

PREPARING FOR YOUR NEXT VISIT

Instructions

Please take 10-minutes (or more if you choose) to review this packet and answer the questions that feel most important to you. This is not a survey, and you do not have to answer any of these questions if you do not want to.

Why Am I Receiving This Packet?

Studies show that some doctors forget to ask patients about their personal preferences when making medical treatment recommendations. Yet, there is often more than ONE best treatment option for advanced breast cancer, and your personal preferences might help decide on the best treatment for you. The purpose of this packet is to help you identify what is most important to you as you consider your treatment plan.

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WHAT TO EXPECT AS YOU PLAN YOUR CARE

Every individual is unique. However, most women with advanced breast cancer experience the phases outlined below in their care. Right now, you are at the **Treatment Planning phase**, and during your next appointment with your cancer specialist, you will discuss your treatment options and may decide on what treatment option is best for you.



Signs & Symptoms

In your first meeting with your doctor after experiencing concerning signs or symptoms, your doctor will determine if work-ups are necessary.



Initial Testing & Referral to Cancer Specialist

This is when your doctor orders tests to learn more about your signs and symptoms. Depending on the results, your doctor may refer you to a doctor that specializes in cancer.



Testing and Diagnosis

When a doctor that specializes in cancer reviews your test results, they may order more tests and then makes a diagnosis. If you receive a breast cancer diagnosis, the doctor may order even more tests to identify the type, stage, and features of the cancer.



Treatment Planning

This is when you and your doctor(s) discuss treatment options and your preferences to agree on a treatment plan that is best for you



Treatment

This is when you undergo the treatment that you and your doctor(s) decided on in your treatment planning.



Recovery, Monitoring, & Treatment Evaluation

This is when you and your doctor(s) evaluate how well the treatment is working for you and decide on whether to continue with current treatment or consider other options. This may require further testing.



Supportive Care

This is support that you can receive throughout your care. This can include pain management, advice about nutrition and exercise, financial support, one-on-one counseling and/or a support group.

CLARIFYING YOUR GOALS & NEEDS

Think through the questions below with your loved ones before your next visit and take notes *if you would like to*. You might choose to discuss your answers with your doctors during your next visit to help decide on the best treatment options **for you**.

1. What are the most important activities that you enjoy doing (e.g., gardening, walking, exercising, playing instruments, spending time with your family, being productive at work)?

2. Are there any upcoming events in your life that you don't want to miss (e.g., wedding, birth, graduation, holiday)?

3. If during treatment you require help with activities such as eating/drinking, cooking, or dressing yourself, do you already know who might assist you or might you need help finding this assistance?

4. Aside from your breast cancer diagnosis, what else is on your mind right now (e.g., caring for a parent/child/grandchild, continuing to work, paying for care, rent or mortgage payments)?

QUESTIONS TO ANSWER FOR YOUR DOCTOR

Take some time to answer these questions before your next visit and send your answers back to us, so that your doctor can read them before your appointment.

1. How do you like making decisions about your treatment? Please choose 1 answer:

- I prefer to make the final selection about which treatment I will receive.
- I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.
- I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
- I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.
- I prefer to leave all decisions regarding my treatment to my doctor.

2. Who is the most important person in helping you make decisions?

- Spouse or partner
- My child
- My parent
- My friend
- My spiritual or religious advisor
- There is nobody else that I would include in this decision
- Other _____

3. How do you like to get medical information? Please choose 1:

- All the facts including prognosis
- All the facts, but not my prognosis
- Enough to make a decision
- Something else _____

4. Have you ever had trouble obtaining your medications?

- Always
- Never
- Sometimes

5. In the last 12 months, did you skip medications because of high costs?

- Yes
- No

6. Does your spirituality influence you in your healthcare decision making? Please choose 1:

- Always
- Never
- Sometimes

7. Treatment for cancer can impact many aspects of a person's life. We are interested in what are the most important things to you when choosing a treatment. Please choose up to three of your biggest concerns:

- Physical side effects (e.g., hair loss, neuropathy, nausea, fatigue)
- Emotional or mental side effects (e.g., sadness, anxiety, memory)
- Ability to work (e.g. maintain your job and other work outside your home)
- Personal responsibilities (e.g., caring for a child or parent, household responsibilities)
- Logistics and Convenience (e.g. transportation, lodging, length of time in clinic, taking a pill vs. intravenous medicine)
- Out-of-pocket expenses (e.g., co-pays, costs not covered by your health insurance)
- Impact on activities of daily life (e.g., bathing, dressing, nutrition, hobbies, exercise)
- Burden on family, friends, or care partners (e.g., how your treatment might impact other people in your life)
- Important events and activities (e.g., attend wedding, travel, financial planning)
- Being on a clinical trial or newly approved medications (e.g., access to new treatments)
- Sexual concerns (e.g., sexual intimacy, physical appearance)
- Fertility (e.g., ability to have children)

QUESTIONS TO ASK YOUR DOCTOR & CARE TEAM

Below are questions you might choose to discuss with your doctors and care team during your next visit. If there are specific questions that you want to discuss with someone during your next visit, **please indicate those with a check mark.**

MY TREATMENT OPTIONS		
Check the questions you want to discuss	Questions	Notes / Answers <i>(to track during your discussion)</i>
<input type="checkbox"/>	What are my treatment options?	
<input type="checkbox"/>	What clinical trials might be an option for me?	

