT: If your hair falls out as a result of cancer treatments, it will not grow back.

TRUE OR FALSE? False.

EXPLANATION: Certain cancer treatments, such as chemotherapy and radiation therapy, may result in hair loss. This is because these treatments do not exclusively target cancer cells. Rather they target any cells in the body that are actively dividing, including healthy cells like those that cause hair to grow. However, once you are done with your cancer treatments, your normal healthy cells will grow back and you will be able to grow hair once again.

HANDOUT: Cancer: True or False? (continued)

STATEMENT: A girl who had pediatric cancer will pass the gene which caused the abnormal cells to grow to her children.

TRUE OR FALSE? False

EXPLANATION: Not all cancers are caused by inherited genes which create the abnormal cells. Abnormal cells may be caused by environmental factors, such as exposure to certain chemicals. They may also occur spontaneously by randomly-occurring mutations that cannot be predicted or avoided. While abnormal cells may be caused by genes passed from one or both parents, it is not a certainty that these genes will pass through the generations, or that the genes will cause cancer in a subsequent generation. Genes are merely one risk factor.

STATEMENT: You do not need to tell your doctor if any members of your family have been diagnosed with cancer.

TRUE OR FALSE? False

EXPLANATION: Cancer can run in families. Having a family member who has been diagnosed increases your risk of developing the disease. Let your doctor know of family members who have been diagnosed, included extended family members such as aunts, uncles, and grandparents.

AWARD CERTIFICATE

AWARD CERTIFICATE

PRESENTED TO

**For Being an Official
Cancer Myth-Buster**



Familias Fuertes

HANDOUT: Needs Assessment Case Studies

Parent with Cancer	Child with Cancer
You are undergoing treatment for breast cancer and have two children—one is school-aged and one stays home with you.	You, your husband, and your 3-year-old child have recently come to the U.S. from South America. You noticed that lately your child has been extremely tired and bruises easily. You take him to a free clinic, and they refer you to a hospital for tests.
Parent with Cancer	Child with Cancer
Your husband is the breadwinner of the family and works out of the house while you care for your three children. He was recently diagnosed with prostate cancer.	Your child is undergoing treatment for cancer. He has Medicaid but you speak very little English and have difficulty getting to the treatment center.
Parent with Cancer	Child with Cancer
You and your husband both work outside the house. You were diagnosed with cervical cancer and started treatment. Your two children are 6 and 8-years old.	Your child was diagnosed with cancer and you were given information flyers and booklets about treatment options. They are in Spanish, but you do not feel like you really understand the information.
Parent with Cancer	Child with Cancer
You are undergoing treatment for cancer and notice that your normally cheery 13-year-old child has started acting out. He gets angry easily and spends much of his time upset.	You and your husband own one car and have three children ages 6, 9, and 17. Your husband works and you take care of the house and the children. The 9-year-old was recently diagnosed with cancer.
Parent with Cancer	Child with Cancer
You are the grandparent and primary caregiver of four boys. They are all in school during the day and you work for a friend's business cleaning houses. You do not have insurance and were recently diagnosed with cancer.	Your 7-year-old son was diagnosed with cancer, underwent treatments, and is in remission. He has been talking more and more about wanting to return to school and his friends.

HANDOUT: Child Needs Assessment—Child With Cancer

Fill out this form like you would a questionnaire. You will be asking a parent or caregiver these questions about their child with cancer. Write the response next to each question. You will not need to ask all the questions depending on the situation. For example, when the answer to a question is either “yes” or “no,” there will be a different follow-up question for those parents who answered “yes” and for those who answered “no.”

Names of persons who currently live in this household*

_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____

*indicate which child has cancer

Medical information

1. With what type of cancer was _____ (name of child) diagnosed?
2. When?
3. Is he/she undergoing treatment?
 - If yes:
 - a. What kind of treatment?
 - b. How frequent are the treatments?
 - c. Please describe any side effects, including changes in behavior, that you have noticed.
4. Who are the child’s main doctors?

School information

1. Is he/she in school?
 - If yes:
 - a. How many days per month does he/she miss because of cancer treatments and/or side effects?
 - If not in school (but is school aged):
 - a. How long has he/she been out of school?
 - b. Does he/she do any schoolwork at home?
 - c. Do you keep in contact with any teachers or school officials/social workers?
2. Please give me the names and contact information of teachers and school officials.

Family communication

1. How was the child told about his or her diagnosis?
2. Does he/she ask questions about the cancer? What kinds of questions?
3. Do you feel comfortable answering the questions that your child may ask you?

HANDOUT: Child Needs Assessment—Child With Cancer **(continued)**

About siblings (if any)

Sections for three children are provided. Complete one for each child, adding more sections if necessary.

Name of child:

1. Is he/she school aged?
If yes:
 - a. Is he/she in school?
 - b. Does he/she miss any days because of (name of child with cancer) doctor's appointments?If not school aged:
 - a. Does he/she stay home with you?
If no:
 - i. Who provides child care?
2. Does he/she know about the siblings' cancer?
If yes:
 - a. Who told him/her?
 - b. What was his/her reaction?
 - c. Have you noticed any change in behavior since he or she was told?If the child has not been told about the sibling's cancer:
 - a. How do you respond to questions about what is happening with his/her brother/sister (i.e., missing school, going to doctor's appointments, feeling tired, etc.)?
3. Would you like me to talk to him/her about his/her sibling who has cancer?
4. Are there any needs he/she has that you would like me to help with?

Name of child:

5. Is he/she school aged?
If yes:
 - c. Is he/she in school?
 - d. Does he/she miss any days because of (name of child with cancer) doctor's appointments?If not school aged:
 - b. Does he/she stay home with you?
If no:
 - i. Who provides child care?
6. Does he/she know about the siblings' cancer?
If yes:
 - d. Who told him/her?
 - e. What was his/her reaction?

HANDOUT: Child Needs Assessment—Child With Cancer **(continued)**

Name of child:

13. Is he/she school aged?

If yes:

- g. Is he/she in school?
- h. Does he/she miss any days because of (name of child with cancer) doctor's appointments?

If not school aged:

- d. Does he/she stay home with you?

If no:

- i. Who provides child care?

14. Does he/she know about the siblings' cancer?

If yes:

- j. Who told him/her?
- k. What was his/her reaction?
- l. Have you noticed any change in behavior since he or she was told?

If the child has not been told about the sibling's cancer:

- d. How do you respond to questions about what is happening with his/her brother/sister (i.e., missing school, going to doctor's appointments, feeling tired, etc.)?

15. Would you like me to talk to him/her about his/her sibling who has cancer?

16. Are there any needs he/she has that you would like me to help with?

Support

1. In the past month, did you or your children receive clothing, medical care, food, childcare, counseling or emotional support, help with transportation or some other type of help?

If yes:

- a. Who provided the support?
- b. What kind of support was provided?

2. What kind of support do you need to help your child with cancer?

3. What kind of support do you need to help your other children?

4. What kind of support does your child with cancer need that he or she is not currently getting?

HANDOUT: Child Needs Assessment–Family Member With Cancer

Fill out this form like you would a questionnaire. You will be asking a parent or caregiver these questions about their child(ren) affected by a family member with cancer. Write the response next to each question. Depending on the situation, you will not need to ask all the questions. For example, when the answer to a question is either “yes” or “no,” there will be a different follow-up question for those parents who answered “yes” and for those who answered “no.”

Names of persons currently living in this household*

_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____
_____	Male/Female	Age _____	Relationship to you _____

*Indicate which family member has cancer.

Medical information

This questionnaire assumes the parent has cancer. If it is a different family member, change questions accordingly.

1. With what type of cancer have you been diagnosed?
2. When?
3. Are you undergoing treatment?
 - If yes:
 - a. What kind of treatment?
 - b. When did treatment start?
 - c. Have there been any side effects of treatment?

About children

Sections for three children are provided. Complete one for each child, and add more sections if necessary.

Name of child:

1. Is he/she school aged?
 - If yes:
 - a. Is he/she in school?
 - b. Does he/she miss any days because of your doctor’s appointments?
 - If no:
 - a. Does he/she stay home with you?
 - If no:
 - i. Who provides child care?

HANDOUT: Child Needs Assessment–Family Member With Cancer (continued)

2. Does he/she know about the parent's cancer?

If yes:

- a. Who told him/her?
- b. What was his/her reaction?
- c. Please describe any changes in behavior since he or she was told?

If no:

- a. Does he/she ask questions about what is happening with you (i.e., missing work, going to doctor's appointments, feeling tired, etc.)?

3. Would you like me to talk to him/her about your cancer?

4. Are there any needs he/she has that you would like me to help with?

Name of child:

1. Is he/she school aged?

If yes:

- a. Is he/she in school?
- b. Does he/she miss any days because of your doctor's appointments?

If not school aged:

- a. Does he/she stay home with you?

If no:

- i. Who provides child care?

2. Does he/she know about the parent's cancer?

If yes:

- a. Who told him/her?
- b. What was his/her reaction?
- c. Please describe any changes in behavior since he or she was told?

If no:

- d. Does he/she ask questions about what is happening with you (i.e., missing work, going to doctor's appointments, feeling tired etc.)

3. Would you like me to talk to him/her about your cancer?

4. Are there any needs he/she has that you would like me to help with?

Name of child:

1. Is he/she school aged?

If yes:

- a. Is he/she in school?
- b. Does he/she miss any days because of your doctor's appointments?

If not school aged:

- a. Does he/she stay home with you?

If no:

- i. Who provides child care?

HANDOUT: Child Needs Assessment–Family Member With Cancer (continued)

2. Does he/she know about the parent's cancer?

If yes:

- a. Who told him/her?
- b. What was his/her reaction?
- c. Please describe any changes in behavior since he or she was told?

If no:

- a. Does he/she ask questions about what is happening with you (i.e., missing work, going to doctor's appointments, feeling tired, etc.)?
- b. Would you like me to talk to him/her about your cancer?

3. Are there any needs he/she has that you would like me to help with?

Barriers

1. In what language do you prefer to speak, read, and write?
2. What languages does/do your child/children prefer?
3. Do you supplement your medical care with herbs, or visits to a healer?
If yes:
 - a. Does your doctor know you do so?
4. Do you have any form of transportation? How do you get to appointments?
5. Do you have insurance?
6. Do you or your partner/spouse work?
7. Have you or your spouse had to stop work because of the cancer diagnosis and subsequent treatments?

Support

1. In the past month, did you or your children receive clothing, medical care, food, childcare, counseling or emotional support, help with transportation, or some other type of help?
If yes:
 - a. Who provided support?
 - b. What kind of support was provided?
2. Is there any additional support you need to help your children?

SESSION 4: NEEDED RESOURCES FOR CHILDREN COPING WITH CANCER

INTRODUCTION

Identifying the resources and information a child coping with cancer needs is only half the work. The next step is to navigate the US healthcare system on behalf of the family, and locate and connect the child with the resources they need. It is the job of the promotora to know what types of resources exist and how they can be accessed. The first two activities in this session review the common resources needed by children coping with cancer and how to find them.

Many of the resources children coping with cancer need are practical, such as transportation and interpretation services. However, it is likely that upon diagnosis, promotoras will be required to research additional information about the specific cancer and how it can be treated. With the accessibility of the internet, acquiring information about cancer can be relatively easy. However determining if the information is reliable can be more difficult. Information posted online or passed along by friends and coworkers is not necessarily accurate. Promotoras need the skills to assess the reliability of information they find before passing it along to their clients. The final activity in this session teaches promotoras the skills to assess the reliability of information from different sources.

Session Learning Objectives

After completing this session, promotoras will have:

the knowledge to...

- Recognize the types of assistance and resources their clients may need

and the skills to...

- Locate needed resources for their clients
- Research additional information about cancer and treatment options
- Determine the validity of information sources

MATERIALS NEEDED

- ✓ Blank paper
- ✓ Pens
- ✓ Flipchart pages
 - *Needed Resources*
 - *Locating Needed Resources*
 - *Reliable*

HANDOUTS

- ✓ *Commonly Needed Resources for Children and Families Coping with Cancer*
- ✓ *Checking for Reliable Sources*
- ✓ *Am I Reliable?*
- ✓ *Am I Reliable? Answer Sheet*

ACTIVITY 1: *Types of needed resources needed by children coping with cancer*

Time: 15 minutes

Activity goal: This activity will help promotoras identify the types of resources and assistance their clients will need.

Facilitator notes: This activity asks the promotoras to reflect on the needs assessments they conducted in the last activity (Session 3, Activity 4). They will work in the same pairs as during the needs assessment activity and should have all of their materials from Session 3, Activity 4 available for reference.

Activity Description:

1. Ask the promotoras to work with the same partners as during the needs assessment activity.
2. Ensure each pair has a blank sheet of paper and a pen.
3. Ask the promotoras to reflect on the needs assessment activity and the children's needs they identified, and write a list of resources that will meet these needs. Remind the promotoras to consider all the different barriers the children in their case studies face, and what they would need in order to overcome those barriers. Remind the promotoras that barriers are objects, ideas, structures, beliefs, or systems that block a person's ability to obtain healthcare when needed. Barriers include childcare, interpretation, understanding treatment options, finances, and lack of insurance.
4. Display the flipchart page *Needed Resources* for the promotoras to replicate on their sheet of paper.
5. After the pairs have completed their lists, regroup and ask each pair to share their lists with everyone.

6. Compose a master list of resources on a flipchart page.
7. Hand out the chart *Commonly Needed Resources for Children and Families Coping with Cancer* and say that the promotoras may want to refer to this as a reminder about some of the most common resources needed by children and their families when coping with cancer. Emphasize that the list is not exhaustive.
8. Wrap up the activity by telling the promotoras that identifying the resources their clients need is one important step. The next step is to learn how to locate these resources. The next activity will teach them how to do this.

ACTIVITY 2: How to locate needed resources

Time: 15 minutes

Activity goal: This activity will teach the promotoras how to locate the resources that their clients need.

Facilitator notes: Over time, promotoras develop knowledge about the resources available in their communities. It is a good idea for them to develop and keep a file of resources that is well organized by the type of resource. It is very important that they keep this information current (i.e., phone numbers change and doctors move). Therefore, emphasize to the class the importance of keeping information updated and ensuring that all information given to a client is correct.

Activity Description:

1. Tell the promotoras that now they have identified the resources their clients need, their next task is to find and connect their clients to them.
2. Display the flip chart page: *Locating Needed Resources*. The flip chart page should list all of the resources found on the handout titled: *Commonly Needed Resources for Children and Families Coping with Cancer*.
3. Go through the list and ask the promotoras to suggest sources for each resource. Ask them “How would you find _____ [name of resource] in your community?” Encourage them to think about resource lists that community-based organizations or hospitals might have. In addition, information can be obtained from the Internet, phone books, and word of mouth.
4. Write the suggestions in the column “How to Find It” next to the appropriate resource.
5. Suggest that the promotoras maintain a well organized file or binder of resources that they continually update. They can divide a binder into sections by type of resource where they keep track of contact information and any additional notes. This will prevent them from having to spend time researching resources from scratch with each new client.
6. Wrap up the activity by reiterating the importance of connecting clients to the appropriate resources for assistance. Inform the promotoras that sometimes, however, their clients’ needs may be for more information on their diagnosis or questions about treatment options. In these instances, the promotoras will need to research the answers. They will also need to determine if the information is reliable. The next activity will teach them how to research for valid and reliable information about cancer.

ACTIVITY 3: How to research information about cancer and determine its validity

Time: 30 minutes

Activity goal: This activity will teach promotoras how to research for information about cancer, cancer treatments, side-effects, and more, to share with their clients. They will also learn how to decide if the information is valid and from a reputable source.

Facilitator notes: There will be times when clients have questions for which the promotoras must research the answers. There are many ways to research for information (e.g., Internet, libraries, and resources at hospitals or community-based organizations). However, the information promotoras find will not always be reliable and accurate, and they must know how to distinguish between good and poor information sources. Be sure to thoroughly review the activity handouts before beginning the activity so you are familiar with the content.

Activity Description:

1. Explain that you are going to read aloud a scenario about a family whose child has recently been diagnosed with cancer. Based on the scenario, the promotoras will then conduct activities. Read aloud the following scenario:

You are a promotora working for the community-based organization Niños Sanos. Two days ago, your supervisor connected you to the Alfaro family. Ramón and Marcela Alfaro have three children: Daniela, 14, David, 10, and Alex, 7. The Alfaros found out last week that their middle child, David, has Hodgkin lymphoma. They were told that David has a few options for treatment, but they do not know what they should choose or what to expect during and after treatment. They also are not sure they really understand what “Hodgkin lymphoma” means and what is happening in their son’s body. Their doctor tried to answer some of their questions but, even with a medical interpreter present, the Alfaros still have questions and concerns. The doctor referred them to Niños Sanos for assistance. You have worked with children coping with cancer before, but not specifically Hodgkin lymphoma. You and the Alfaros have a lot of researching to do.
2. Ask the promotoras to call out different methods for gathering more information on Hodgkin lymphoma. The list should include, but is not limited to:
 - Researching online (Googling “Hodgkin lymphoma”)
 - Looking on cancer organization websites (e.g., American Cancer Society, National Cancer Institute, Mayo Clinic.)
 - Contacting local community organizations
 - Searching for books on different cancers or Hodgkin lymphoma, specifically at the local library
 - Talking to doctors and specialists
 - Asking for written information from hospitals, doctors’ offices, and treatment centers
3. Write their responses on a flipchart page. Add any from the list above that were not mentioned.
4. Tell the promotoras that when researching information, an extra step needs to be taken to determine the credibility and reliability of the information source.
5. Distribute the *Checking for Reliable Sources* handout. Explain that the handout provides tips about how to determine if an information source is reliable. Display the flipchart *Reliable* and

explain that reliable means that the source is dependable and worthy of trust. Ask the promotoras to spend a few minutes reading through the handout.

6. Next, ask the promotoras to get into groups of three or four.
7. Give each group a copy of the *Am I Reliable?* handout. Explain that the handout describes six different sources of information that they found when researching Hodgkin lymphoma for the Alfaro.
8. Ask the groups to read the description of each source, and write in the space provided if they think it is reliable information, and the reasons why or why not. Give the groups no more than 10 minutes to complete the task.
9. After the groups finish going through each information source, bring the group back together and quickly compare each group's answers.
10. Hand out the *Am I Reliable? Answer Sheet* and highlight any corrections to the groups' answers.

CONCLUSION

For a family who has a child coping with cancer, the prospect of finding needed resources and reliable information can be overwhelming. Despite (and perhaps because of) the vast quantities of information available, most people do not know where to begin. Promotoras serve a vital function by doing the legwork for these families. Knowing that the promotora is working to find reliable resources allows the family to focus on the child's wellbeing.

FLIPCHART PAGE: Needed Resources

Activity 1

Resources For Child With Cancer	Resources For Child With Family Member With Cancer

FLIPCHART PAGE: Locating Needed Resources**Activity 2**

Resources	How To Find It
Transportation	I
Parking fees	
Lodging near the treatment center	
Meals/ meal vouchers for restaurants in/near the treatment center	
Childcare	
Entertainment for children	
Insurance programs	
Financial assistance (e.g. medication not covered by insurance)	
Easy to understand written or pictorial information	
Stress management strategies	
Psychological support/ counseling	
Assistance leaving/Reentering school	
Social support groups	
Interpretation/ translation services	
Access to healthy foods	

FLIPCHART PAGE: Reliable**Activity 3**

Reliable information is dependable and trustworthy. This means that you can depend on the information to be accurate and you can trust the source of the information.

