

Staying in the Circle of Life (SITCOL)

Facilitation Guide Session 3

To begin:

- Arrive 30 minutes before the session
- Prepare materials for activities and surveys
- Arrange the room so chairs are in a circle
- Review session goals

Goals	
Review previously established agreements	
Understanding Advocacy and why it is important	
3. Where to find reliable health information	
4. Identify ways to get the most out of doctor visits	
Define and understand advance directives	
Administer Pre and Post test	
7. Administer the Cancer Care/Survivorship plan	

Materials and Handouts	
Name tags	Cancer Care Plan
Permanent Markers	Paper & pen for participant activity
Flip Chart	Pre-assessment, Post-assessment
Example advance directive	

Activities	
Role Play	
Closing Circle	

Notes:

- Complete these tasks prior to start of group:
 - o Display "Agreements" on flip chart/board/or powerpoint
 - Make sure each participant has paper and pen for activity
 - o Make sure each participant has the handouts listed above
 - o Have a clock to refer to in order to guide the discussion and cover all material
- Total time for session one is 90 minutes.

Staying in the Circle of Life



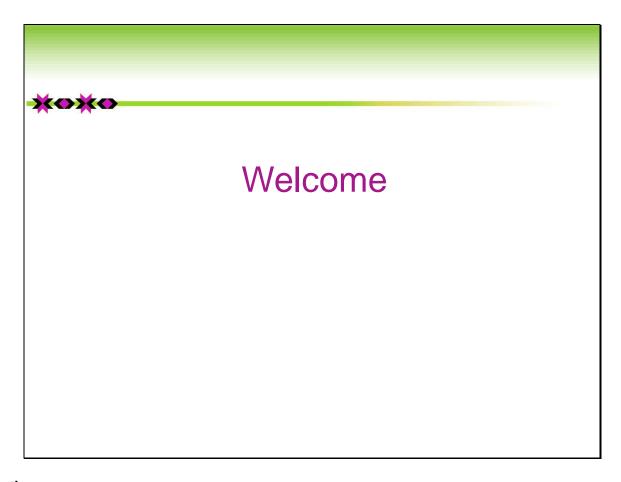
Medical Advocacy and Advance Directives

Session 3









Greeting

- Begin the session on-time.
- Greet each participant by name as they arrive.
- Each person should write their **first name** on a name tag.
- Provide each participant with paper and pen

Agreements



We want to do what we can to make sure everyone feels comfortable while they're here. Some examples:

- Keep it confidential everything anyone says stays in the room
- · Listen with respect
- Stay on topic we have a lot of information to go over and we want to make sure we cover it all
- Other things we can do?

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What We Will Talk About Today



- Understanding advocacy and why it's important
- Finding reliable health information
- Learning how to get the most out of doctor visits
- Learning about survivorship care plan and advance directives and why they're important

What Is Medical Advocacy?



Medical advocacy involves -

- Knowing as much as you can about your own health situation
- Using that knowledge to exercise your right to receive high-quality healthcare

What is medical advocacy?

- Go around the room, ask if people have any examples to offer
- Ask for participants to give examples of why medical advocacy is important

Ways You Can Be Proactive



- Find information from as many reliable sources as you can
- Talk with your care team (doctors, nurses, community health workers) about what you're learning
- Ask your family, friends, and support network to help you solve problems
- Incorporate traditional ways of wellness into your life

Ways to be proactive

•	Discuss what reliable means, and note that
	we will offer examples and discuss more in
	depth later in the session

Finding Reliable, Accurate Information



- Who wrote the information?
- When was the information written?
- Who paid for the research and published the information?
- Don't rely on the Internet for information on diagnosis or treatment options!!

How to get the most out of your appointment . . .

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 - Make a list of questions, concerns, and positive progress to bring with you.
 - · Ask as many questions as you want!
 - Make sure you leave your appointment with all of your questions addressed, and speak up if you don't understand something.
 - Be assertive when necessary

How to get the most out of your appointment

- Talk about the importance of regular checkups and making appointments, post treatment
- Discuss the importance of preparing for each appointment in advance, developing a list of questions, writing them down to review with the doctor.
- Stress for each participant that it's okay to ask for more time to cover questions or concerns during a medical visit, even if the doctor seems rushed.

How to get the most out of your appointment . . .

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- If possible, bring a family member or community health worker with you to your appointment – they can help take notes!
- If you can't make your appointment, let your provider know right away, and reschedule right away.

Talking With Your Doctors



- Tell your doctor if a medication or other parts of your treatment are not working for you.
- Tell your doctors that you are a cancer survivor.
- It's OK to ask for a second opinion.
- If you are not getting along with your doctor, it's OK to ask for a new doctor.
- Thank your healthcare team for their time!

Talking with you doctors

 Acknowledge that there is may be situations in which a participant felt uncomfortable with their medical provider, or that there may be some patient/provider mistrust. Then you can outline the options for participants if this has happened to them (ask for another provider, ask for another opinion).

Activity

Role Play: Doctor Visit



- Do you know what medications I am on now?
- Do you have medical records that tell you about my cancer?
- Does being a cancer survivor impact how often I see you?
- I am feeling really tired. Does this have something to do with my cancer?
- I am feeling a lot of stress. Can I talk to you about it?
- Can I exercise as a cancer survivor?

Activity - Role Play

- Pass out the list of practice questions
- Roles: Patient, Doctor, Caregiver (optional)
- Directions: Have participants take turns being the patient, doctor, (and caregiver if they choose). Below are tips and sample questions the "patient" can ask the "doctor". This is good practice to get comfortable asking questions and advocating for yourself!
- Tip 1: Every cancer survivor should ask for a complete care summary and follow-up plan from their oncologist once they complete their treatment. Patients should ask their doctor the following questions once cancer treatment ends. The answers can help inform the patient about their care and what to expect next.
- Tip 2: Many patients find it helpful to write these questions down and take notes or tape record their discussions with the doctor to refer to at a later time.