HOW WELL THE TREATMENT WORKS		
Check the questions you want to discuss	Questions	Notes / Answers <i>(to track during your discussion)</i>
<input type="checkbox"/>	How likely is this treatment to stop my cancer from growing or shrink my cancer? How likely is this treatment to help me live longer?	

<input type="checkbox"/>	<p>How does my unique medical history affect my condition and treatment? (e.g., is my diabetes relevant? Does my family history of breast cancer make a difference?)</p>	
<input type="checkbox"/>	<p>What will we do if this treatment is not successful?</p>	

IMPACT ON MY QUALITY OF LIFE		
Check the questions you want to discuss	Question	Notes / Answers <i>(to track during your discussion)</i>
<input type="checkbox"/>	<p>How might these treatment options impact my quality of life? For example, how might they impact:</p> <ul style="list-style-type: none"> • Being able to do my normal activities (e.g., dressing, bathing, and using the toilet)? • Being able to do what I enjoy (e.g., preparing or eating food, walking or exercising, spending time with friends)? • My state of mind and how I feel emotionally (e.g., irritable/depressed, difficulty concentrating, difficulty remembering things)? 	

<input type="checkbox"/>	<p>What options are available that will help reduce my pain and symptoms, and improve my quality of life during my cancer treatment (e.g., palliative care for symptom management or complementary therapies such as acupuncture)?</p>	
<input type="checkbox"/>	<p>Are there other support services I can access? (e.g., advice about nutrition and exercise, financial support, one-on-one counseling, joining a support group)?</p>	
SAFETY, SIDE EFFECTS AND COMPLICATIONS		
Check the questions you want to discuss	Questions	Notes / Answers <i>(to track during your discussion)</i>
<input type="checkbox"/>	<p>What are the most common short- and long-term complications/side effects of each treatment option? (e.g., bone, joint, or muscle pain, loss of appetite, unwanted weight loss or gain, nausea, diarrhea, fatigue, anemia)</p>	
<input type="checkbox"/>	<p>What is the range of symptom severity that I could experience?</p>	

HOW, WHERE, AND FOR HOW LONG I WILL TAKE THESE TREATMENTS

Check the questions you want to discuss	Questions	Notes / Answers <i>(to track during your discussion)</i>
<input type="checkbox"/>	<p>How will I take these different treatment options (e.g., through an IV, a pill, radiation)?</p> <p>Are there options for where I can take each of these treatments (e.g., at home, at the hospital, in my doctor's office)?</p> <p>How often will I need to take each of these treatments, and for how long?</p>	

OUT-OF-POCKET COSTS TO ME & MY FAMILY

Check the questions you want to discuss	Questions	Notes / Answers <i>(to track during your discussion)</i>
<input type="checkbox"/>	<p>How much will these treatment options cost me out of my own pocket, including any supportive care I need (e.g., counseling, physical therapy, pain management medications)?</p>	
<input type="checkbox"/>	<p>Who should I talk with about options to help me with planning for these costs?</p> <ul style="list-style-type: none"> • Travel costs linked to my treatment (e.g. bus tickets, gas, parking, taxi, family travel and hotel expenses) • Someone else to take care of my child/elderly parent during my treatment • Paying for treatments and medications 	

OTHER CONSIDERATIONS WHEN PLANNING

Check the questions you want to discuss	Questions	Notes / Answers <i>(to track during your discussion)</i>
<input type="checkbox"/>	How should I change my diet/nutrition and exercise? What other lifestyle changes might help me feel better during treatment or help the treatment work better? How much could these cost me?	
<input type="checkbox"/>	Will these treatment options impact my ability to work? Are there options that require me to take less time off work?	
<input type="checkbox"/>	What kind of support will my family member/caregiver need to provide for me? How much time will they need to spend helping me with my care? For example: <ul style="list-style-type: none"> • Attending medical appointments • Transportation • Coordinating medical care and talking to the health insurance company • Everyday activities (e.g., cooking/bathing) 	
<input type="checkbox"/>	Do I or my family members/caregivers need to learn any new skills to support me during treatment (e.g., how to give an injection, how to work an oxygen tank, cleaning a port)?	

About Us

Avalere is a vibrant community of innovative thinkers dedicated to solving the challenges of the healthcare system. We deliver a comprehensive perspective, compelling substance, and creative solutions to help you make better business decisions. As an Inovalon company, we prize insights and strategies driven by robust data to achieve meaningful results. For more information, please contact info@avalere.com. You can also visit us at avalere.com.

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