HANDOUT: Common Resources Needed for Children and Families Coping With Cancer

Resources	Child With Cancer			Family Member With Cancer		
	Diagnosis	Treatment	Remission	Diagnosis	Treatment	Remission
Transportation		X			X	
Parking fees		X	X		X	X
Lodging near treatment center		X			X	
Meals/meal vouchers for restaurants in/near the treatment center		X			X	
Childcare		X			X	
Entertainment for children		X			X	
Insurance programs	X	X	X	X	X	X
Financial assistance (e.g. medication not covered by insurance)		X			X	
Easy to understand written or pictorial information	X	X		X	X	
Stress management strategies	X	X	X	X	X	X
Psychological support/counseling	X	X	X	X	X	X
Assistance leaving/reentering school		X	X			
Social support groups	X	X	X	X	X	X
Interpretation/translation services	X	X		X	X	
Access to healthy foods		X	X		X	X

**This list is not exhaustive—add to the list as you start working with children coping with cancer.

HANDOUT: Checking for Reliable Sources

There are a few things to consider when deciding if information you find during your research is credible:

Primary or secondary: Primary sources of information come directly from the person(s) who conducted the research, a research article published in a journal, for example. Information that comes from a primary source has been tested and verified as true.

Secondary sources of information retell information from a primary source. Secondary sources of information include newspaper articles, television stories, and some websites. Primary sources of information are often the most reliable, but secondary sources can be good sources of information if you can discern the reliable ones from those that are unreliable. To determine if a secondary source is reliable, examine it using the rules listed below.

Rules for assessing secondary sources of information:

Host: When looking for reliable information, avoid blogs, forums, or testimonials where the information does not require verification. If you find information on a website, check to see whose website it is. Websites run by a government or nonprofit organization or a college or university often offer reliable information. Look for websites ending in .org (nonprofit), .edu (college or university), or .gov (government) as these are usually more reliable than sites ending in .com.

Date: Look at the date that the source was produced or when the website was last updated. Information may appear to be from a credible source, but if it has not been updated recently then the information may be outdated and inaccurate.

Citations: If the source discusses research or study results, check to see if it cites the primary source of the information. Be wary of information that is not backed up by other sources.

Bias: Some sources of information may have a vested interest or specific opinion about the research they are presenting. For example, a pharmaceutical company's website advocating the use of a particular treatment or drug may report only studies that support this drug, while ignoring numerous studies concluding that the therapy is typically ineffective.

Examine all sources carefully to determine if they have any connections or vested interests that may bias the information they disseminate. The interest and beliefs of those discussing the research may affect what aspects of the research they report, the conclusions they make regarding the findings of the study, and the research studies that they choose to discuss.

HANDOUT: Am I Reliable?

As you research Hodgkin lymphoma for the Alfaros, you come across lots of information. You must determine if the information is accurate, the source is reliable, and that it provides valid information you can share with the family. Reliable means that the source is dependable and worthy of trust. Below are six different types of information you find in your search. Read each description of the information and write underneath whether you find the information reliable and why or why not.

Information source #1

You type: "Hodgkin lymphoma" into Google and the first thing that comes up is a Wikipedia page. Wikipedia is an online encyclopedia written by volunteers and can be edited and changed by users. The page has information about the disease including the history, signs, how it is diagnosed, and treatment options. The site was last updated January of 2011.

Is this source reliable? Yes or No _____

Why or why not? _____

Information source #2

After typing "Hodgkin lymphoma in children" into a search engine, you come across an online support group for parents of children who have been diagnosed with Hodgkin lymphoma. You read through some postings and find an extensive posting from a mother about her child's experience undergoing treatment and the alternative methods of treatment they sought.

Is this source reliable? Yes or No _____

Why or why not? _____

Information source #3

You have read information from the National Cancer Institute in the past, so you navigate directly to its website and the Hodgkin lymphoma section to begin reading about the diagnosis. The article you are reading was posted in 2010.

Is this source reliable? Yes or No _____

Why or why not? _____

Information source #4

You visit the local library and search for books on childhood cancer. You locate a book put out by the Mayo clinic and begin flipping through it. It was published in 2002 and seems to have a lot of information that could help the Alfaros.

Is this source reliable? Yes or No _____

Why or why not? _____

HANDOUT: Am I Reliable? (continued)**Information source #5**

You sign up to receive email newsletters from the local children's hospital. In the recent edition, they link to an article in the *New England Journal of Medicine* about new cutting edge treatment options for children diagnosed with Hodgkin lymphoma.

Is this source reliable? Yes or No _____

Why or why not? _____

Information source #6

While flipping through files in a cabinet at *Niños Sanos* you find a pamphlet on Hodgkin lymphoma produced by an employee of *Niños Sanos* and written especially for children in 1995.

Is this source reliable? Yes or No _____

Why or why not? _____

HANDOUT: Am I Reliable? Answer Sheet**Information source #1**

You type: "Hodgkin lymphoma" into Google and the first thing that comes up is a Wikipedia page. Wikipedia is an online encyclopedia written by volunteers and can be edited and changed by users. The page has information about the disease including the history, signs, how it is diagnosed, and treatment options. The site was last updated January of 2011.

Is this source reliable? Yes or No NO

Why or why not? Wikipedia allows anyone to edit the content of the articles. While the site monitors the content, it is not known how quickly incorrect information is removed.

Information source #2

After typing "Hodgkin lymphoma in children" into a search engine, you come across an online support group for parents of children who have been diagnosed with Hodgkin lymphoma. You read through some postings and find an extensive posting from a mother about her child's experience undergoing treatment and the alternative methods of treatment they sought.

Is this source reliable? Yes or No NO

Why or why not? This information is based on someone's personal experience and should not be considered fact since the experience can vary greatly for other people. The information is also heavily biased since it is based on a personal experience.

Information source #3

You have read information from the National Cancer Institute in the past, so you navigate directly to its website and the Hodgkin lymphoma section to begin reading about the diagnosis. The article you are reading was posted in 2010.

Is this source reliable? Yes or No YES

Why or why not? The National Cancer Institute is a reputable, reliable, national organization and the information they post can be considered accurate and trustworthy.

Information source #4

You visit the local library and search for books on childhood cancer. You locate a book put out by the Mayo Clinic and begin flipping through it. It was published in 2002 and seems to have a lot of information that could help the Alfaros.

Is this source reliable? Yes or No MAYBE

Why or why not? The book was published in 2002 which could mean the information in it is outdated. You may wish to see if the Mayo Clinic has a more recent publication to make sure the information is up-to-date.

HANDOUT: Am I Reliable? Answer Sheet (continued)**Information source #5**

You sign up to receive email newsletters from the local children's hospital. In the recent edition, they link to an article in the New England Journal of Medicine about new cutting edge treatment options for children diagnosed with Hodgkin lymphoma

Is this source reliable? Yes or No YES

Why or why not? The New England Journal of Medicine is a respected source of information and is considered a leading medical journal for important medical information. This is a "primary source of information" as the articles in the journal are written by the people who conducted the research.

Information source #6

While flipping through files in a cabinet at *Niños Sanos* you find a pamphlet on Hodgkin lymphoma produced by an employee of *Niños Sanos* and written especially for children in 1995.

Is this source reliable? Yes or No NO

Why or why not? The pamphlet is too outdated and is considered a "secondary source of information" since it is written by someone else based on information he or she found from another source. It is best to find a different source.

SESSION 5: COMMUNICATING WITH CHILDREN, FAMILIES, AND SCHOOLS

INTRODUCTION

Deciding what to tell a child about cancer is a big decision. If the child is ill, how much should the parents tell him or her about the disease? If it is a family member who is ill, should the parents burden the child with this knowledge? The critical point to remember is that withholding information from children will only increase their confusion. Children create explanations for what they see happening around them—even the youngest children will perceive a change in behavior in their parents, and respond in some way. Therefore, it is crucial for promotoras to know what kind of information they should discuss with children and how.

In order to accurately convey information about cancer to a child, promotoras should be aware of how a child's comprehension of disease changes as he or she ages. The first activity in this session describes how a child's understanding of disease and the types of questions that he or she may ask about cancer, changes as a child grows older.

Promotoras are not counselors. There are, however, occasions when they are well placed to help a family communicate better. Open family communication prevents misunderstandings and ensures a child's needs are identified and met quickly. The second activity in this session offers tips that promotoras can use to encourage open communication between family members.

Promotoras also need the skills to communicate with schools to ensure that the staff is properly informed about the child coping with cancer and that the school makes adequate educational accommodations. A child who is affected by cancer is likely to exhibit changes in behavior, health, and performance at school. In addition, the child may be frequently absent from school or for extended periods of time. The final activity of this session teaches promotoras how to liaise with the school on behalf of the family, and in which circumstances they can be most effective.

Session Learning Objectives

After completing this session, promotoras will have:

the knowledge to...

- Anticipate the types of questions a child might ask about cancer
- Understand the types of situations that might require them to work with the school on the client's behalf

and the skills to...

- Communicate with children about cancer in an age-appropriate way.
- Improve family communication.
- Liaise with schools during screening and diagnosis, treatment, and after care.

MATERIALS NEEDED

- ✓ Computer, LCD projector, and screen (optional)
- ✓ Communicating with families PowerPoint presentation
- ✓ A pair of dice
- ✓ Pens/pencils
- ✓ *Working With the School-Child With Cancer* game board
- ✓ *Working With the School-Family Member With Cancer* game board

HANDOUTS

- ✓ *Communicating With Children About Cancer*
- ✓ *Answering a Child's Questions About Cancer*
- ✓ *Communicating With Families* presentation
- ✓ *Working With the School-Child With Cancer*—game play instructions
- ✓ *Problem and Solution* game cards for the *Working With the School-Child With Cancer* game (cut out and shuffled)
- ✓ *Working With the School-Family Member With Cancer*—game play instructions
- ✓ *Problem and Solution* game cards for the *Working With the School-Family Member With Cancer* game (cut out and shuffled)
- ✓ *Working With the School-Child With Cancer*
- ✓ *Working With the School-Child With Cancer Answer Sheet*
- ✓ *Working With the School-Family Member With Cancer*
- ✓ *Working With the School-Family Member With Cancer Answer Sheet*

ACTIVITY 1: How to communicate with children about cancer

Time: 25 minutes

Activity goal: The purpose of this activity is to provide promotoras with the skills and tools to communicate at an age-appropriate level about cancer.

Facilitator notes: Prior to beginning this activity, review the *Developmental Stages Matching Answer Key* from Session 1—Activity 2—*Working With Children Coping With Cancer*.

Activity Description:

1. Give each promotora a copy of the *Communicating With Children About Cancer* handout and an *Answering a Child's Questions About Cancer* worksheet.
2. Divide promotoras into five groups and assign each group a different age range:
 - Infant to 2-year-old
 - 2 to 6-year-old
 - 6 to 9-year-old
 - 9 to 12-year-old

- Teenager
3. Tell each group to review the information for their age group on the *Communicating With Children About Cancer* handout and to come up with age-appropriate answers for the questions listed on the handout. Tell each group to write the answers for their age group in the space provided on the *Answering a Child's Questions About Cancer* worksheet. Allow 5 to 10 minutes for brainstorming. (Note: Direct the Infant to 2-year-old group to think about verbal and nonverbal ways to communicate since few children in this age group will be able to communicate well using language.)
 4. Ask each group to assign one person to play the role of the child asking the questions and have the other members of the group divide up the answers amongst themselves. Starting with the youngest age group—Infant to 2-year-old—have the groups role play their questions and answers as the other groups take notes on the *Answering a Child's Questions About Cancer* worksheet.
 5. As each group concludes, ask other groups if they can think of anything to add either to the cancer explanation or to the types of questions that a child in that age range might ask.
 6. Wrap up the activity by explaining that promotoras must always have the permission of the parent to discuss sensitive issues with the child coping with cancer. However, parents may be reluctant to share details with their child. In these circumstances, promotoras should explain to the parent that withholding information from children can do more harm than good and that there are age-appropriate ways to communicate key facts to their child. Promotoras can also help the parent understand the benefits of communicating with their child about cancer. The next section discusses how to improve family communication.

ACTIVITY 2: Improving family communication

Time: 15 minutes

Activity goal: The purpose of this lesson is to give promotoras practical tips they can pass along to parents about how they can improve communication with their children.

Facilitator notes: Promotoras are not counselors and should not try to improve family communication directly. However, indirectly, they can pass along advice to the parent about how to communicate with their children about cancer. Thoroughly review the *Communicating With Families* PowerPoint presentation and practice delivering the information several times so that it feels more like a discussion and less like a lecture.

Activity Description:

1. Hand out copies of the *Communicating With Families* PowerPoint presentation handout to all promotoras.
2. Present the *Communicating With Families* PowerPoint presentation. Allow time for questions at the end.
3. Wrap up by reiterating that promotoras are not counselors but can help steer families in a healthy direction. Explain that the next activity will help promotoras learn how to help families communicate with the child's school.

Activity 3: Working with the school

Time: 40 minutes

Activity goal: The purpose of this activity is to learn how to liaise with school personnel on behalf of the family with a child coping with cancer.

Facilitator notes: Familiarize yourself with the game instructions and make sure you have all pieces of the board games cut out and ready to use prior to beginning the activity. Also, review the *Working with the school-child with cancer* and *Working with the school-family member with cancer* answer sheets.

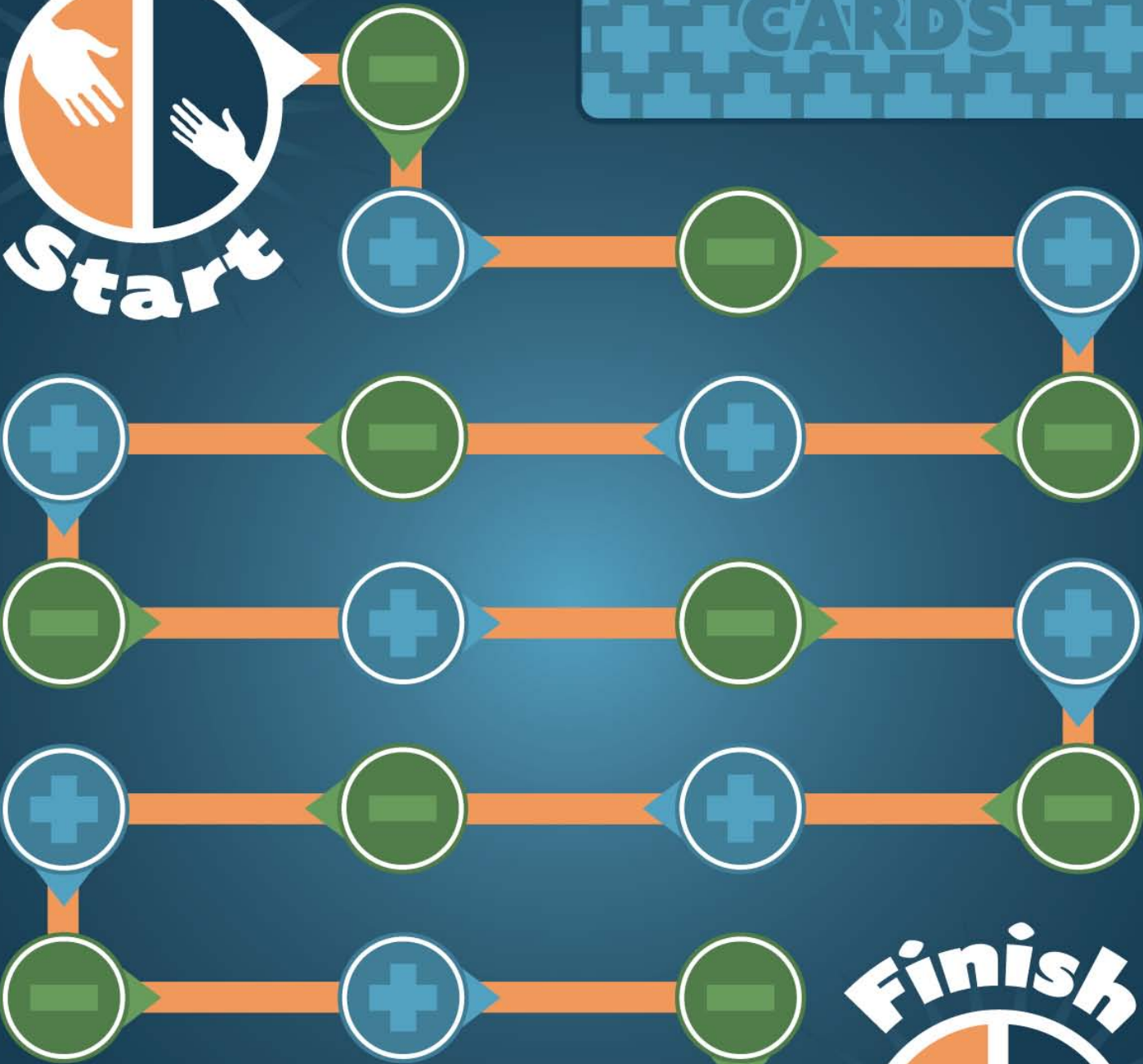
Activity Description:

1. Divide the promotoras into two groups.
2. Explain that the groups will be playing board games. The games will be almost identical, except that one of the games is geared toward working with the school on behalf of a child with cancer, and the other is about working with the school on behalf of a child who has a family member with cancer.
3. Hand out a copy of the *Game play* instructions to each team. Make sure that the correct directions go to the correct group, since the introductory scenarios are different for the two groups.
4. Go through the instructions briefly aloud and then allow 20-25 minutes for game play.
5. Hand out the *Working with the school-child with cancer* and *Working with the school-family member with cancer* handouts. These handouts list the problems that were on each of the *Problems* cards from the game.
6. Read each problem aloud and ask for solutions to these problems based on the solutions that were on the *Solutions* cards from the game. Have promotoras write in the solutions in the space provided.

CONCLUSION

It is ultimately the parents' decision how much or how little to tell others about their family circumstances. Still, even if constrained by the type of information she can convey, a promotora must master the art of *how* to talk to a variety of audiences. A successful promotora should know how to interact with children of all ages and how to anticipate the types of questions a child may ask. She should understand how to encourage open family discussions and be available to intercede when a parent needs help. Additionally, a promotora must know how to liaise with the school on behalf of the family. Knowing how to communicate is key to the success of promotoras and their clients.