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Survivorship Care Planning

http://www.oncolink.org/oncolife/questions.cfm?app=0

Survivorship Care Planning

Pass out the OncoLife questionnaire.

Sample:

Once someone has completed cancer therapy, they should be provided with a summary of the treatments received and a follow up "care plan." Care plans summarize effects of cancer and cancer treatment down the road and recommend future screenings and healthy activities.

If you'd like, you can complete a cancer care plan questionnaire and we will provide you with a care plan next session. Or you can visit this website and complete your care plan online.

Remember to review your care plan with your doctor so that they can explain your risk and clarify the recommendations.

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What Is An Advance Directive?



- An advance directive is a legal document that tells what kind of care people want to have when they can no longer express their own wishes.
- · Two common examples are:
 - Living Will
 - Medical Durable Power of Attorney (also called Healthcare Power of Attorney)
- An advance directive can also include instructions about your healthcare decisions, such as donating an organ or tissue.

- Note: Given the medical background of the participants, you may ask the group who has experience with Ads.
- Distribute example sheet of advanced directive

Why are advance directives important?



- You have the right to make decisions about your own health and treatment.
- It's important for family members and health care providers to know what kind of medical care someone wants at the end of life.

When should you complete an advance directive?



- Advance directives should be filled out while you're healthy.
- This gives you time to think about the end-oflife care you would choose if you were unable to communicate your wishes.
- It also gives you time to discuss your wishes with your loved ones.

http://www.cancer.gov/cancertopics/factsheet/Support/advance-directives

Important Things to Know . . .

The laws about advance directives vary from state to state, so it's important to complete and sign an advance directive for the state where you live or where you expect to receive medical treatment.

http://www.cancer.gov/cancertopics/factsheet/Support/advance-directive

Example: Five Wishes



Five Wishes is an advance directive that combines a living will and a healthcare power of attorney in addition to addressing matters of comfort and spirituality.

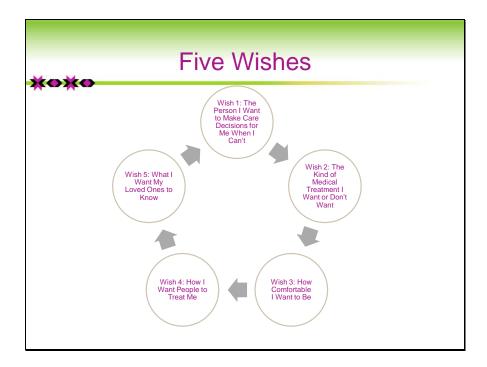


http://www.rwjf.org/reports/grr/029110s.htm

Example: Five Wishes

Developing an advanced directive plan could be a difficult conversation with your family. One way to make that easier is the Five Wishes plan. There may be others that include the spiritual and cultural wishes of you and your family

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Five Wishes

- Distribute Five Wishes Handout
- The first 2 wishes meet legal requirements for an AD in most states, but Oregon has additional requirements. The 3-5 wishes address matters of comfort care, spirituality, forgiveness, and final wishes.
- Wish 1: This section is an assignment of a health care agent (also called proxy, surrogate, representative, or health care power of attorney). This person makes medical decisions on your behalf if you are unable to speak for yourself.
- Wish 2: This section is a living will—a
 definition of what life support treatment
 means to you, and when you would and
 would not want it.
- Wish 3: This section addresses matters of comfort care: What type of pain management you would like, personal grooming and bathing instructions, whether you would like to know about options for hospice care, among others.
- Wish 4: This section speaks to personal matters, such as whether you would like to be at home, whether you would like someone to pray at your bedside, etc.
- Wish 5: This section deals with matters of forgiveness, how you wish to be remembered, and final wishes regarding funeral or memorial plans.

Discussion Questions



- How do you advocate for yourself?
- Where do you go for health information?
- Why might people want to exercise their right to make decisions about their own treatment?
- What barriers can you see to completing an advance directive?

Discussion Questions

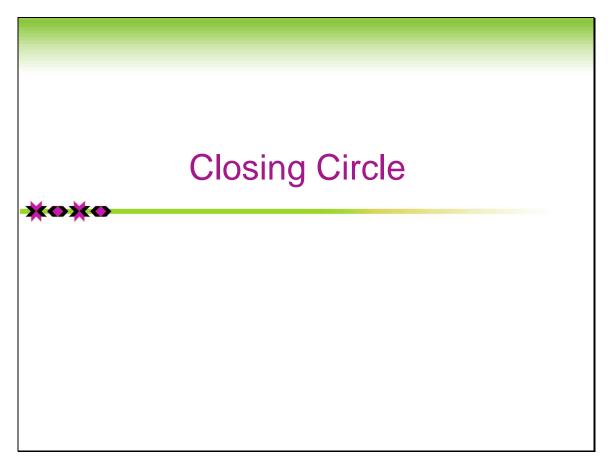
- Go around the room, as for people to respond to any of the questions on the powerpoint slide.
- Note: It's okay if you add others that come up during the session

Things to Think About



- You can play an active role in getting the care you want at all stages of your life.
- There's a lot of information out there! Ask someone to help you find what is most reliable.
- Advocate to ensure that you get the most out of your doctor visits.
- Advance directives can help you plan how you want to be taken care of. They can be helpful for you and your family.

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Closing Circle

- Administer Post-Assessment
- Go around the room
 - o I learned
 - o I hope
 - o I feel