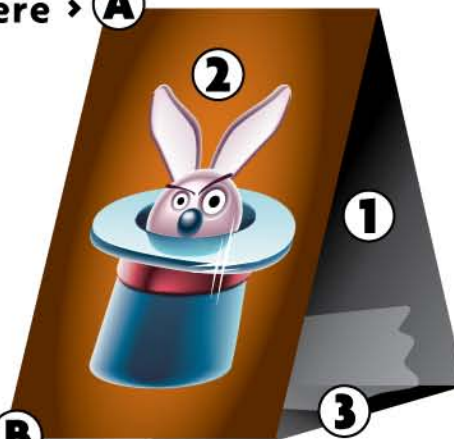
Working with the
school-child with cancer



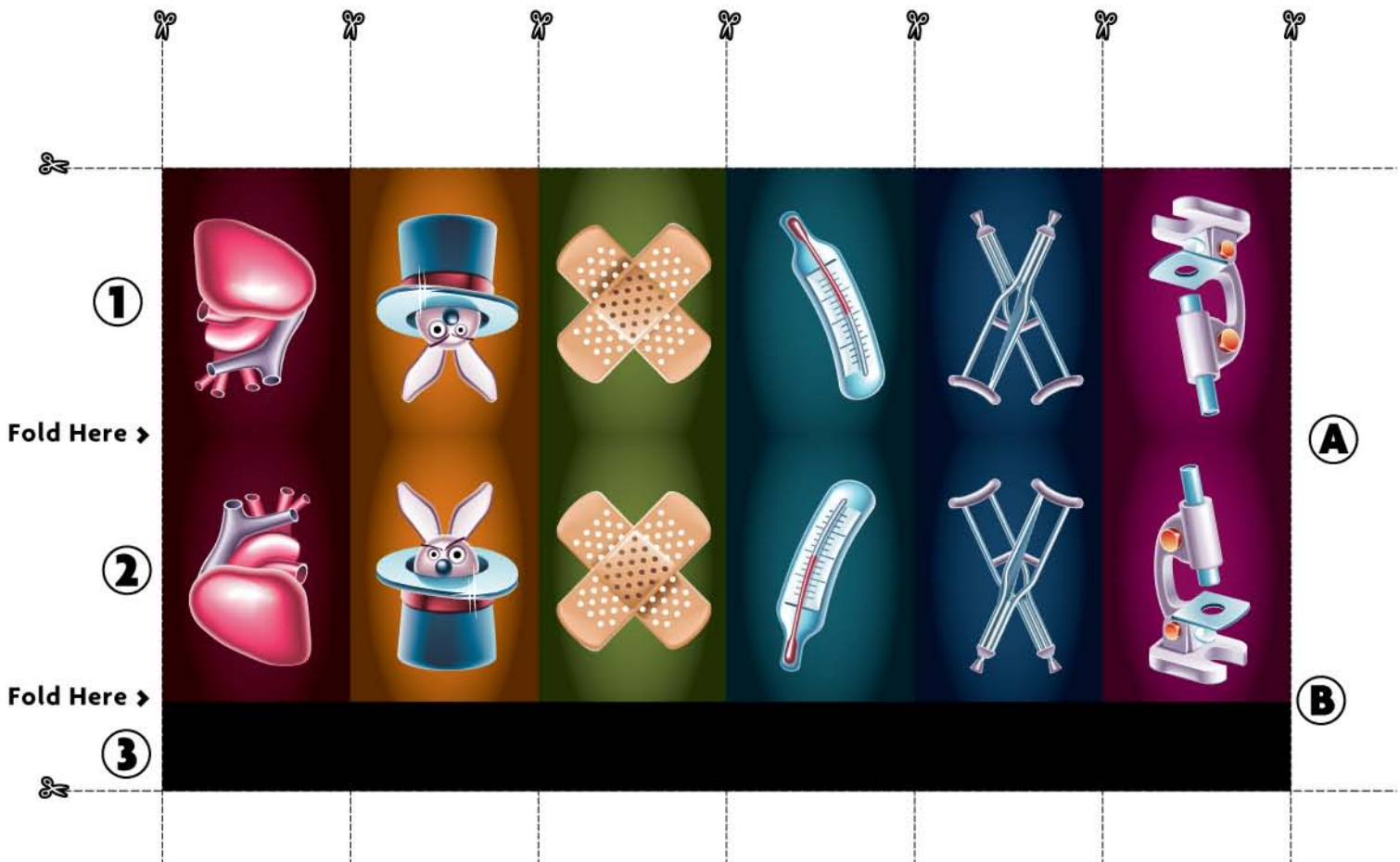
Game Pieces

Fold Here > **A**

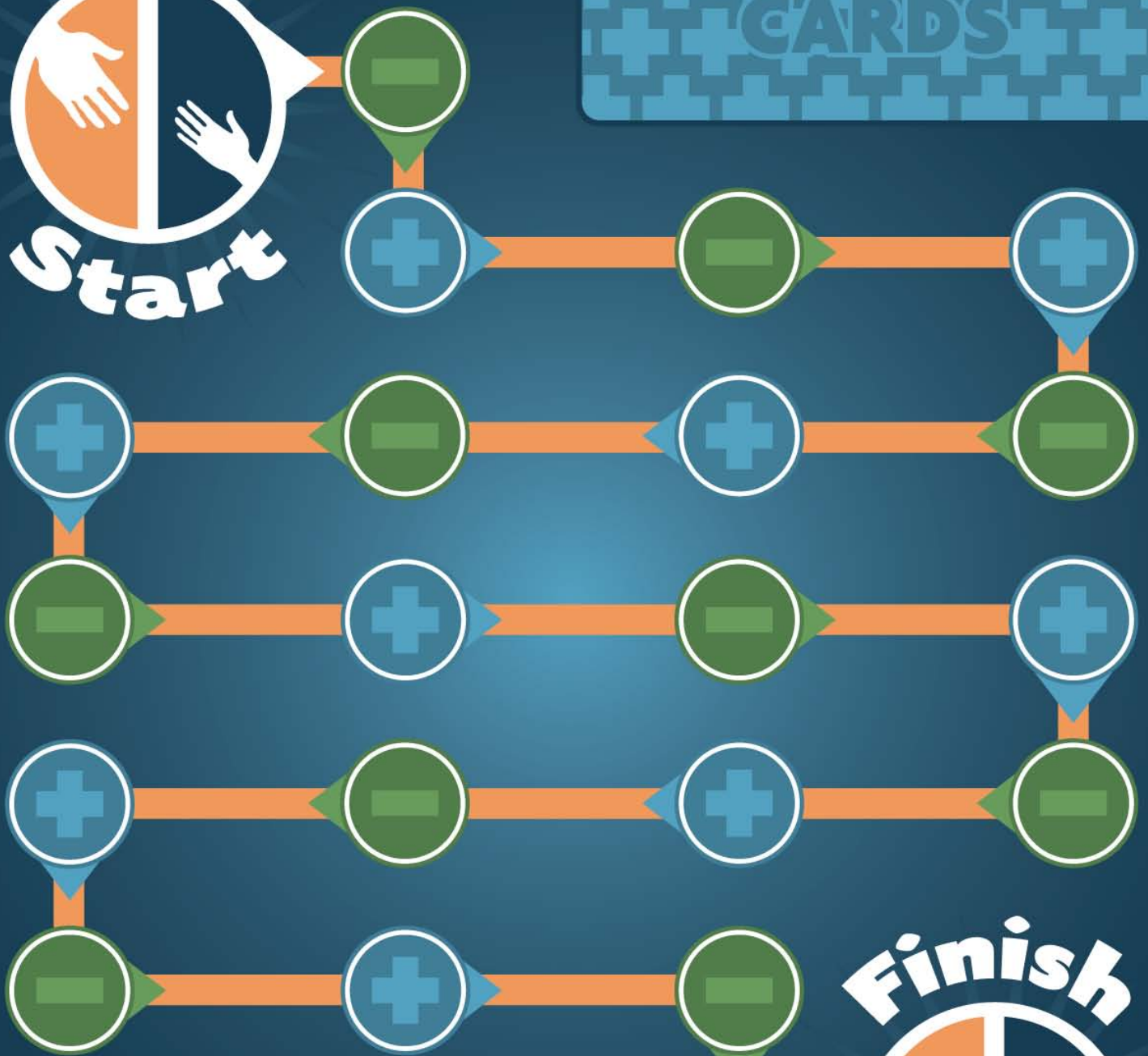
Fold Here > **B**



Please cut out the playing piece, fold at A and B. Then place a piece of tape on the inside of panels 1 and 3.



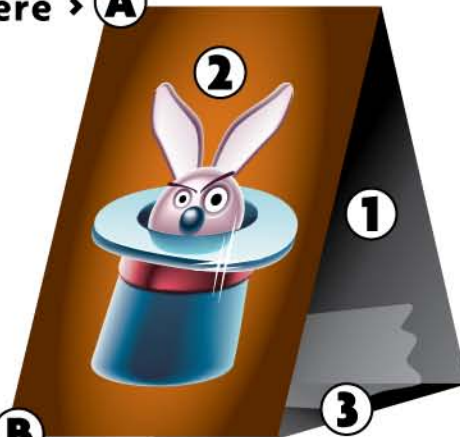
Working with the school-family member with cancer



Game Pieces

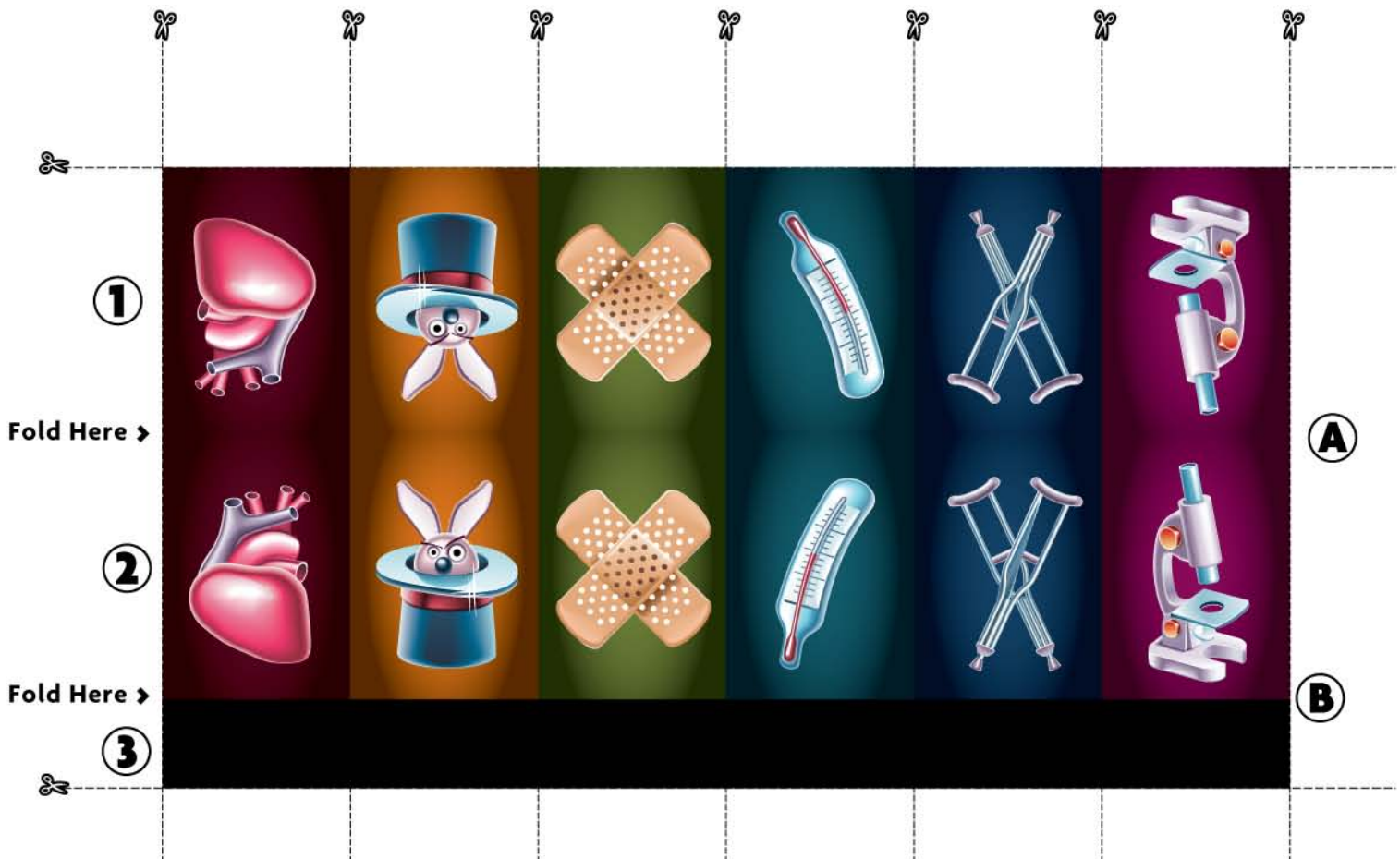
Fold Here > **A**

Fold Here > **B**



Please cut out the playing piece, fold at A and B. Then place a piece of tape on the inside of panels 1 and 3.

< Tape Here



HANDOUT: Communicating With Children About Cancer

The table below describes how much a child is capable of understanding about cancer, and provides examples of the types of questions a child might ask.

Age Range	Understanding of Disease	Types of Questions They May Ask	Best Communication Techniques
Infant to 2-Year-Olds	<ul style="list-style-type: none"> • These children have a very limited understanding of disease. • They may understand that mommy or daddy does not feel well. 	<ul style="list-style-type: none"> • Are you sick? • What's wrong? • Where is mommy/daddy? <p><i>Note: Very verbal 18-month-olds and older may be able to ask these questions, but this age group will typically display concern through behavior.</i></p>	<ul style="list-style-type: none"> • Picture books • Simple words • Dolls allow them to mimic what they are seeing and experiencing
2 to 6-Year-Olds	<ul style="list-style-type: none"> • These children understand the idea of germs and may believe that cancer is contagious. • They may also believe that they said or did something to cause the cancer. • They will have a hard time understanding what is going on inside the body, and will likely focus on outward symptoms that they can see (e.g., hair loss, weight changes, etc). • They know the basics of what a doctor does. 	<ul style="list-style-type: none"> • Can I catch cancer if I hug/kiss you? • Is the cancer my fault? • What caused the cancer? • Why is your hair falling out? • Does cancer always make your hair fall out? • Why is mommy/daddy so tired/crabby? • Why can't mommy/daddy play with me today? 	<ul style="list-style-type: none"> • Simple story books or videos with situations and families that mimic your own. • During play time, incorporate a doctor's kit to familiarize them with basic medical tools.

HANDOUT: Communicating With Children About Cancer (continued)

Age Range	Understanding of Disease	Types of Questions They May Ask	Best Communication Techniques
6 to 9-Year-Olds	<ul style="list-style-type: none"> These children may understand the basics of human anatomy. They understand cause and effect. 	<ul style="list-style-type: none"> Where is your cancer? What kind of cancer do you have? Why do you have cancer? Who will take care of me? Can I catch cancer? Did I do something to cause the cancer? Is there a cure? 	<ul style="list-style-type: none"> More complex books or videos with situations and families that mimic your own. Work together to create a family photo album or scrapbook and talk about the memories as you work.
9 to 12-Year-Olds	<ul style="list-style-type: none"> These children understand what cells are and should be able to understand that cancer cells act differently than normal cells. They will likely be familiar with cancer and some forms of treatments. They understand that illness can lead to death. 	<ul style="list-style-type: none"> What kind of cancer do you have? What treatments are you getting? Are you going to die? What caused the cancer? Is it contagious? 	<ul style="list-style-type: none"> The child is generally talkative at this age, so listen to what he or she has to say. Provide factual explanations and explain what is to come.
Teenagers	<ul style="list-style-type: none"> These children understand human anatomy in detail. They understand the basics of the immune system. They will understand what cancer is, be familiar with some of the treatment options, and understand remission. 	<ul style="list-style-type: none"> What are your treatment options? What kind of cancer do you have? What's your prognosis? Are you going to have to be in the hospital for long? How am I going to get to/from school? What do I tell my friends? 	<ul style="list-style-type: none"> Have conversations <i>with</i> the child, do not talk <i>at</i> the child. Listen to the child and answer all questions factually. Use open-ended questions to encourage discussion.

HANDOUT: Answering a Child's Questions About Cancer

In the space provided, fill in age-appropriate answers that children with cancer, or who have a parent with cancer, might ask.

Age range	Types of questions they may ask	Age-appropriate answers/response
Infant to 2-Year-Olds	<ul style="list-style-type: none"> • Are you sick? • What's wrong? • Where is mommy/daddy? 	
2 to 6-Year-Olds	<ul style="list-style-type: none"> • Can I catch cancer if I hug/kiss you? • Is the cancer my fault? • What caused the cancer? • Why is your hair falling out? • Does cancer always make your hair fall out? • Why is mommy/daddy so tired/crabby? • Why can't mommy/daddy play with me today? 	

HANDOUT: Answering a Child's Questions About Cancer (continued)

Age range	Types of questions they may ask	Age-appropriate answers/response
6 to 9- Year-Olds	<ul style="list-style-type: none"> • Where is your cancer? • What kind of cancer do you have? • Why do you have cancer? • Who will take care of me? • Can I catch cancer? • Did I do something to cause the cancer? • Is there a cure? 	
9 to 12- Year-Olds	<ul style="list-style-type: none"> • What kind of cancer do you have? • What treatments are you getting? • Are you going to die? • What caused the cancer? • Is it contagious? 	
Teenagers	<ul style="list-style-type: none"> • What are your treatment options? • What kind of cancer do you have? • What's your prognosis? • Are you going to have to be in the hospital for long? • How am I going to get to/from school? • What do I tell my friends? 	

HANDOUT: Communicating with Families

Emotional Response to a Cancer Diagnosis

- When a child hears that he or she has cancer, or that a family member has cancer, that child will likely experience an emotional response known as *grief*.
- In order to encourage communication between a child and his or her family members after a cancer diagnosis it is important to understand the emotional state of the child.

What is Grief?

- Grief is a normal reaction to a serious change or loss. A child who is diagnosed with cancer or has a close family member diagnosed with cancer will likely experience grief in one form or another. In order to understand how to interact with the child you should first understand the common reactions to grief.

Common Reactions to Grief

- **Sadness/Depression**—the most universal symptom of grief.
- **Denial**—the inability to accept the diagnosis.
- **Anger**—may involve looking for someone to blame for the cancer.
- **Guilt**—may include feeling like the cancer could have been prevented.
- **Fear**—the feeling of anxiety or helplessness.
- **Physical pain**—may include feeling tired or nauseated, experiencing a change in weight, having problems sleeping, and experiencing aches and pains.

Understanding the Family Dynamic

- A family works together as a unit. Changes to one family member directly impact other members of the family unit.
- Families are not always blood-relatives who live together in the same house. Some families include close friends or blood-relatives who live elsewhere.
- Family members do not always see eye to eye when it comes to making decisions about cancer treatment and getting second opinions.
- Communication among family members is crucial when dealing with cancer in the family.

Child's Reaction to Cancer in the Family

- Children who have a sibling with cancer may feel neglected and resentful toward the ill child. They are likely to be angry, depressed, and socially withdrawn.
- Younger children who have a parent with cancer may feel like they did something to cause the illness. They may become withdrawn and try to avoid talking to anyone about their feelings for fear that someone will find out it is their fault.
- Older children who have a parent with cancer may feel resentful toward that parent for being too sick for them to invite friends over or for giving them even more household chores and responsibilities.

How to Talk About Cancer

- It is the job of the parent to establish open communication with their child.
 - They should do so early to ensure that if the child does experience grief the family is better equipped to address the child's issues
 - However, parents may not know how to talk to their children
- As a promotora, you can gently advise parents to do the following things with their children to help family communication and ultimately better coping.

Tips for Encouraging a Family Discussion About Cancer

- If the child feels safe and secure, he or she will feel more comfortable talking about cancer.
 - Show the child love and attention each day
 - Try to keep the family to a daily routine
- The child will be more likely to go to a parent with questions if he or she knows the parent will answer truthfully.
 - Be honest and direct with the child
 - Children can sense when someone is being dishonest or keeping a secret

Tips for Encouraging a Family Discussion About Cancer (continued)

- Speak to the child at an age-appropriate level.
- Try to sound hopeful and positive.
- Talk calmly to the child.
 - The child is less likely to feel anxious or scared if the parent is calm and in control
- Praise the child for asking questions and discussing his or her feelings openly.

Tips for Encouraging a Family Discussion About Cancer (continued)

- Encourage the child to talk about his or her feelings.
 - With young kids, paint or put on a puppet show
 - With older kids, encourage drawing or poetry
- Encourage the child to talk about how he or she is feeling physically.
 - If it is the child who has cancer, even minor changes in health can be important
 - If it is a family member with cancer, the child may experience grief as physical pain

Tips for Encouraging a Family Discussion About Cancer (continued)

- Try to educate the child little by little.
 - Do not overwhelm the child with information about cancer
 - Allow time for the child to think of questions
- Share stories of other families who have overcome cancer.
 - This helps the child understand that cancer can be cured

What to Expect

- Just because the child understands what is happening, and feels comfortable talking to the parent, do not expect that he or she will not experience grief. The child may still withdraw socially, act out, or feel guilty.

Helpful Books

- Do not be afraid to talk about cancer. There are books for all ages designed to help children understand cancer and deal with the various emotional and physical challenges they encounter.

Helpful Books (continued)

- *My ABC Book of Cancer*
 - A 10-year-old girl with cancer explains cancer to other children.
 - Chamberlain, S. (1990). *My ABC Book of Cancer*. Synergistic Press.
- *Our Family Has Cancer Too*
 - For ages 7 to 12. This illustrated book discusses how a family coped with cancer.
 - Clifford, C. (2002). *Our family has cancer too*. University of Minnesota Press, Minneapolis, Minnesota.

Helpful Books (continued)

- *The Paper Chain*
 - This book was designed to help open up the channels of communication between parents and children when a parent is diagnosed with cancer.
 - Blake, C., Blanchard, E., & Parkinson, K. (1998). *The paper chain*. Health Press: Albuquerque, New Mexico.
- *What Is Cancer, Anyway?: Explaining Cancer to Children of All Ages*
 - For kids of all ages. This book provides information about cancer in a clear, reassuring manner.
 - Carney, K. L. (1998). *What is cancer, anyway?: Explaining cancer to children of all ages*. Dragonfly Publishing, Inc.: Oklahoma, USA.

Additional Resources

- CancerCare for Kids® has a team of oncology social workers who provide free professional support to parents and children coping with cancer.
 - www.cancercareforkids.org

References

Cancer.Net, American Society of Clinical Oncology. (2011). *Family life*. Retrieved from <http://www.cancer.net/patient/Coping/Relationships+and+Cancer/Family+Life>

National Cancer Institute, National Institutes of Health. (2010). *Cancer in the family: What it's like for you*. Retrieved from <http://www.cancer.gov/cancertopics/when-someone-in-your-family-archived/page7>

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- When a child hears that he or she has cancer, or that a family member has cancer, that child will likely experience an emotional response known as *grief*.
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- **Denial**—is the inability to accept the diagnosis.
- **Anger**—may involve looking for someone to blame for the cancer.
- **Guilt**—may include feeling like the cancer could have been prevented.
- **Fear**—is the feeling of anxiety or helplessness.
- **Physical pain**—may include feeling tired or nauseated, experiencing a change in weight, having problems sleeping, and experiencing aches and pains.

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- A family works together as a unit. Changes to one family member directly impact other members of the family unit.
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Communicating with Family

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Communicating with Family

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- It is the job of the parent to establish open communication with their child.
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 - However, parents may not know how to talk to their children.
- As a promotora you can gently advise parents to do the following things with their children to help family communication and ultimately better coping.

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Communicating with Family

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Communicating with Family

NOTES:

Tips for Encouraging a Family Discussion About Cancer (continued)

- Speak to the child at an age-appropriate level.
- Try to sound hopeful and positive.
- Talk calmly to the child.
 - The child is less likely to feel anxious or scared if the parent is calm and in control
- Praise the child for asking questions and discussing his or her feelings openly.

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Communicating with Family

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Tips for Encouraging a Family Discussion About Cancer (continued)

- Encourage the child to talk about his or her feelings.
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 - If it is a family member with cancer, the child may experience grief as physical pain

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Communicating with Family

NOTES:

Tips for Encouraging a Family Discussion About Cancer (continued)

- Try to educate the child little by little.
 - Do not overwhelm the child with cancer information
 - Allow time for the child to think of questions
- Share stories of other families who have overcome cancer.
 - This helps the child understand that cancer can be cured

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Communicating with Family

NOTES:

What to Expect

- Do not expect that just because the child understands what is happening and feels comfortable talking to the parent that he or she will not experience grief. The child may still withdraw socially or act out or feel guilty.

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Communicating with Family

NOTES:

Helpful Books

- Do not be afraid to talk about cancer. There are books for all ages designed to help children understand cancer and deal with the various emotional and physical challenges that they encounter.

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Communicating with Family

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Communicating with Family

NOTES: _____

HANDOUT: Working With the School-Child With Cancer—Game Play Instructions

Scenario: You are working closely with a family who just found out that their son has cancer. The family wants to make sure that all of the necessary accommodations are in place so that their child does not fall behind in school.

Before the start of the game:

- Each person will choose a game piece and place it on the START space. If there are more players than game pieces, ask players to pair up.
- Each player starts the game with 4 *Health Points*.
 - A *Health Point* is a small square piece with a picture of a health pack on it.
 - All remaining *Health Points* are pooled together in the Points Bank.
- Each player will roll the die to see who goes first. The player with the highest roll goes first and play continues to that player's left.



Game play:

- Each player will roll the die to determine how many spaces to move.
- If a player lands on a green space, that player must pick up a green card from the PROBLEM deck. If a player lands on a blue space, that player must pick up a blue card from the SOLUTION deck.
 - Once all of the cards from a deck have been picked, shuffle and use them again.
- The game continues until all players have crossed the FINISH line.
- The first player to cross the FINISH line receives 2 extra *Health Points*.

Winning the game:

- Once all of the players have crossed the FINISH line, they should count their *Health Points*. The player with the most *Health Points* at the end of the game wins.

Health Points and cards:

- **PROBLEM cards:** A PROBLEM card describes a possible problem or difficulty the family that you are working with might encounter while trying to work with the school system. At the end of each situation the card will either say LOSE A TURN or LOSE ONE HEALTH POINT.
 - **LOSE A TURN:** If a player picks a card that says this, that player is skipped during his or her next turn.
 - **LOSE ONE HEALTH POINT:** If a player picks a card that says this, that player must discard one *Health Point*.
 - If a player runs out of *Health Points* during the game—that player loses his or her next turn. On that player's next available turn, he or she can roll the die and continue with the game. For each time a player is out of *Health Points* and cannot complete the action required on the card, he or she loses the next turn.

HANDOUT: Working With the School-Child With Cancer—Game Play Instructions (continued)

- **SOLUTION cards:** A SOLUTION card describes an action that you, as a promotora, can take to help the family deal with a particular challenge they encounter while trying to work with the school. At the end of each situation, the card will say either ROLL AGAIN or COLLECT ONE *HEALTH POINT*.
 - **ROLL AGAIN:** If a player picks a card that says this, that player immediately takes another turn.
 - **COLLECT ONE *HEALTH POINT*:** If a player picks a card that says this, that player can take one *Health Point* from the Points Bank.
 - If the Points Bank runs out of *Health Points* while you are playing and you are instructed to COLLECT ONE *HEALTH POINT*, take a *Health Point* from the player of your choice, as long as that player has not already crossed the FINISH line.
- *All players must read the problem or solution card aloud to the rest of the group.*

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The child experiences health complications and must stay in the hospital for several weeks. As a result, he misses school and ends up behind the rest of the class.

LOSE ONE HEALTH POINT.

The child is withdrawn in class. He does not participate in discussions, will not contribute to group work, and has stopped turning in his homework.

LOSE A TURN.

The parents are overwhelmed by information about Hospital Homebound services, which provides educational services to chronically ill children who cannot attend school. They do not understand the paperwork. As a result, their son has not yet been approved for these services and is falling behind his classmates.

LOSE ONE HEALTH POINT.

The child's doctor believes he has cancer. Due to extensive medical testing he misses a lot of school.

LOSE A TURN.

The child is away from school for several months while undergoing cancer treatment. He is feeling lonely and becoming depressed.

LOSE ONE HEALTH POINT.

The child leaves school early to attend his cancer treatments. Because he is still able to attend school he does not qualify for Hospital Homebound services, which provides educational services to chronically ill children who cannot attend school. But he is falling behind in school.

LOSE A TURN.

The child's treatments are working and he is able to attend school. However, he tires easily and does not seem to be able to concentrate by the end of the day.

LOSE ONE HEALTH POINT.

The child is in remission and will return to school after a long absence. He experiences great anxiety about seeing his classmates, teachers, and friends again.

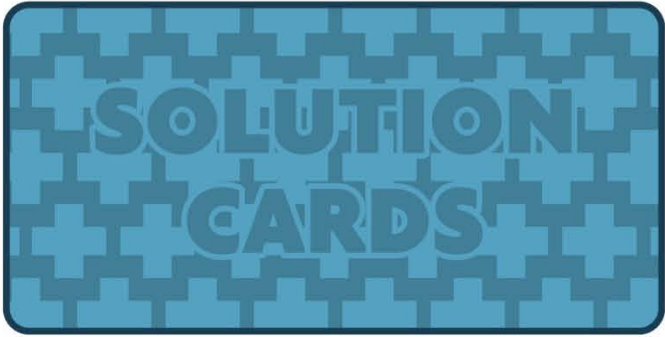
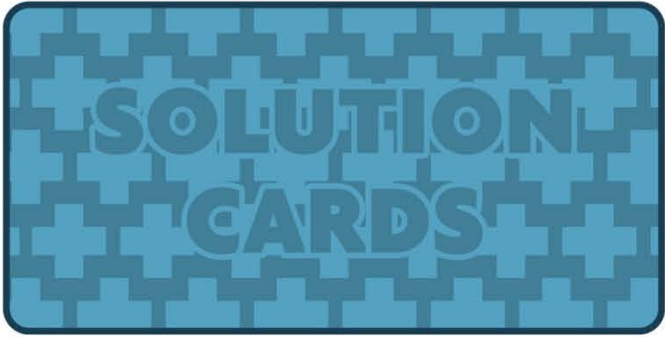
LOSE ONE HEALTH POINT.

The child is losing his hair as a result of his treatment and he is too self-conscious to attend school.

LOSE ONE HEALTH POINT.

The child's teacher contacted his parents and said that she does not feel adequately prepared to have him in the classroom in case he has a medical emergency.

LOSE ONE HEALTH POINT.



The child is away from school for several months while undergoing cancer treatment. He is feeling lonely and becoming depressed. If the child is well enough, you arrange for some of his classmates to stop by from time to time. If the child is not well enough, you work with his teacher to have the class make a card or write a story for him to show him how much he is missed.

COLLECT ONE HEALTH POINT.

The child's doctor believes he has cancer. Due to extensive medical testing he misses a lot of school. You work with school officials and the child's parents to establish a plan of action.

COLLECT ONE HEALTH POINT.

The child's teacher contacted his parents and said that she does not feel adequately prepared to have him in the classroom in case he has a medical emergency. You arrange for the school nurse and the boy's parents to meet with the teacher to discuss his or her specific concerns and to educate the teacher about what to do in case of an emergency.

ROLL AGAIN.

The parents are overwhelmed by information about Hospital Homebound services, which provides educational services to chronically ill children who cannot attend school. They do not understand the paperwork. As a result, their son has not yet been deemed eligible for these services and is falling behind his classmates. You contact the school to get the relevant paperwork and go through the paperwork together.

COLLECT ONE HEALTH POINT.

The child experiences health complications and must stay in the hospital for several weeks. As a result, he misses school and ends up behind the rest of the class. You provide the parents with information about the Hospital Homebound program, which provides educational services to chronically ill children who cannot attend school. You set up a meeting for the parents with the appropriate school official to discuss their options.

COLLECT ONE HEALTH POINT.

The child was just diagnosed with cancer but can attend school during treatment. However, his parents do not know how much to tell the school about their child's health. You immediately work with the family to arrange a meeting with the boy's teacher(s) and help the parents explain the diagnosis so that the teacher is prepared for any physical or emotional changes the child may experience while in school.

ROLL AGAIN.

The child leaves school early to attend his cancer treatments. Because he is still able to attend school he does not qualify for Hospital Homebound services, which provides educational services to chronically ill children who cannot attend school. But he is falling behind in school. To help him keep up, you arrange for another student in his class to collect his books, handouts, and assignments for him to pick up later.

COLLECT ONE HEALTH POINT.

The child's treatments are working and he is able to attend school. However, he tires easily and does not seem to be able to concentrate by the end of the day. You explain to his teacher that his body is still healing and that fatigue is common among those recovering from cancer. You arrange for him to have space in the nurse's office to lie down if he needs to.

COLLECT ONE HEALTH POINT.

The child is in remission and will return to school after a long absence. He experiences great anxiety about seeing his classmates, teachers, and friends again. To help make the transition easier for him, you contact his teacher and arrange for the class to write cards or letters about how much they're looking forward to having him back in class.

ROLL AGAIN.

The child is losing his hair as a result of his treatment and he is too self-conscious to attend school. You provide him and his family information about local aestheticians who specialize in helping kids with cancer.

COLLECT ONE HEALTH POINT.

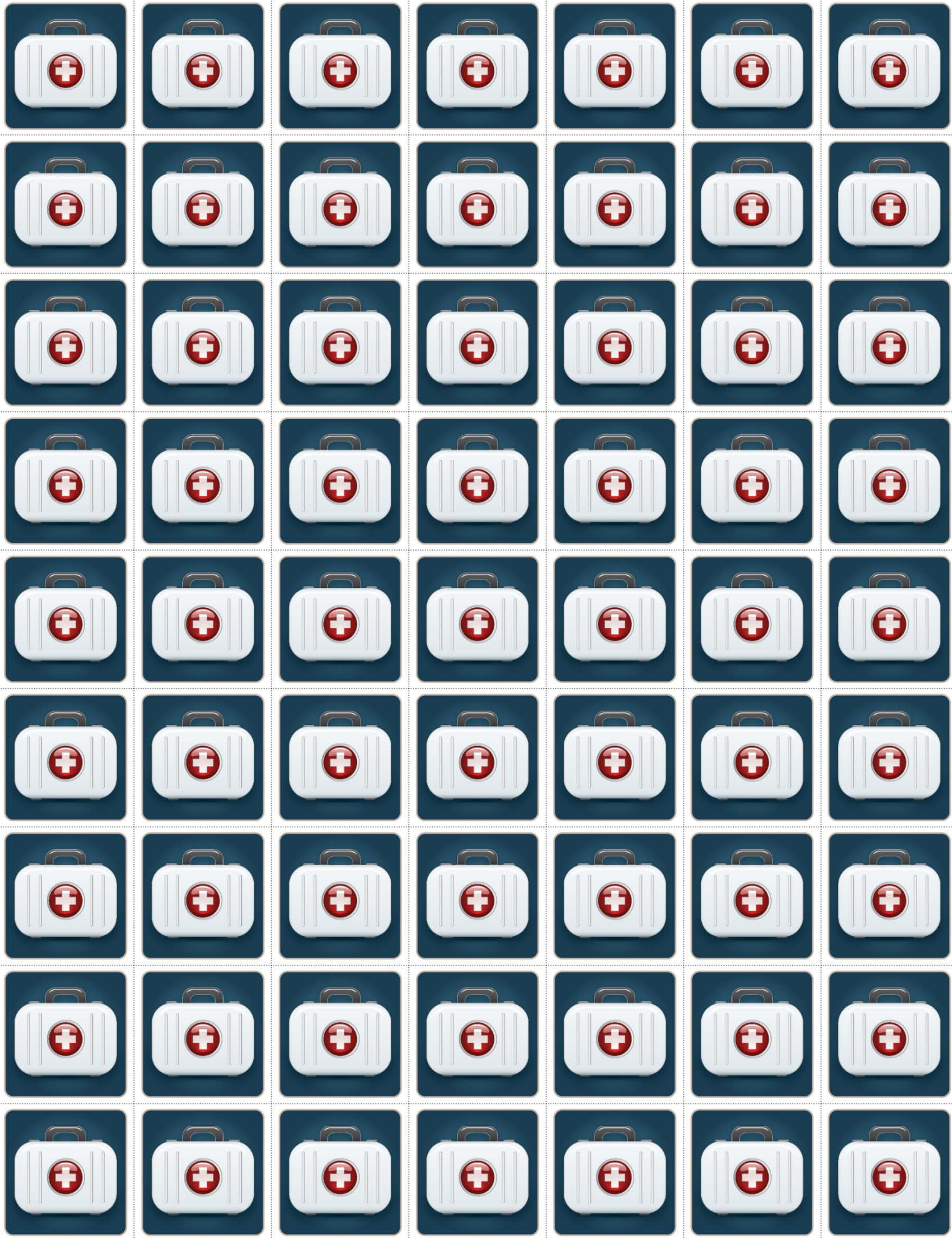


The child was just diagnosed with cancer but can attend school during treatment. However, his parents do not know how much to tell the school about their child's health.

LOSE ONE HEALTH POINT.

The child is withdrawn in class. He does not participate in discussions, will not contribute to group work, and has stopped turning in his homework. You immediately alert the school counselor/social worker about the child's circumstances and arrange a meeting between the child, the parents, and the counselor/social worker.

ROLL AGAIN.



HANDOUT: Working With the School-Family With Cancer—Game Play Instructions

Scenario: You are working closely with a family who just found out that their son has cancer. The family wants to make sure that all of the necessary accommodations are in place so that their son does not fall behind in school, but they are encountering challenges.

Before the start of the game:

- Each person will choose a game piece and place it on the START space. If there are more players than game pieces ask players to pair up.
- Each player starts the game with 4 *Health Points*.
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HANDOUT: Working With the School-Family With Cancer—Game Play Instructions (continued)

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The child's mother experiences health complications and must stay in the hospital for several weeks. His father puts in extra time at work. As a result, the boy misses school and ends up behind the rest of the class.

LOSE ONE HEALTH POINT.

The child is withdrawn in class. He does not participate in discussions, will not contribute to group work, and has stopped turning in his homework.

LOSE A TURN.

The parents are told that the child no longer plays with his friends at school and seems to be intentionally isolating himself.

LOSE ONE HEALTH POINT.

The child leaves school early every day to go home and take care of his mother. As a result he is falling behind in school.

LOSE A TURN.

Due to the various health and financial concerns of the parents, they forget to send their son to school with lunch or lunch money. As a result he has not been eating. **LOSE ONE HEALTH POINT.**

The child does not have any place to go after school since neither of his parents are home.

LOSE ONE HEALTH POINT.

The child is physically ill and goes to the nurse's office much more than usual.

LOSE ONE HEALTH POINT.

Other kids at school ask the child and the teacher about cancer—what it is, what causes it, if it's contagious.

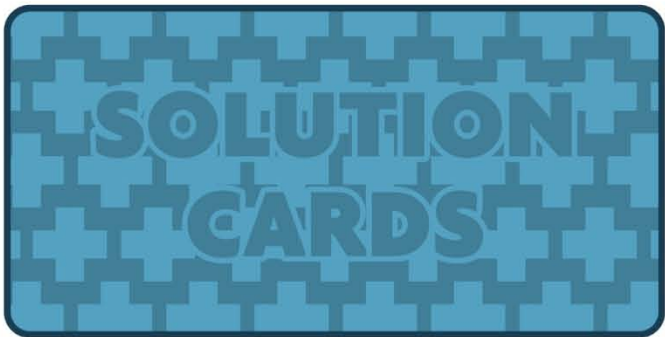
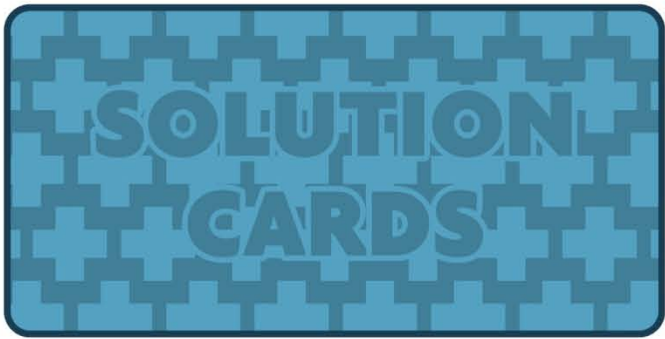
LOSE ONE HEALTH POINT.

The child is not motivated to participate in sports or music activities after school.

LOSE ONE HEALTH POINT.

The child's mother has just been diagnosed with cancer and the parents don't know what or how much to tell the school.

LOSE ONE HEALTH POINT.



The parents are told that the child no longer plays with his friends at school and seems to be intentionally isolating himself. You immediately alert the school counselor/social worker about the child's circumstances and arrange a meeting between the child, the parents, and the counselor/social worker.

COLLECT ONE HEALTH POINT.

The child leaves school early every day to go home and take care of his mother. As a result he is falling behind in school. To help him keep up, you arrange for another student in his class to collect his books, handouts, and assignments for him to pick up later.

COLLECT ONE HEALTH POINT.

The child is withdrawn in class. He does not participate in discussions, will not contribute to group work, and has stopped turning in his homework. You immediately alert the school counselor/social worker about the child's circumstances and arrange a meeting between the child, the parents, and the counselor/social worker.

ROLL AGAIN.

Due to the various health and financial concerns of the parents, they forget to send their son to school with lunch or lunch money. As a result he has not been eating. You provide the family information about the school's free school lunch program and help them determine if they are eligible.

COLLECT ONE HEALTH POINT.

The child does not have any place to go after school since neither of his parents are home. You meet with the parents to see if there are any family friends who can watch him after school. You also check with the school to see what afterschool programs they offer.

COLLECT ONE HEALTH POINT.

The child's mother has just been diagnosed with cancer and the parents don't know what or how much to tell the school. You immediately work with the family to arrange a meeting with the child's teacher(s) to explain the circumstances so that the teacher is prepared for any behavioral or emotional changes the child may experience while in school.

ROLL AGAIN.

The child's mother experiences health complications and must stay in the hospital for several weeks. His father puts in extra time at work. As a result, the boy misses school and ends up behind the rest of the class. You talk to the school social worker to explain the situation. You work with the school and the family to maximize the child's time in school and arrange for a tutor, if possible.

COLLECT ONE HEALTH POINT.

The child is physically ill and goes to the nurse's office much more than usual. You are aware that feelings of guilt and anger about a loved one having cancer can manifest as physical pain, so you schedule a meeting with the school counselor to brainstorm ways to address the situation.

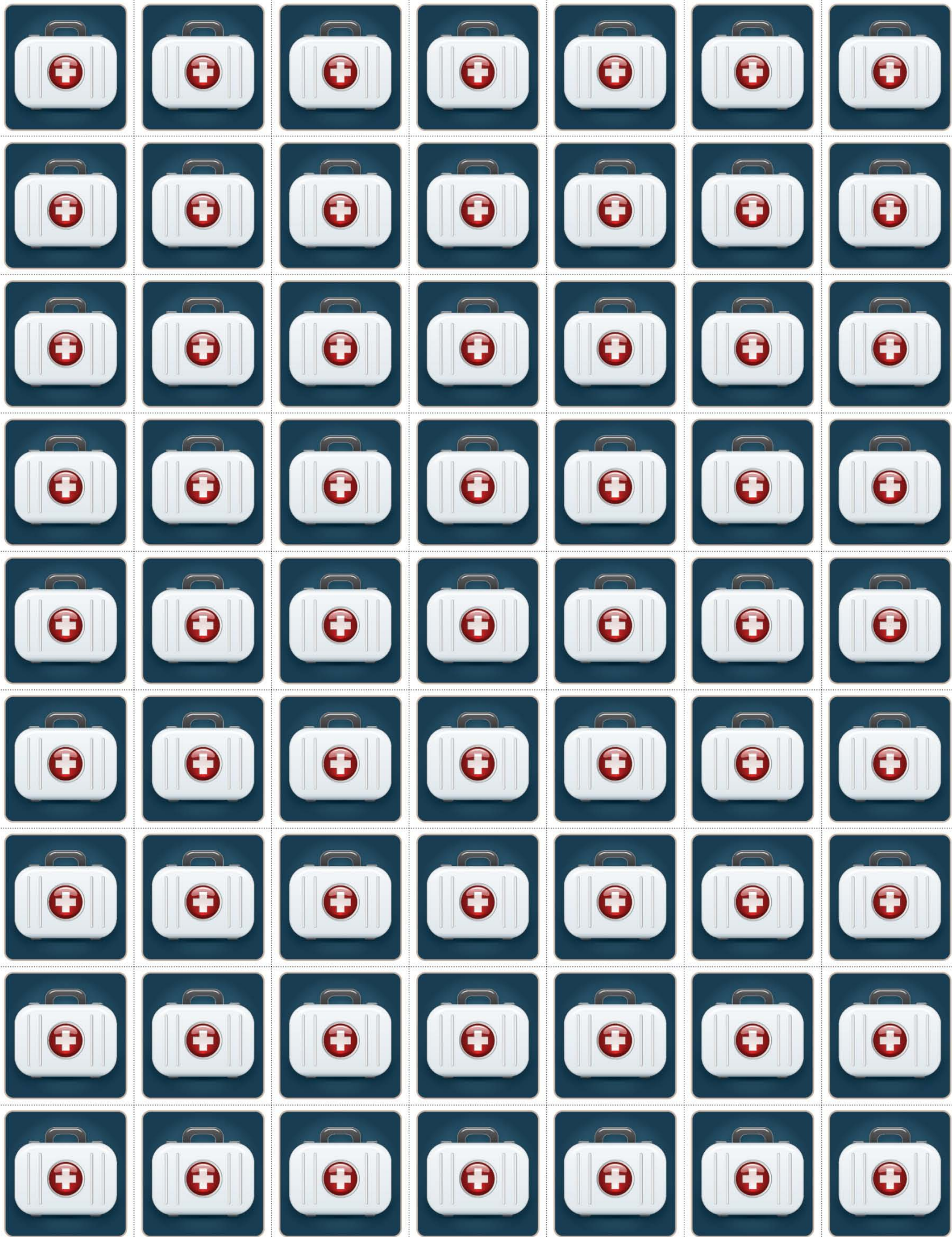
COLLECT ONE HEALTH POINT.

Other kids at school ask the child and the teacher about cancer—what it is, what causes it, if it's contagious. If the child is old enough, you ask him if he wants to explain cancer to his class, with your help. If he is not old enough or comfortable talking about cancer, ask if he would be ok with his teacher or the school nurse talking about it. Then work with them to set it up.

ROLL AGAIN.

The child is not motivated to participate in sports or music activities after school. You understand how important it is for him to have a hobby and stay involved with his peers, so you meet with the child's coach or music teacher to explain the child's family situation. Together you brainstorm ways to get the child interested again.

COLLECT ONE HEALTH POINT.



HANDOUT: Working With the School-Child With Cancer

Below are school-related problems that a child dealing with cancer and his family may encounter. In the space provided, give examples of ways in which you can help the child and his family overcome these problems.

PROBLEM: The child experiences health complications and must stay in the hospital for several weeks. As a result, he misses school and ends up behind the rest of the class.

SOLUTION: _____

PROBLEM: The child is withdrawn in class. He does not participate in discussions, will not contribute to group work, and has stopped turning in his homework.

SOLUTION: _____

PROBLEM: The parents are overwhelmed by information about Hospital Homebound services, which provides educational services to chronically ill children who cannot attend school. They do not understand the paperwork. As a result, their son has not yet been approved for these services and is falling behind in school.

SOLUTION: _____

PROBLEM: The child's doctor believes he has cancer. Due to extensive medical testing he misses a lot of school.

SOLUTION: _____

PROBLEM: The child is away from school for several months while undergoing cancer treatment. He is feeling lonely and becoming depressed.

SOLUTION: _____

PROBLEM: The child's treatments are working and he is able to attend school. However, he tires easily and does not seem to be able to concentrate by the end of the day.

SOLUTION: _____

HANDOUT: Working With the School-Child With Cancer
(continued)

PROBLEM: The child leaves school early to attend his cancer treatments. Because he is still able to attend school he does not qualify for Hospital Homebound services, which provides educational services to chronically ill children who cannot attend school. But he is falling behind in school.

SOLUTION: _____

PROBLEM: The child is in remission and will return to school after a long absence. He experiences great anxiety about seeing his classmates, teachers, and friends again.

SOLUTION: _____

PROBLEM: The child is losing his hair as a result of his treatment and he is too self-conscious to attend school.

SOLUTION: _____

PROBLEM: The child's teacher contacted his parents and informed them that she does not feel adequately prepared to have him in the classroom in case he has a medical emergency.

SOLUTION: _____

PROBLEM: The child was just diagnosed with cancer, but can attend school during treatment. However, his parents do not know how much to tell the school about their child's health.

SOLUTION: _____

HANDOUT: Working With the School-Child With Cancer**Answer Sheet**

Below are school-related problems that a child dealing with cancer and his family may encounter. In the space provided, give examples of ways in which you can help the child and his family overcome these problems.

PROBLEM: The child experiences health complications and must stay in the hospital for several weeks. As a result, he misses school and ends up behind the rest of the class.

SOLUTION: You provide the parents with information about the Hospital Homebound program, which provides educational services to chronically ill children who cannot attend school. You set up a meeting for the parents with the appropriate school official to discuss their options.

PROBLEM: The child is withdrawn in class. He does not participate in discussions, will not contribute to group work, and has stopped turning in his homework.

SOLUTION: You immediately alert the school counselor/social worker about the child's circumstances and arrange a meeting between the child, the parents, and the counselor/social worker.

PROBLEM: The parents are overwhelmed by information about Hospital Homebound services, which provides educational services to chronically ill children who cannot attend school. They do not understand the paperwork. As a result, their son has not yet been approved for these services and is falling behind in school.

SOLUTION: You contact the school to get the relevant paperwork and go through the paperwork together.

PROBLEM: The child's doctor believes he has cancer. Due to extensive medical testing he misses a lot of school.

SOLUTION: You work with school officials and the child's parents to establish a plan of action.

PROBLEM: The child is away from school for several months while undergoing cancer treatment. He is feeling lonely and becoming depressed.

SOLUTION: If the child is well enough, you arrange for some of his classmates to stop by from time to time. If the child is not well enough, you work with his teacher to have the class make a card or write a story for him to show him how much he is missed.

PROBLEM: The child's treatments are working and he is able to attend school. However, he tires easily and does not seem to be able to concentrate by the end of the day.

SOLUTION: You explain to his teacher that his body is still healing and that fatigue is common among those recovering from cancer. You arrange for him to have space in the nurse's office to lie down if he needs to.

HANDOUT: Working With the School-Child With Cancer

Answer Sheet (continued)

PROBLEM: The child leaves school early to attend his cancer treatments. Because he is still able to attend school he does not qualify for Hospital Homebound services, which provides educational services to chronically ill children who cannot attend school. But he is falling behind in school.

SOLUTION: To help him keep up, you arrange for another student in his class to collect his books, handouts, and assignments for him to pick up later.

PROBLEM: The child is in remission and will return to school after a long absence. He experiences great anxiety about seeing his classmates, teachers, and friends again.

SOLUTION: To help make the transition easier for him, you contact his teacher and arrange for the class to write cards or letters about how much they're looking forward to having him back in class.

PROBLEM: The child is losing his hair as a result of his treatment and he is too self-conscious to attend school.

SOLUTION: You provide him and his family information about local aestheticians who specialize in helping kids with cancer.

PROBLEM: The child's teacher contacted his parents and said that she does not feel adequately prepared to have him in the classroom in case he has a medical emergency.

SOLUTION: You arrange for the school nurse and the boy's parents to meet with the teacher to discuss his or her specific concerns and to educate the teacher about what to do in case of an emergency.

PROBLEM: The child was just diagnosed with cancer but can attend school during treatment. However, his parents do not know how much to tell the school about their child's health.

SOLUTION: You immediately work with the family to arrange a meeting with the boy's teacher(s) and help the parents explain the diagnosis so that the teacher is prepared for any physical or emotional changes the child may experience while in school.

HANDOUT: Working With the School-Family Member With Cancer

Below are school-related problems that a child dealing with cancer in his family may encounter. Provide examples of ways in which you can help the child and his family overcome these problems in the space provided.

PROBLEM: The child's mother experiences health complications and must stay in the hospital for several weeks. His father puts in extra time at work. As a result, the boy misses school and ends up behind the rest of class.

SOLUTION: _____

PROBLEM: The child is withdrawn in class. He does not participate in discussions, will not contribute to group work, and has stopped turning in his homework.

SOLUTION: _____

PROBLEM: The child leaves school early every day to go home and take care of his mother. As a result he is falling behind in school.

SOLUTION: _____

PROBLEM: The child's mother has just been diagnosed with cancer and the parents don't know what or how much to tell the school.

SOLUTION: _____

PROBLEM: The parents are told that the child no longer plays with his friends at school and seems to be intentionally isolating himself.

SOLUTION: _____

PROBLEM: Due to the various health and financial concerns of the parents, they forget to send their son to school with lunch or lunch money. As a result he has not been eating.

SOLUTION: _____

HANDOUT: Working With the School-Family Member With Cancer (continued)

PROBLEM: The child does not have any place to go after school since neither of his parents are home.

SOLUTION: _____

PROBLEM: The child is physically ill and goes to the nurse's office much more than usual.

SOLUTION: _____

PROBLEM: Other kids at school ask the child and the teacher about cancer—what it is, what causes it, if it's contagious.

SOLUTION: _____

PROBLEM: The child is not motivated to participate in sports or music activities after school.

SOLUTION: _____

HANDOUT: Working With the School-Family Member With Cancer Answer Sheet

Below are school-related problems that a child dealing with cancer in his family may encounter. Provide examples of ways in which you can help the child and his family overcome these problems in the space provided.

PROBLEM: The child's mother experiences health complications and must stay in the hospital for several weeks. His father puts in extra time at work. As a result, the boy misses school and ends up behind the rest of the class.

SOLUTION: You talk to the school social worker to explain the situation. You work with the school and the family to maximize the child's time in school and arrange for a tutor, if possible.

PROBLEM: The child is withdrawn in class. He does not participate in discussions, will not contribute to group work, and has stopped turning in his homework.

SOLUTION: You immediately alert the school counselor/social worker about the child's circumstances and arrange a meeting between the child, the parents, and the counselor/social worker.

PROBLEM: The child leaves school early every day to go home and take care of his mother. As a result he is falling behind in school.

SOLUTION: To help him keep up, you arrange for another student in his class to collect his books, handouts, and assignments for him to pick up later.

PROBLEM: The child's mother has just been diagnosed with cancer and the parents don't know what or how much to tell the school.

SOLUTION: You immediately work with the family to arrange a meeting with the child's teacher(s) to explain the circumstances so that the teacher is prepared for any behavioral or emotional changes the child may experience while in school.

PROBLEM: The parents are told that the child no longer plays with his friends at school and seems to be intentionally isolating himself.

SOLUTION: You immediately alert the school counselor/social worker about the child's circumstances and arrange a meeting between the child, the parents, and the counselor/social worker.

PROBLEM: Due to the various health and financial concerns of the parents, they forget to send their son to school with lunch or lunch money. As a result he has not been eating.

SOLUTION: You provide the family information about the school's free school lunch program and help them determine if they are eligible.

HANDOUT: Working With the School-Family Member With Cancer Answer Sheet (continued)

PROBLEM: The child does not have any place to go after school since neither of his parents are home.

SOLUTION: You meet with the parents to see if there are any family friends who can watch him after school. You also check with the school to see what afterschool programs they offer.

PROBLEM: The child is physically ill and goes to the nurse's office much more than usual.

SOLUTION: You are aware that feelings of guilt and anger about a loved one having cancer can manifest as physical pain, so you schedule a meeting with the school counselor to brainstorm ways to address the situation.

PROBLEM: Other kids at school ask the child and the teacher about cancer—what it is, what causes it, if it's contagious.

SOLUTION: If the child is old enough, you ask him if he wants to explain cancer to his class, with your help. If he is not old enough or comfortable talking about cancer, ask if he would be ok with his teacher or the school nurse talking about it. Then work with them to set it up.

PROBLEM: The child is not motivated to participate in sports or music activities after school.

SOLUTION: You understand how important it is for him to have a hobby and stay involved with his peers, so you meet with the child's coach or music teacher to explain the child's family situation. Together you brainstorm ways to get the child interested again.

SESSION 6: ASSISTANCE DURING TREATMENT

INTRODUCTION

Receiving treatment for cancer can be physically and emotionally stressful. Promotoras can make the treatment process as stress-free as possible for their clients by helping them navigate through the entire process. This session provides promotoras with the skills to support their clients as they embark on their course of treatment.

Treatment centers are often large and confusing places. While they offer a multitude of resources for cancer patients, patients may either not know about them or be unable to find them. The first activity in this session teaches promotoras how to familiarize themselves and their clients with the treatment center.

Clinical trials can be a great resource for people who have cancer. They give people access to some of the best researchers in the field, usually at no cost. Clinical trials may also be the last hope for successful treatment for a rare cancer or a cancer unresponsive to traditional treatments. However, most people do not know how to enroll in a clinical trial, or may incorrectly fear that clinical trials are not subject to regulation and control. The second activity in this session provides an overview of clinical trials and teaches promotoras how to find an appropriate clinical trial for their client.

Because treatment can be such a stressful time, and the outcome of treatment is not always favorable, it is important that promotoras can identify stress in their clients and offer solutions. However, talking about death and dying in the Latino culture is still taboo, and a difficult topic for even the most skilled promotora to broach. The last two activities in this session give promotoras the skills to assess stress in their client and encourage open discussion about death and dying.

Session Learning Objectives

After completing this session, promotoras will have:

the knowledge to...

- Understand what clinical trials are
- Connect clients to resources to manage stress
- Handle sensitive topics such as death, dying, and spirituality

and the skills to...

- Assist their clients in navigating their treatment centers
- Locate clinical trials and enroll their clients
- Assess the stress levels of their clients

MATERIALS NEEDED

- ✓ Flipchart
- ✓ Paper and pens
- ✓ Computer, LCD projector and screen (optional)
- ✓ *Understanding Clinical Trials* PowerPoint presentation
- ✓ Flipchart pages:
 - *Treatment Center Scavenger Hunt*

HANDOUTS

- ✓ *Hospital Hunt*
- ✓ *Treatment Center Checklist*
- ✓ *What is a Clinical Trial?*
- ✓ *Stress Assessment for Adults*
- ✓ *Stress Assessment for Children*
- ✓ *Things to Consider When Discussing Death, Dying, and Spirituality*

ACTIVITY 1: Navigating the treatment center

Time: 15 minutes

Activity goal: This activity will teach the promotoras to develop individual treatment center tour plans and resource packets for their clients.

Facilitator notes: Promotoras can help their clients at the beginning of treatment by helping them become familiar with the treatment center. It is not necessary for the *Familias Fuertes* training, but if possible, schedule a trip for the promotoras to visit a local treatment center to familiarize themselves with it. They can also use this trip to add to the *Scavenger Hunt* handout and gather resources and materials they can use in information packets for future clients.

Activity Description:

1. Explain to the promotoras that they are going to create a scavenger hunt to help familiarize their clients with the treatment center. A hospital or treatment center can be a scary and intimidating place. A scavenger hunt will allow the child(ren) to feel more comfortable with the environment. Preferably, clients will do the scavenger hunt the first time they go to the treatment center in conjunction with a tour of the facility led by the promotora. Promotoras can arrange the tour and the scavenger hunt before treatment begins, or on the first day of treatment. As the parents learn practical information about parking, vouchers, and childcare, and the children learn about TV and game rooms, the whole family will begin to feel at ease.
2. Explain that this activity can be used with children who have cancer, children who accompany their parents to the treatment center, and siblings of a child undergoing treatment. Scavenger hunts will likely vary between different treatment centers, based on the resources available.

3. Display the *Treatment Center Scavenger Hunt* flipchart page. Ask the promotoras to imagine they are a child entering a treatment center, either for their own treatment or accompanying a parent or sibling who is undergoing treatment. Ask the promotoras to call out what information they would want to know if they were a child. Remind them that children can be any age, and while teenagers may not want to participate in a scavenger hunt, they will still likely be interested in the information it provides. Here are some prompts you can use with the group to get the ideas flowing:
 - Where is the room we are going?
 - What am I going to do while my mom/dad/sister/brother is getting their treatment?
 - Where is the cafeteria and TV room?
4. Write down the suggestions in the *What the Child Needs to Know* column on the *Treatment Center Scavenger Hunt* flipchart page.
5. Now, ask the promotoras to suggest information the parents would want to know. Here are some suggestions:
 - Where do we park?
 - Where do we check in?
 - Is there childcare available?
6. Write down the suggestions in the *What the Parent Needs to Know* column of the flipchart.
7. Give each promotora a copy of the *Hospital Hunt* handout, and tell them they can use this handout as a guide to create a scavenger hunt for their client's treatment center, and to tailor it to fit the child's situation. They can fill in the name of the treatment center or hospital and add features of the center that may be fun or unique to that location. Preferably, the promotoras will visit (or call) the treatment center to help them prepare the materials for the tour. Promotoras should pay particular attention to any special resources available for children.
8. Give each promotora a copy of the *Treatment Center Checklist* handout and read through it with them as a reminder of the information they should gather prior to the tour, and things to remember when they meet with their clients.
9. Inform the promotoras that they can also create a small information packet with a map, highlighting important resources for the child and family and include any vouchers available, such as for nearby restaurants. Hospitals may have a printable map available online, or have hard copies available at the information desk.
10. Wrap up the activity by reiterating that a simple tour of the treatment center will help the entire family feel more at ease. In the next activity, the promotoras will learn how to find and enroll their clients in clinical trials.

ACTIVITY 2: Understanding clinical trials

Time: 10 minutes

Activity goal: This activity will teach promotoras about clinical trials and how to refer their clients to a clinical trial.

Facilitator notes: It is important to emphasize that clinical trials are approved studies and are closely regulated by the federal government. Before enrolling in a trial, people interested in participating are informed of the benefits and any potential risks of taking part in a trial. Read through the handout titled *What is a Clinical Trial?* before beginning this activity. If possible, familiarize yourself with the government's clinical trial website (www.clinicaltrials.gov).

Activity Description:

1. Explain that this activity presents information on clinical trials, which are different from regular cancer treatments. Unlike regular cancer treatments, clinical trials can provide treatment at no cost and give patients access to cutting edge techniques and world-class experts. The knowledge presented through this activity will enable the promotoras to locate clinical trials for their patients.
2. Begin the activity by presenting the *Understanding Clinical Trials* PowerPoint presentation. Give the promotoras copies of the slides so they can make notes.
3. Give each promotora a copy of the *What is a Clinical Trial? Handout*. Tell the promotoras that this handout provides them with background information on clinical trials and step-by-step instructions on how to navigate the clinicaltrials.gov website. Ask the promotoras to read through it.
4. If you have a computer with Internet access, allow the promotoras to click through the website and search for studies.
5. Wrap up the activity by telling the promotoras that, so far, the activities in this session have focused on the treatment process—a process that can be daunting and stressful for their clients. An important role of the promotora is assessing the stress level of their clients and, if necessary, referring them to resources to help manage it. In the next activity, the promotoras will learn how to conduct a stress assessment with their clients.

ACTIVITY 3: Stress and coping

Time: 20 minutes

Activity goal: This activity will teach promotoras how to identify stress in their clients and refer them to appropriate resources.

Facilitator notes: Stress can become an issue for the child and the parents when a child is coping with cancer. Stress can damage a person's health, mood, relationships, and quality of life. It can affect the immune system—the body's defense against infection and disease. It is important for promotoras to learn how to identify if their client is severely stressed and what services are available to support them. There are physical and emotional signs and symptoms of stress in both children and adults.

Before starting the activity, read the stress assessment handouts to become familiar with the signs and symptoms of stress in children and adults.

Activity Description:

1. Ask the promotoras to raise their hands if they have ever felt stressed about something.
2. Now, ask the group to call out the signs or symptoms they experienced when they were stressed. Write these on a flipchart page.
3. Explain to the promotoras that their clients, both children and adults, will likely experience high levels of stress. As promotoras, they need to connect their clients to resources to help them manage their stress. Managing stress will help their clients remain as healthy as possible during treatment. Also, explain that many of the signs and symptoms (especially physical symptoms) of stress can be attributed to treatment side effects if the person they are assessing is undergoing

treatment. Hence, it is very important for the promotoras to pay attention to signs and symptoms that may be *in addition* to those expected as a result of treatment, and to be aware that these may indicate high levels of stress. For example, weight loss may be a normal side effect while undergoing a particular treatment, but severe headaches may not be. Promotoras can find out what symptoms are side effects of treatment by talking to doctors or conducting their own research.

4. Give each promotora a copy of both stress assessment handouts and explain that they are questionnaires they will conduct with their clients to determine if they have high stress levels.
5. Ask the promotoras to break into pairs and explain that they will take turns conducting the child stress assessments with each other. Each promotora will take a turn answering the questions as if they were either a child coping with cancer or the parent of a child coping with cancer. Ask the promotoras to role-play the answers. Give the groups about 10 minutes to complete the assessments.
6. Bring the groups back together and ask the promotoras to reflect on the types of resources their client would need based on the answers to the stress assessment. Lead a brief discussion on the types of resources they can provide to their clients to alleviate stress.
7. After 5 minutes, wrap up the discussion by telling the promotoras that recognizing signs of stress and referring clients to appropriate resources is important in helping the client stay as healthy as possible throughout the treatment process. Tell the promotoras that the next activity covers another very important skill. While the subjects of death, dying, and spirituality are, and will be, difficult to discuss, the ability to talk about these issues is important to the role they will play in their client's experience with cancer.

ACTIVITY 4: Death, dying, and spiritual support

Time: 15 minutes

Activity goal: This activity will teach promotoras how to discuss death and dying, and offer appropriate resources, including spiritual support.

Facilitator notes: Discussing death and dying is never an easy topic, but it is part of the promotora's role to aid the family during this time. It is often best for a promotora to wait until the client is ready to discuss the subject of death and dying, rather than attempt to raise the subject themselves. However, as always, encouraging open communication is the best option.

There are two main points at which discussions of death are likely to occur. The first is upon diagnosis, when a person might think he or she is going to die because they have cancer. In this scenario, a promotora can offer the following help:

1. Speak with the client's doctor to understand the diagnosis and prognosis. The prognosis may be more positive than the client first realizes.
2. Conduct research on the client's diagnosis to find out survival rates.
3. Refer the client to hospital resources or counseling to help the client understand the diagnosis and ease his or her fears.
4. Offer reassurance that for the majority of people, a diagnosis of cancer is not a death sentence.

The second situation will be more difficult and emotionally trying for promotoras to deal with. There will be times when a client's treatment is not successful and end-of-life, or "hospice" care, is needed. However, even at this time, some clients may limit the information they wish to disclose to family

members. It is important to respect the client's wishes while encouraging open communication. When the timing is right and clients indicate they would like help, promotoras can assist families in several ways, such as:

- Making funeral arrangements by calling funeral homes to get information and financial assistance.
- Connecting clients to spiritual leaders or groups, if they show an interest. Promotoras should respect clients' individual beliefs and provide referrals to diverse religious groups in the community if a client indicates no preference.
- Liaising with hospices if a doctor refers the patient there for end-of-life care.
- Locating support groups and counseling options.

Before starting the activity, read through the *Things to Consider when Discussing Death, Dying, and Spirituality* handout. Use this handout and the information in these facilitator notes to guide the activity.

Activity Description:

1. Begin the activity by presenting, in your own words, the information from the facilitator notes.
2. Next, explain that the group will have a discussion about death, dying and spirituality that may be emotionally difficult. Ask the promotoras to continue to respect their fellow promotoras, especially if they choose to share personal experiences.
3. Guide a discussion about how the Latino community talks about and deals with death. Ask the promotoras if they have had any experience working with a family who has lost a child, or if they have worked with a child who lost a family member. Use the following questions to guide the discussion:
 - What was this family's experience?
 - How did they discuss death, if at all?
 - What resources did they need at this time?

As you lead this discussion, use the *Things to Consider When Discussing Death, Dying, and Spirituality* handout as a guide. For example, if a promotora suggests that promotoras should always tell a child about his or her family member's prognosis, gently remind the promotora that it is important to discuss this with the parents first. Some parents may not want their child to know this information, and it is crucial to follow their wishes. Spend 10 minutes on this discussion.

4. Give each promotora a copy of *Things to Consider when Discussing Death, Dying, and Spirituality* to keep.
5. Wrap up the discussion by reminding the promotoras that they should always take the client's lead and only discuss this sensitive issue if the client brings it up. Death, dying, and spirituality are all sensitive topics that can be difficult for people to discuss. Tell the promotoras that they can and will play an important role in these discussions. They can ease concerns at diagnosis that cancer is not necessarily a death sentence, and guide families through the difficult tasks that accompany end-of-life care. In this activity, the promotoras learn that although open communication is crucial, it is best to wait for the client to initiate these tough conversations.

CONCLUSION

Treatment can be a hopeful time, but it can also be a time of immense stress. Promotoras need to be able to assess the stress levels of their clients and help minimize their stress whenever possible. Simple things like explaining the layout of the treatment center ahead of time, or going through the clinical trial

requirements together can reduce the amount of stress a client experiences. And, while discussing death and dying will never be easy, it is important that the client knows, even in the worst of times, the promotora is there to ease their burden.

FLIPCHART PAGE: Treatment Center Scavenger Hunt

Activity 2

What The Child Needs To Know	What The Parents Need To Know

HANDOUT: Hospital Hunt

A hospital can feel like a big place if you don't know your way around. Let's go on a tour to hunt for some cool stuff! When you find something on the Hospital Hunt list, mark it off with a pen or sticker. Let's go!



There is some pretty cool stuff to see here at _____ Hospital.

See if you can find the:

Fish tanks	_____
Gift shop	_____
Bright colored art	_____
Garden	_____
Fountain	_____

There are many people to meet here at _____ Hospital and all of them are all excited about meeting you. Add a mark next to the people you have met. Add TWO marks if you learn their name!

Nurse	_____
Doctor	_____
Anesthesiologist	_____
Child Life specialist	_____
Housekeeping staff	_____
Nurse	_____
Surgeon	_____

Did you notice how big the hospital is when you walked in? That's because it is full of many different rooms and places to explore. Place a mark next to the places you visit on your tour!

Play room	_____
Lobby	_____
Nurses' station	_____
Patient rooms	_____
Shop	_____
Information desk	_____
Cafeteria	_____
Waiting room	_____

What I liked best about the Hospital Hunt:

_____.

I still have questions about:

_____.

HANDOUT: Treatment Center ChecklistBefore the first appointment and prior to the tour with the family:

If possible, call or visit the treatment center to find out the following information:

Where do families park?

Is there a fee to park? How much?

Where do families check in?

What floor do they need to go to?

What resources are available at the center?

1. Childcare for children or siblings
2. Wig or scarf store
3. TV room or playroom
4. Parking vouchers
5. Food vouchers
6. Lodging accommodations
7. Others

Who are the main hospital staff the child and family will encounter?

1. Doctors
2. Nurses
3. Child life specialists

Day of tour with family or first day of treatment

Does the family have transportation to the appointment?

1. Ensure the transportation is arranged and will have the family arrive at the treatment center in time for the appointment.

Where are you meeting the family?

1. Arrange a clear and visible place where you will meet the family at the treatment center.

Do you have all the materials for the family?

1. Make sure you bring the packet of information you compiled for the family, including the map, the scavenger hunt sheet, and markers or stickers for the children to use on the scavenger hunt.

HANDOUT: Treatment Center Checklist (Continued)

Where are you going on the tour?

1. Have a plan of where you will take the family. If it is the first day of treatment, guide them through check-in and the hospital building to the appropriate center. Give a brief tour of the main facilities of relevance to the child and family.

Has the family met the doctor or nurses before?

1. Introduce the child and family to all hospital staff they encounter.

HANDOUT: Understanding Clinical Trials

A clinical trial is a medical study that examines new treatments or new ways to use existing treatments. Clinical trials compare new treatments to existing treatments to determine which is more effective.

Clinical trials can offer the patient access to top researchers and new treatment options. This option for treatment can be of benefit to the patient because there is no cost for the patient, and sometimes participants are paid for their involvement.

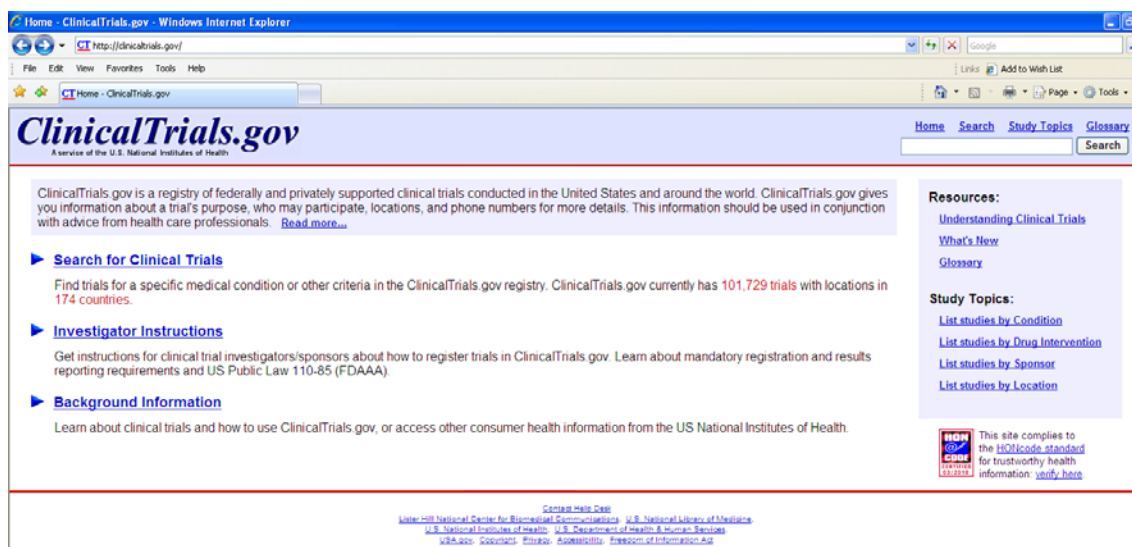
The federal government has guidelines that protect participants of clinical trials from unnecessary risk. Additionally, all clinical trials must pass review by institutional review boards to ensure they are ethical and the benefits of participation outweigh the risks.

Before enrolling in a clinical trial, participants are made aware of the benefits and known risks of participating. They are then able to make an informed decision about participating. Participants in clinical trials are made aware of their rights to withdraw from the study whenever they want without fear of reprimand.

How to find a clinical trial

Before searching on your own, ask the doctor if he or she knows of any clinical trials for which your client/client's relative may be eligible. Also, you can call treatment centers in the surrounding area to ask about clinical trials they are currently conducting. To search for clinical trials on the federal government's clinical trial website, go to www.clinicaltrials.gov

On the homepage, click "Search for Clinical Trials"

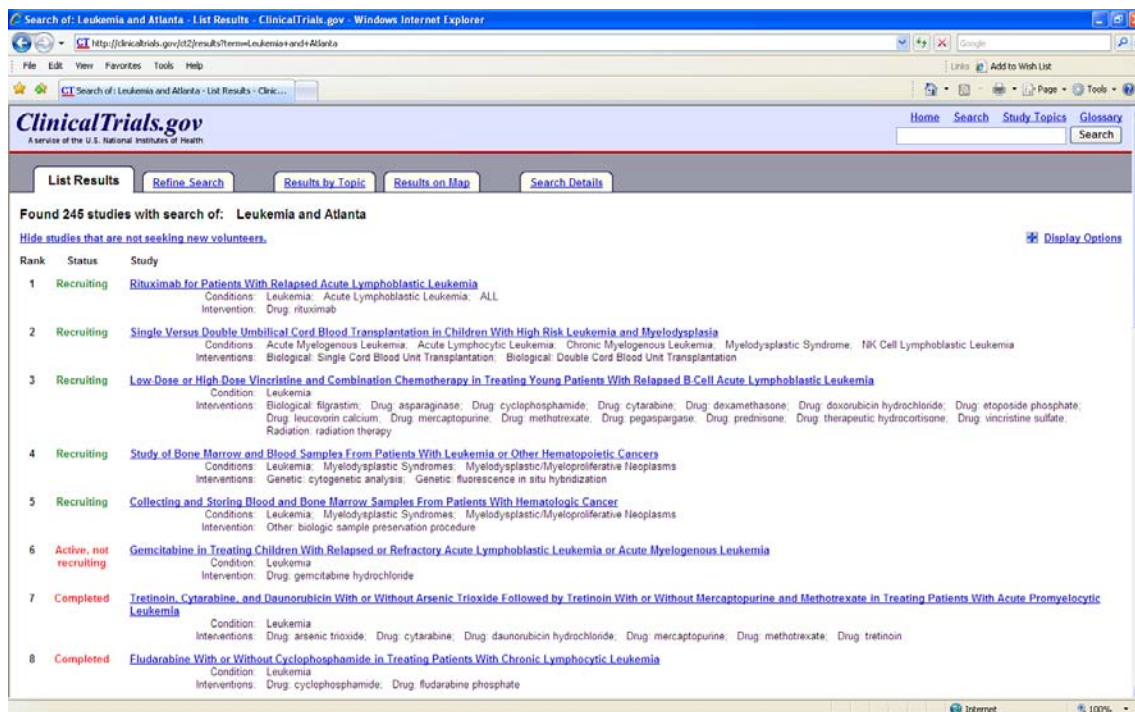


HANDOUT: Understanding Clinical Trials (continued)

This will bring you to the Basic Search page. Here you can enter search terms connected with the word “and” to search for clinical trials in your area. For example, enter the words *Leukemia and Atlanta*.



After clicking Search you will see the results of your search. The first results listed have “Recruiting” written out to the left side in green. This means that they are actively seeking participants to be a part of the clinical trial.



HANDOUT: Understanding Clinical Trials (continued)

Clicking on a study link will bring you to a page about the study and will give you information on who is sponsoring the study, the purpose of the study, and the eligibility criteria (including the ages and genders accepted into the study and diagnosis, among others).

Rituximab for Patients With Relapsed Acute Lymphoblastic Leukemia - Full Text View - ClinicalTrials.gov

[Previous Study](#) [Return to Search Results](#) [Next Study](#)

Full Text View | [Tabular View](#) | [No Study Results Posted](#) | [Related Studies](#)

Rituximab for Patients With Relapsed Acute Lymphoblastic Leukemia

This study is currently recruiting participants.
Verified by Emory University, September 2010

First Received: October 23, 2010 | Last Updated: October 28, 2010 | [History of Changes](#)

Sponsor:	Emory University
Information provided by:	Emory University
ClinicalTrials.gov Identifier:	NCT01230788

Purpose

This is a pilot study of a drug called rituximab used together with other drugs—prednisone, etoposide, and ifosfamide. Prednisone, etoposide, and ifosfamide have been used as part of standard chemotherapy for relapsed Acute Lymphoblastic Leukemia (ALL). Rituximab was approved by the Food and Drug Administration in 1997. However, the use of rituximab with prednisone, etoposide, and ifosfamide in pediatric patients with relapsed or refractory ALL is considered experimental.

This study is for patients who have ALL in second or greater relapse, or in first relapse and not responding to treatment.

The goals of this study are:

- To see if using rituximab with prednisone, etoposide, and ifosfamide is beneficial to leukemia treatment
- To find out what side effects this combination of drugs can cause

A total of 15 participants (30 years old or younger) will be enrolled, over a period of 2 years.

Condition	Intervention
Leukemia Acute Lymphoblastic Leukemia ALL	Drug rituximab

This page also lists contact information if you want to find out more information on the clinical trial, have questions, or are interested in getting your client enrolled.

Contacts and Locations

Please refer to this study by its ClinicalTrials.gov identifier: NCT01230788

Contacts

Contact: Sindy Midoro 404-795-1441 sindy.midoro@choa.org
Contact: Jaclyn Smith, MBA 404-795-0692 jaclyn.smith@choa.org

Locations

United States, Georgia

Children's Healthcare of Atlanta **Recruiting**
Atlanta, Georgia, United States 30322
Contact: Sindy Midoro 404-795-1441 sindy.midoro@choa.org
Contact: Jaclyn Smith, MBA 404-795-0692 jaclyn.smith@choa.org
Principal Investigator: Tanya Watt, MD
Principal Investigator: Todd Cooper, DO

Emory University **Recruiting**
Atlanta, Georgia, United States 30322
Contact: Sindy Midoro 404-795-1441 sindy.midoro@choa.org
Contact: Jaclyn Smith, MBA 404-795-0692 jaclyn.smith@choa.org
Principal Investigator: Tanya Watt, MD
Principal Investigator: Todd Cooper, DO

Sponsors and Collaborators

Emory University

Investigators

Principal Investigator: Tanya Watt, MD Emory University/Children's Healthcare of Atlanta
Principal Investigator: Todd Cooper, DO Emory University/Children's Healthcare of Atlanta

More Information

No publications provided

Responsible Party: Emory University (Tanya Watt, Asst Professor - TT)
ClinicalTrials.gov Identifier: [NCT01230788](#) [History of Changes](#)

HANDOUT: Stress Assessment for Adults

Ask these questions of your client as if it were a questionnaire.

How many of the symptoms of stress in the list below have you experienced in the last two weeks?

1. Are you easily startled or irritated?
2. Are you increasingly forgetful?
3. Do you have problems sleeping?
4. Do you continually worry about events in you and your family's future?
5. Do you feel as if you are constantly under pressure to produce?
6. Do you frequently have to use tobacco, alcohol, or other drugs to help you relax?
7. Do you often feel as if you have less energy than you need to finish the day?
8. Do you have recurrent stomachaches or headaches?
9. Do you experience unexplained mood swings?
10. Are you often disappointed in yourself and others?
11. Are you overly concerned with being liked or accepted by others?
12. Have you lost interest in friends and family?
13. Are you concerned about finances and your ability to afford things you need?

Symptoms of Stress

Indicate which of the symptoms of stress are being experienced by your client in the last two weeks. Ask your client which of the symptoms he or she has experienced, or indicate them based on your own observations.

Physical Symptoms

Dry mouth
Excessive perspiration
Loss of appetite
Gastrointestinal problems
Grinding of teeth
Headaches
High blood pressure
Pounding heart

Emotional Symptoms

Anxiety or edginess
Depression
Fatigue
Hypervigilance
Impulsiveness
Inability to concentrate
Irritability
Trouble remembering things

Behavioral Symptoms

Crying
Disrupted eating habits
Irregular sleeping habits
Harsh treatment of others
Problems communicating
Sexual problems
Social isolation
Increased use of tobacco, alcohol, or other drugs
Relationship changes with close friends or family

Stiff neck or aching lower back Mood swings

Weight gain or loss Low self esteem

Responding "yes" to a few of these questions is normal. Recognizing a few symptoms is also normal. However, checking "yes" to the majority of the questions or recognizing numerous physical, emotional, and behavioral symptoms indicates a high level of stress. Counselors and support groups are good resources for learning stress management techniques and coping skills.

HANDOUT: Stress Assessment for Children

Ask these questions of your client as if it were a questionnaire.

You can either ask these questions to the child or talk to the parent about the signs and symptoms exhibited by the child, depending on your relationship with the child, the child's age and ability to communicate, and the child's willingness to talk about these issues.

How many of the symptoms of stress in the list below has the client experienced in the last two weeks?

Does the child:

1. Find it hard to settle his or her mind down and sleep at night?
2. Feel guilty or that people are constantly disappointed in him or her?
3. Get freaked out by things that usually do not bother him or her?
4. Get overwhelmed with all the things he or she has to do?
5. Show disinterest in things that he or she used to enjoy?
6. Indicate he or she does not want to spend time with friends?
7. Hold on to anger longer than is typical for the child?
8. Seem more distracted than normal?
9. Find him or herself upset with any changes in appearance?
10. Starting to act out or bully other children?
11. Have a hard time getting it together for school each morning?
12. Start getting lower than usual grades?
13. Show that he or she is picking up new habits like hair twirling or thumb sucking?

HANDOUT: Stress Assessment for Children (continued)**Symptoms of Stress**

Indicate which of the symptoms of stress your client experienced in the last two weeks. Ask the client (or his or her parents) which of the symptoms he or she has experienced, or indicate them based on your own observations.

Physical Symptoms

Muscle aches
Incredibly tired
Loss of appetite
Upset stomach
Grinding of teeth
Headaches
Weight loss or gain
Pounding heart

Sweaty palms

Emotional Symptoms

Anxiety or edginess
Depression
Fatigue
Worried often
Confused
Inability to concentrate
Irritability
Trouble remembering things
Mood swings

Behavioral Symptoms

Crying
Disrupted eating habits
Irregular sleeping habits
Harsh treatment of others
Problems communicating
Easily overwhelmed
Social isolation
Easily distracted

Relationship changes with close friends or family

Responding “yes” to a few of these questions is normal. Recognizing a few symptoms is also normal. However, checking “yes” to a majority of the questions, or recognizing numerous physical, emotional, and behavioral symptoms indicates a high level of stress. Counselors and support groups are good resources for learning stress management techniques and coping skills.

HANDOUT: Things to Consider When Discussing Death, Dying, and Spirituality

A client may have no interest in talking about death and dying. It is not the job of the promotora to bring up this subject. However, keep in mind that, as in everything we have discussed in Familias Fuertes, open communication is the healthiest approach. If the client does wish to talk about these issues and asks questions, it is the promotora's job to connect him or her to appropriate resources.

Realize that there are two general scenarios you will face:

1. A client has just been diagnosed with cancer and is fearful of death.
2. The client's treatment is not successful and he or she must come to terms with end-of-life care.

Depending on the scenario, there are many resources clients may need. Should the client bring up the individual subjects, the promotora should be prepared to provide information on the following resources:

1. Facts about cancer and survival statistics
2. Counseling
3. Hospice (end-of-life care)
4. Support groups
5. Funeral arrangements
6. Funeral homes
7. Financial assistance for funeral

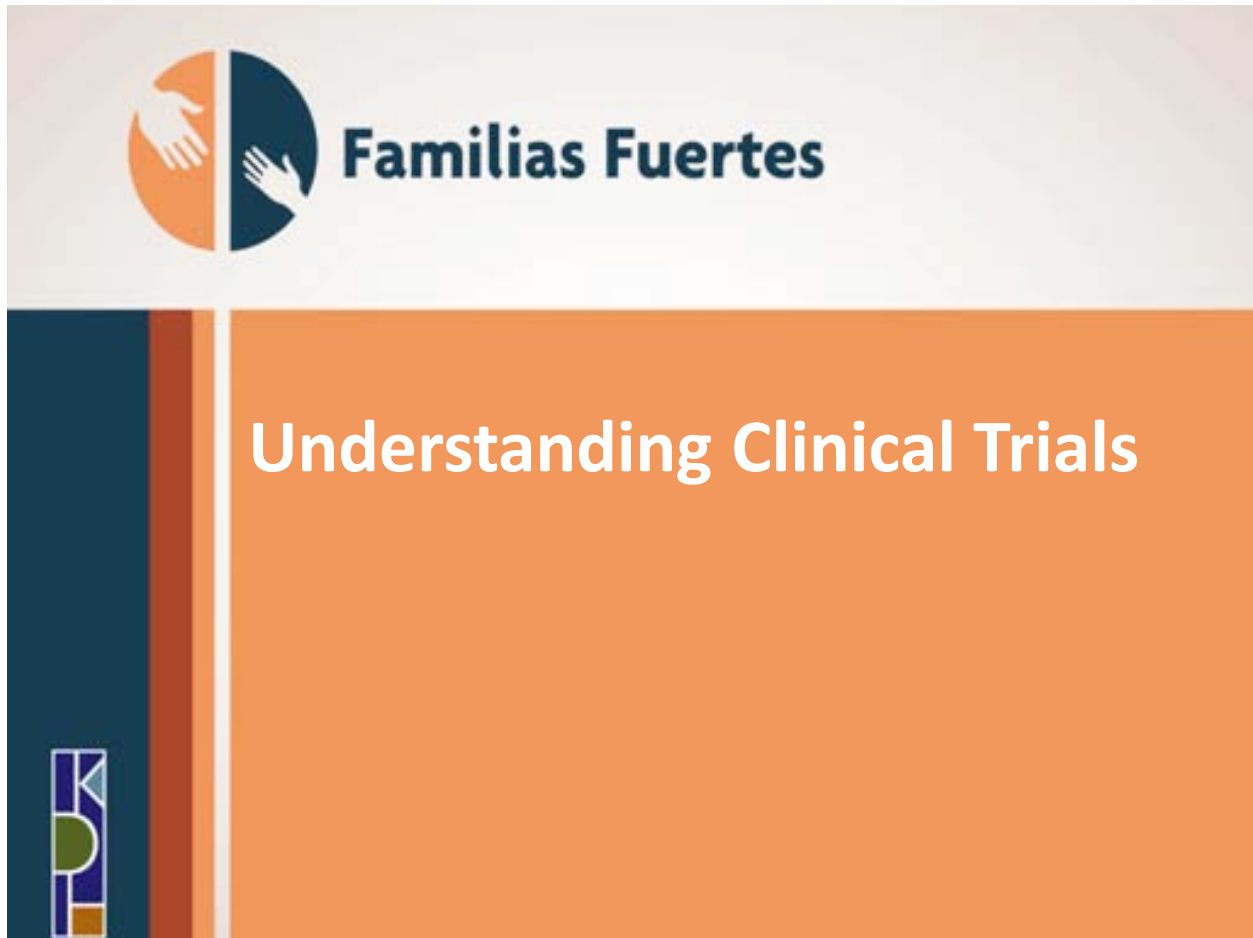
Some clients limit the information they wish to disclose to family members even during end-of-life situations. It is important to respect the client's wishes, but do let clients know that open communication will benefit the entire family.

A client may not wish for his or her children to know about the client's prognosis. It is normal for a parent to feel emotions such as anger, guilt, and frustration. Always make sure you understand the client's wishes before speaking to the children.

A client may or may not be interested in issues of spirituality. If he or she does express interest, you can connect him or her to spiritual leaders. If the client is a member of a particular church and says it is OK, you can contact the church to request they pray for the client and to make sure someone is available to provide last rites (if applicable).

Never push issues of spirituality upon your client.

Hospital staff can help you locate counselors or support groups for your clients.

HANDOUT: Understanding Clinical Trials (Presentation Slides)

What is a Clinical Trial?

- A clinical trial is a medical study that examines new treatments or new ways to use existing treatments.
- Clinical trials compare new treatments to existing treatments to determine which is more effective.

How Can Clinical Trials Benefit the Patient?

- They can offer the patient access to top researchers and new treatment options.
- There is no cost to the patient.
- Sometimes participants are paid for their involvement.

Do Clinical Trials Have Risks?

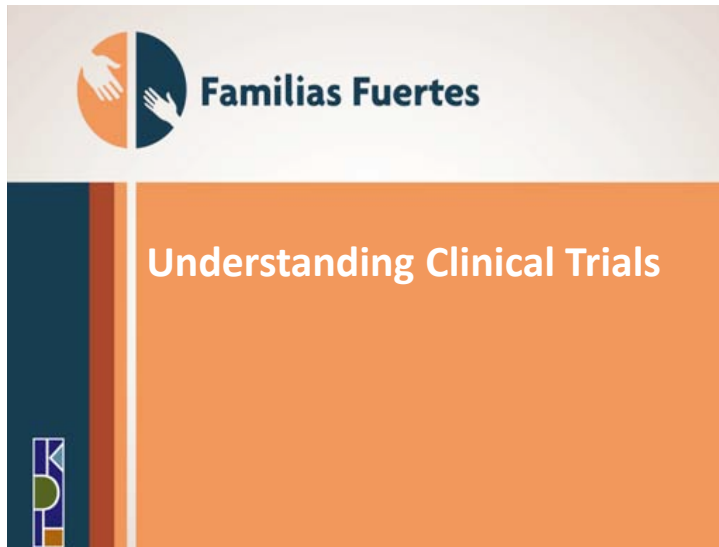
- The federal government has guidelines that protect participants of clinical trials from unnecessary risk.
- All clinical trials must pass review by institutional review boards to ensure they are ethical and the benefits of participation outweigh the risks.

Do Clinical Trials Have Risks? (continued)

- The benefits and known risks of participating in the trials are explained to the participants.
- Participants are then able to make an informed decision about taking part.
- Participants also have the right to withdraw from the study at any point without fear of reprimand.

How to Find Clinical Trials in Your Area

- First ask the doctor if he or she knows of any clinical trials for which the client/client's relative may be eligible.
- Go to www.clinicaltrials.gov
- Call treatment centers in the surrounding area to ask about clinical trials they are currently conducting.



NOTES: _____



NOTES: _____



NOTES: _____

Do Clinical Trials Have Risks?

- The federal government has guidelines that protect participants of clinical trials from unnecessary risk.
- All clinical trials must pass review by institutional review boards to ensure they are ethical and the benefits of participation outweigh the risks.

Page 4

Understanding Clinical Trials

NOTES: _____

Do Clinical Trials Have Risks? (continued)

- The benefits and known risks of participating in the trials are explained to the participants.
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Page 5

Understanding Clinical Trials

NOTES: _____

How to Find Clinical Trials in Your Area

- First ask the doctor if he or she knows of any clinical trials for which the client/client's relative may be eligible.
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- Call treatment centers in the surrounding area to ask about clinical trials they are currently conducting.

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Understanding Clinical Trials

NOTES: _____

SESSION 7: REMISSION AND BEYOND

INTRODUCTION

Promotoras' assistance during remission centers on helping clients resume their daily lives and maintain their health and wellbeing. For child cancer survivors especially, returning to school can be a difficult transition as few people at school will understand what they have been through. Even for children who have been coping with a family member with cancer, resuming normal life may be challenging. In the first activity of this session, promotoras will learn how to develop a plan to help a child coping with cancer through remission and to resume his or her daily life.

The final activity in this session wraps up the entire Familias Fuertes training program. You will guide promotoras through a reflection on the lessons they have learned, followed by a short course evaluation. Finally, you will help the group celebrate by handing out certificates of completion. If time and resources permit, you may wish to have refreshments to create a celebratory atmosphere.

Session Learning Objectives

After completing this session, promotoras will have:

the knowledge to...

- Help children resume their daily lives

and the skills to...

- Support children coping with cancer during remission
- Assist parents in liaising with schools to secure appropriate accommodations for the child coping with cancer
- Be a Familias Fuertes promotora!

MATERIALS NEEDED

- ✓ Flipchart
- ✓ Paper and pens
- ✓ Refreshments (optional)
- ✓ Flipchart pages:
 - *Resuming daily life plan*

HANDOUTS

- ✓ *Special education accommodations fact sheet*
- ✓ *Remission case study cards*
- ✓ *Remission case study answers*
- ✓ *Certificate of completion*
- ✓ *Familias Fuertes training evaluation*

ACTIVITY 1: Resuming daily life during remission

Time: 40 minutes

Activity goal: This activity will provide promotoras with the skills and knowledge needed to help children resume their daily lives.

Facilitator notes: Reentering school after a long absence can be difficult. (For general tips on liaising with the school during this time, refer to Session 5, Activity 3.) Promotoras help with social support and social reintegration in several ways during remission. Specifically, they can

Make referrals to:

- Camps with other survivors
- Counseling
- Online groups for social support

Research:

- Local support resources

Liaise with the school:

- Work with the parents, school, and relevant staff (like social workers) to reenroll absent children
- Prepare the child's peers to welcome the student back
- Provide the school with medical information about the student (e.g., what activities may tire the child).
- Assist the parents with any reenrollment paperwork

Case management:

- Check in on a regular basis to see if the child needs any assistance
- Continue to help a client attend their follow-up appointments
- Help clients maintain a healthy lifestyle by suggesting healthy foods and exercise

If a child is physically disabled after treatment, promotoras should research what extra school support services or special education classes are available. Legally, schools must provide equal access to education for all students. There are two main frameworks to ensure this type of support: an Individual Education Plan (IEP) and a Section 504 plan. See the *Special Education Accommodations Fact Sheet* for a review of IEPs and Section 504 plans.

Promotoras can also suggest to the child's teacher ways of creating peer understanding and acceptance. For example, before a child reenters school, the promotora can help the teacher lead a session about what cancer is and why it is important to be a good friend. This would be a good opportunity to bust any myths children have (e.g., "catching cancer") and to answer questions (e.g., why does the child wear a hat to school?).

Activity Description:

1. Introduce the topic by repeating, in your own words, the information we provide in the Introduction and in the facilitator notes above. Also hand out the *Special Education Accommodations Fact Sheet*, and explain that promotoras should be familiar with these programs.
2. Divide the group into pairs.
3. Give each pair one *Remission Case Study card* to read. (It is fine to give the same case study to more than one pair if you have more than six pairs.) Each case study presents the story of a child who is either in remission, or whose close family member is in remission. The case study details what the child has been through and particular challenges he or she faced.
4. Each pair must write a plan for how they will help the child resume their daily life. In particular, how will the promotora work with the school to welcome the child back? How will the promotora give the child the social support he or she needs? How will the promotora help the child pick up old hobbies, or start new ones?
5. Display flipchart *Resuming Daily Life Plan* on the wall so everyone can see the main points their plan should incorporate.
6. After 15 minutes of working in pairs, bring the class together to discuss each pairs' plan.
7. Have the pair briefly describe their client and review their plan.
8. Ask the class if they would add to the plan or make any changes. Make suggestions as needed.
Note: We provide suggestions on the *Remission Case Study Answers* handout in response to each case study for your own information and to guide the discussion. Please note these suggestions are not exhaustive.
9. Repeat with all pairs.
10. Explain to the promotoras that remission is not the end of their job. For a child coping with cancer, remission can be just as stressful and emotional as the diagnosis and treatment. A child may feel self-conscious about physical changes caused by cancer treatments, or feel isolated because none of his or her friends understand what is happening. Promotoras must work with the child and the family to ease the child's transition back to normal life. Finally, it is good practice for a promotora to conduct continued case management with a client by occasionally checking in to see if the child needs any further help.

11. Wrap up by telling promotoras that this activity concludes the main sessions of the Familias Fuertes training program and next they will reflect on what they have learned, conduct a course evaluation, and have a certificate ceremony.

ACTIVITY 2: Course wrap-up, evaluation, and certificate ceremony

Time: 20 minutes or longer, as schedules permit

Activity goal: To reflect on key lessons learned, evaluate the course, and congratulate promotoras by handing out certificates.

Activity description:

1. Ask promotoras to reflect on the goals they had at the start of Familias Fuertes, and what they have learned and achieved.
2. On a blank flipchart page, ask each promotora to come up to the front and write one takeaway lesson. The promotoras can choose to represent this as a picture and give a brief explanation.
3. Congratulate everyone! Wrap up with a motivational speech that emphasizes how much the promotoras have learned during Familias Fuertes and what an important role they play in their communities.
4. One at a time, call each promotora up to the front of the class and give them their *Certificate of Completion*. Lead a round of applause for each promotora.
5. If schedules and resources allow, celebrate with refreshments. Before this session begins, you could ask promotoras if they would like to have a celebratory party, and ask each to bring a dish to share.
6. Hand out the *Familias Fuertes Training Evaluation* and ask the promotoras to complete the evaluation and return it to you before they leave.

CONCLUSION

Promotoras who have completed Familias Fuertes will feel comfortable with the topics discussed in this guide, and confident in their abilities to work with children of all ages, as they cope with cancer in their lives. Familias Fuertes provides foundational knowledge about cancer, child developmental stages and how they relate to a child's response to coping with cancer, and the kinds of resources these children will need. Promotoras now have a set of skills to meet the needs of children coping with cancer, including being able to communicate with them on an age-appropriate level. Every child and every cancer is different. It is up to the individual promotora to add to the knowledge and skills gained through Familias Fuertes with her own strategies.

FLIPCHART PAGE: Resuming daily life**Activity 1**

Remission: When the signs and symptoms of cancer are absent from the body.

- How will you work with the school to welcome the child back?
- How will you give the child the social support he or she needs?
- How will you help the child pick up old hobbies, or start new ones?
- How will you help maintain the child's health and wellbeing?

HANDOUT: Special Education Accommodation Fact Sheet

School districts are legally mandated to create and maintain certain records for children eligible for special education services. These records include Individual Education Plans and Section 504 plans.

Individual Education Plans (IEP)

- An IEP is a document that:
 - Describes the strengths and challenges of a child with special needs
 - Establishes a blueprint for the child's academic and social goals for the school year
 - Describes the necessary school accommodations to help the child
- An IEP is developed through a collaborative process with the child's parents and a team of professionals, including the school.
- Not all children with a disability are eligible for an IEP, however, many children with disabilities who are ineligible for an IEP will receive accommodations through a Section 504 plan.

Section 504 plans

- Contained in the Rehabilitation Act of 1973, Section 504 acts as an antidiscrimination law that prevents discrimination based on disability, and ensures that a student with a disability receives equal access to an education.
- Under this law, a disability includes a "physical or mental impairment that substantially limits one or more major life activities," (e.g., walking, seeing, hearing).
- Anyone can refer a child for review of eligibility for protection under Section 504.
- Schools typically create Section 504 plans that detail what a child covered under this law will receive from the school.

Differences between IEPs and Section 504 plans

- While a Section 504 plan ensures some assistance for students with disabilities, it differs from an IEP in two major ways:
 - Unlike an IEP team, the team of professionals making decisions about accommodations for a child with a Section 504 plan does not have to consult with the parent(s).
 - Section 504 plans ensure that a child with a disability has equal access to education such as TTY communication systems for people who are deaf or hard of hearing. The team does not monitor success in school once the child has equal access. In contrast, IEP teams monitor grades and provide a variety of support to improve the student's performance each year (e.g., such as altered instruction and tutoring services).

HANDOUT: Special Education Accommodation Fact Sheet (continued)

For more information on IEPs and Section 504 plans refer to:

- Wrightslaw provides information on education law and laws pertaining to children with disabilities, and includes resources about IEPs and Section 504 plans. To find this information enter the search term “Wrightslaw IEP” or “Wrightslaw Section 504” into Google.
- The Individuals with Disabilities Education Act (IDEA) explains education provisions for children with disabilities, as required by law. For more information on this Act, enter the search term “A great idea: IDEA legislation” into Google.
- The National Dissemination Center for Children with Disabilities (NICHCY) website has 19 modules that address special education provisions under the IDEA. Modules 12 through 14 focus on IEPs and the IEP Team. To access this information, enter the search term “NICHCY IEP team” into Google.
- The New England Center for Hearing Rehabilitation (NECHEAR) website has a section that provides IEP/Planning and Placement Team (PPT) advice. To access this information, enter the search term “NECHEAR PPT/IEP” into Google.

HANDOUT: Remission Case Study Cards**David**

David is five years old and a cancer survivor. He was diagnosed with a spinal cord tumor two weeks after he was born. He underwent five years of treatment and now just goes to the hospital every two months for checkups. However, David is in a wheelchair because the cancer paralyzed him from the waist down (he does have the use of his arms). His mother has stayed at home to look after him, but both parents would now like David to have some educational experience outside the home, and make new friends. Now that David is five and understands more about what being in a wheelchair means, he often gets depressed about not being able to do things like play soccer with the other kids in his apartment complex. His family has some money available to access special services for him.

Orlin

Orlin was diagnosed with acute lymphoma lymphoblastic leukemia at two years old. He was in treatment for three years, but then he relapsed a few months after the treatment ended. Orlin went back for treatment consisting of much more aggressive chemotherapy and heavy radiation. After two years of the new treatment, Orlin's leukemia is in remission, but he visits the hospital every month for checkups that last a full day. Next month at the start of the new school year, Orlin will be going to school for the first time at age 8. Until now, his parents have home schooled him and he has kept up with his peers. Orlin does not know any children at the school and is very nervous because he is still bloated and his hair has not grown back. Orlin's parents have not met with the school yet about Orlin's condition.

Gloria

At age 13, Gloria was diagnosed with acute myeloid leukemia, and received a bone marrow transplant from her younger brother. One year after the transplant, she is in remission and is about to go back to school full-time. Gloria has missed a year of school and is very self-conscious about how she looks after losing all of her long hair. She has lost touch with her former friends, but still visits the friends she made in the treatment center who understand what she has gone through. She used to play lots of sports at school, but she still tires easily and cannot participate like she used to.

Diego

Diego is 14 years old and has two younger siblings. His mother has just been given the "all clear" after two years battling Stage Two acute lymphoma. Diego does not have an active father in his life or any other relatives nearby. Diego has taken on a lot of responsibility for his younger siblings while his mother was ill and frequently skipped school. His mother just received a letter from the principle informing her that Diego's grades have fallen so much that he may not pass his classes. Diego has 3 months until the end of the school year to improve his performance. Diego is struggling to internalize everything that has happened and feels he has had to grow up fast. The communication between Diego and his mother has also deteriorated.

HANDOUT: Remission Case Study Cards (continued)

Luce	Cecilia
<p>Luce's father was diagnosed with multiple myeloma when she was 14 years old. After 18 months of radiation and chemotherapy treatment, he is in remission but still absent from work. Luce's mother was so tied up taking care of her husband, going to work, and looking after her two-year-old son that Luce was neglected a lot. About to turn 16 years old, Luce has just found out she is pregnant and plans to keep the baby. The parents have had little contact with the school and, as a consequence, the school did not know the extent of Luce's situation at home. The school thinks Luce is rebellious and a lost cause. Luce feels misunderstood, but would like to graduate from high school.</p>	<p>Just before her 12th birthday, Cecilia lost her mother to cervical cancer. She lives with her father, an undocumented worker, her younger sister (age 8), her aunt and uncle (permanent residents) and their two boys ages 5 and 8. Cecilia has withdrawn from the world and her family, friends, and teachers are extremely worried about her. Cecilia no longer has any interest in her favorite hobby, scrapbooking, which she used to do with her mother. Cecilia's father does not know where to turn for help and is afraid of being deported and leaving his daughter without either parent.</p>

HANDOUT: Remission Case Study Answers

David	Orlin
<ul style="list-style-type: none"> - Help the family find an elementary school with a good special education program. - Set up a tour of the school for the parents. - Help the parents with enrollment forms. - Liaise with the school about establishing an Individual Education Plan or a Section 504 plan and determining which one David is eligible for. Set up a meeting with the relevant contact at the school and David's parents to discuss the application process for the IEP or Section 504 plan. - Find local sports groups for disabled children (e.g., wheelchair basketball). If none exist, find resources about participating in disabled sports. Perhaps there is a summer camp David's parents can enroll him in. - Help David make friends by setting up a play date with a future classmate. 	<ul style="list-style-type: none"> - Help the parents arrange a meeting with the school to discuss Orlin's enrollment and how the school can ease his school entry. - Suggest strategies to the school for creating peer acceptance. - Help the parents with enrollment forms. - Help Orlin make friends before school starts by setting up a play date with a future classmate. - Talk with the school about any restrictions Orlin has because of his illness. - Help the parents establish a way for Orlin to catch up on any missed schoolwork when he is at his monthly check-ups. - Take Orlin on a special trip to buy a cool hat to wear to school and perhaps a new pair of sneakers—something to boost his self-esteem. - Encourage Orlin to talk about how he feels.

HANDOUT: Remission Case Study Answers (continued)

Gloria	Diego
<ul style="list-style-type: none"> - Help Gloria's parents arrange a meeting with the school to discuss enrollment, and how the school can ease her first weeks back at school. - Suggest strategies to the school for creating peer acceptance. - Ask Gloria if she wants to try reconnecting with old school friends and, if so, help set up a play date before school begins. - Find child cancer survival support groups (e.g., online) to provide Gloria with support through the transition. - Find ways to improve Gloria's self-esteem before school begins (e.g., a visit to a nail salon, buy a wig, a new top). - Find a new hobby for Gloria that she can easily do while she regains her strength. - Encourage Gloria to talk about how she feels. 	<ul style="list-style-type: none"> - Set up a meeting with the school to brief them on Diego's family situation. - Work with the social worker at the school to develop strategies to improve Diego's school performance. - Develop a relationship with Diego to help him start talking about how he feels. Once the relationship is established, explore counseling options and support groups for children who have gone through similar experiences. - Engage Diego in activities appropriate for his age (e.g. playing soccer). - Implement family communication strategies discussed in Session Four.
Luce	Orlin
<ul style="list-style-type: none"> - Set up a meeting with the school to brief them on Luce's family situation and engage their support to help her continue her education. - Look into education programs for pregnant teens, especially childcare options. - Implement family communication strategies discussed in Session Four. 	<ul style="list-style-type: none"> - Develop a relationship with Cecilia to help her start talking about how she feels. Once the relationship is established, explore counseling options and support groups for children who have gone through similar experiences. - Work with the social worker at the school to develop strategies to support her—maybe a buddy system. - Try to engage Cecilia in a new hobby.

CERTIFICATE OF COMPLETION

THIS CERTIFICATE ACKNOWLEDGES THAT

HAS COMPLETED

**Familias Fuertes: Promotoras de salud supporting
children coping with cancer**

As a trained promotora, this individual will take the information learned and share it with the community in an effort to help families who have a child coping with cancer. The campaign appreciates the time and dedication this promotora put into the training and the efforts this individual will put into this community health program.

TRAINING COMPLETED ON:

SIGNED:



Familias Fuertes

HANDOUT: *Familias Fuertes* Training Evaluation

To help us improve future trainings, please answer the following questions:

1. What are the three most important things you learned during this training?
 - A.
 - B.
 - C.
2. What are the three greatest strengths of this training?
 - A.
 - B.
 - C.
3. What presentation styles helped you learn the best (e.g., case studies, role play, lecture, quiz, and group exercise)?
4. Using the scale below, please rate the trainer's ability in the following areas:

1 = Very poor, 2 = Poor, 3 = Average, 4 = Good, 5 = Very good

Ability Area	1	2	3	4	5
The trainer's ability to present the material clearly.	1	2	3	4	5
The trainer's ability to answer questions from participants.	1	2	3	4	5
The trainer's overall knowledge of the subject area.	1	2	3	4	5

HANDOUT: Familias Fuertes Training Evaluation (continued)

To help us improve future trainings, please answer the following:

6. Using the scale below, please rate the training in terms of its impact and usefulness in the following areas:

1 = Not useful at all, 2 = Somewhat useful, 3 = Very useful

The training course was useful in ...	1	2	3
Increasing my knowledge of cancer	1	2	3
Increasing my ability and skills to work with children who have cancer	1	2	3
Increasing my ability and skills to work with children who have a family member with cancer	1	2	3

7. Please provide one example of how your work will change as a result of this training (if any).
8. What additional assistance, if any, will you need to be able to implement what you have learned at this training (e.g., supervisory support, videos, handouts on different topics). Please be as specific as possible.
9. If you were given the task of making changes to this training, what changes would you make?
10. Other comments:

GOALS & OBJECTIVES

Promotoras de salud training programs

Centers for Disease Control and Prevention. (1998). *Handbook for enhancing community health worker programs: Guidance for the National Breast and Cervical Cancer Early Detection Program and Breast and cervical cancer messages for community health worker programs: A training packet*. Retrieved from <http://www.cdc.gov/cancer/nbccedp/training/community.htm>

Our Bodies Ourselves—*Latina health initiative: Promotoras de salud*. Retrieved from <http://www.ourbodiesourselves.org/programs/lhi/promotoras/promoeng.asp>

Texas Department of State Health Services: <http://www.dshs.state.tx.us/chpr/chw/training.shtm>

Session 1

Cancer prevalence in the Latino population

American Cancer Society. (2006). *Cancer facts & figures for Hispanics/Latinos 2006-2008*. Retrieved from <http://ww2.cancer.org/downloads/stt/caff2006hisppwsecured.pdf>

Stevenson-Perez, H. (1998). *America's cancer prevention, treatment, research, and education programs must include Hispanic Americans*. *Cancer*, 83, 1872-76.

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute (2010). *United States cancer statistics: 1999–2007 incidence and mortality web-based report*. Retrieved from <http://apps.nccd.cdc.gov/uscs/>

Working with children coping with cancer

SUNY Research Foundation/Center for Development of Human Services New York State Child Welfare Training Institute. (1993). *The child development guide*. Retrieved from <http://www.dshs.wa.gov/ca/fosterparents/training/chidev/cd06.htm>

UBM Medica LLC. (2010). *Talking with your child about cancer*. Retrieved from <http://www.healthieryou.com/canctalk.html>

Worden. (2010). *Talking to your child about the loss of a loved one*. In PsychCentral. Retrieved from http://psychcentral.com/library/child_death9.htm

Session 2

Anatomy of the human body

American Medical Association—Atlas of the human body:

- [The urinary system: http://www.ama-assn.org/ama/pub/physician-resources/patient-education-materials/atlas-of-human-body/urinary-system.shtml](http://www.ama-assn.org/ama/pub/physician-resources/patient-education-materials/atlas-of-human-body/urinary-system.shtml)
- [The torso: http://www.ama-assn.org/ama/pub/physician-resources/patient-education-materials/atlas-of-human-body/body-torso-side.shtml](http://www.ama-assn.org/ama/pub/physician-resources/patient-education-materials/atlas-of-human-body/body-torso-side.shtml)

- [The digestive system: http://www.ama-assn.org/ama/pub/physician-resources/patient-education-materials/atlas-of-human-body/digestive-system.shtml](http://www.ama-assn.org/ama/pub/physician-resources/patient-education-materials/atlas-of-human-body/digestive-system.shtml)
- [The endocrine system: http://www.ama-assn.org/ama/pub/physician-resources/patient-education-materials/atlas-of-human-body/endocrine-system.shtml](http://www.ama-assn.org/ama/pub/physician-resources/patient-education-materials/atlas-of-human-body/endocrine-system.shtml)

BBC-Science: Human Body & Mind:

http://www.bbc.co.uk/science/humanbody/body/factfiles/organs_anatomy.shtml

MedlinePlus—Anatomy: <http://www.nlm.nih.gov/medlineplus/anatomy.html>

What is cancer?

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

American Cancer Society. (2009). *Radiation therapy—What it is, how it helps*. Retrieved from <http://www.cancer.org/treatment/treatmentsandsideeffects/treatmenttypes/radiation/radiationtherapy-whatitishowithelps/index>

American Cancer Society. (2010). *Cancer basics*. Retrieved from <http://www.cancer.org/cancer/cancerbasics/index>

American Cancer Society. (2010). *Chemo—What it is, how it helps*. Retrieved from <http://www.cancer.org/Treatment/TreatmentsandSideEffects/TreatmentTypes/chemotherapy/whatitis/howithelps/index.htm>

National Cancer Institute: <http://www.cancer.gov/>

National Cancer Institute in Spanish: <http://www.cancer.gov/espanol>

National Cancer Institute, National Institutes of Health. (2008). *Angiogenesis inhibitors therapy*. Retrieved from <http://www.cancer.gov/cancertopics/factsheet/therapy/angiogenesis-inhibitors>

National Cancer Institute, National Institutes of Health. (2010). *Cancer staging*. Retrieved from <http://www.cancer.gov/cancertopics/factsheet/detection/staging>

National Cancer Institute, National Institutes of Health. (2010). *Radiation therapy for cancer*. Retrieved from <http://www.cancer.gov/cancertopics/factsheet/therapy/radiation>.

Session 5

Communicating with the family about cancer

Cancer.Net, American Society of Clinical Oncology. (2011). *Family life*. Retrieved from <http://www.cancer.net/patient/coping/relationships+and+cancer/family+life>

National Cancer Institute, National Institutes of Health. (2010). *Cancer in the family: What it's like for you*. Retrieved from <http://www.cancer.gov/cancertopics/when-someone-in-your-family-archived/page7>

National Coalition for Cancer Survivorship. (2010). *Section 3: Family communication (1 of 4)*. Retrieved from <http://www.canceradvocacy.org/toolbox/11-living-beyond-cancer/section-3-family.html>

Helpful websites:

CancerCare for Kids: <http://www.cancercareforkids.org>

Helpful books:

Blake, C., Blanchard, E., & Parkinson, K. (1998). *The paper chain*. Health Press.

Carney, K.L. (1998). *What is cancer, anyway?: Explaining cancer to children of all ages*. Dragonfly.

Chamberlain, S. (1990). *My ABC book of cancer*. Synergistic Press.

Clifford, C. (2002). *Our family has cancer too*. University of Minnesota Press.

Session 7

Social support for children

Aesthetics:

Look Good...Feel Better: <http://lookgoodfeelbetter.org/>

Look Good...Feel Better for Teens: <http://www.2bme.org/noflash.html>

Camps:

BASE Camp Childhood Cancer Foundation: <http://basecamp.org/>

Camp Sunshine: <http://www.mycampsunshine.com/>

Kids 'n Kamp: <http://www.kidsnkamp.org/>

Children who have a parent with cancer:

Kids Konected: <http://www.kidskonected.org/about/default.html>

Riprap-Support: http://www.riprap.org.uk/support/forums/show_groups.asp

Hospital programs:

Children's Cancer Association-Chemo Pal: <http://www.joyrx.org/programs/chemo-pal/>

Additional support for children and families:

Hospice:

Children's Hospice International: <http://www.chionline.org/>

National Cancer Institute-Hospice Information:

<http://www.cancer.gov/cancertopics/factsheet/support/resources>

Hospital programs:

Children's Cancer Association—Music Rx: <http://www.joyrx.org/programs/music-rx/>

How to find resources:

National Cancer Institute—How To Find Resources in Your Own Community If You Have Cancer:
<http://www.cancer.gov/cancertopics/factsheet/support/resources>

Children's Cancer Association—Life Support Family Enrichment Program:
<http://www.joyrx.org/programs/lifesupport/>

Lodging and transportation:

Alex's Lemonade Stand—Travel Program: <http://www.alexlemonade.org/travel-fund>

American Cancer Society—Hope Lodge: <http://www5.cancer.org/docroot/subsite/hopelodge/index.asp>

American Cancer Society—Road to Recovery:
<http://www.cancer.org/reatment/supportprogramsservices/programs/road-to-recovery>

Children's Cancer Association-Caring Cabin: <http://www.joyrx.org/programs/caring-cabin/>