



CONSIDERATIONS **OF CARE**

A guide for older adults with breast cancer and their caregivers

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CBCN is governed by a pan-Canadian volunteer Board of Directors who have all had personal or familial experiences with breast cancer. The insights, knowledge, and lived experience of our directors guide the work of CBCN and the development of patient resources. Thank you to the dedicated group of volunteers:

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DISCLAIMER

Considerations of Care: A Guide for Older Adults with Breast Cancer and their Caregivers is offered as a general reference tool for patients and caregivers. Patients should consult with a healthcare professional regarding their specific breast cancer diagnosis and treatment. This resource is based on information available as of the date of publication, 2024. Future medical advances or product information may affect or change the information provided.

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INTRODUCTION

Breast cancer is much more common as we get older.¹ Experts also predict that the number of Canadians with breast cancer could double by 2042, with the largest increase expected in people 65 years of age and older.² Despite more cases of breast cancer occurring in older adults, there are significant gaps in knowledge and care of the people in this age group.

In 2022, the Canadian Breast Cancer Network (CBCN) surveyed individuals across Canada who had been diagnosed with breast cancer to learn about their educational and resource needs. In 2024, CBCN analyzed the data of the 262 Canadian women aged 65 and older who completed the survey. The aim of this analysis was to identify their specific educational needs and to learn more about the care they received.

The analysis found that older women often felt that there isn't enough information about breast cancer for their age group, which makes it hard for them to make informed decisions about their cancer care and treatment.

CBCN committed to creating this resource for older individuals to help lower knowledge gaps in people diagnosed with breast cancer in this age group. While the statistics and information in this resource are based on the responses of women, this handbook is not solely for women. It offers unique considerations for older adults, and the people that help to care for them, when diagnosed with breast cancer.

We hope that you will find the information in this resource helpful. You are encouraged to use the information and checklists in this booklet to help you guide the discussions with your care team.

BREAST CANCER WHEN YOU'RE OLDER

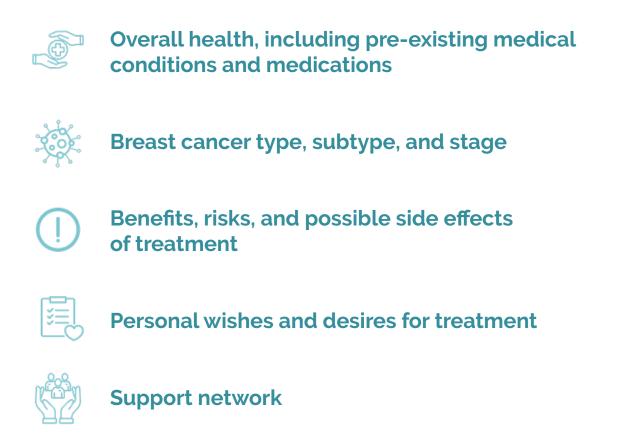
What's the same and what's different

About one in eight Canadian women is expected to be diagnosed with breast cancer in their lifetime.¹ Experts estimate the number of Canadians with breast cancer could double by 2042, with the largest increase expected in people 65 years of age and older.² Aging is also the leading risk factor for developing breast cancer.³

Each person diagnosed with breast cancer is unique and different. Some are very fit, active and healthy, while others may have health conditions that affect their ability to do their daily activities. This can be true regardless of your age. How well you're able to function (such as how well you're able to care for yourself and live independently) and your overall health may impact how well you respond to cancer treatment and the possible side effects.

DID YOU KNOW?

The survival of women with breast cancer has been improving since the 1980s.¹ Research found that 85% of women diagnosed with breast cancer before the age of 85 years were still alive 5 years after their diagnosis.¹ There are several factors that every person with breast cancer and their doctors should discuss when deciding on their treatment options. These can include:



Each of these things can make a difference in breast cancer treatment, care and maintenance. To help you with these conversations, we have included a checklist that will ask you a few questions on each of these topics. This will help you get ready for the discussion with your cancer team.

IT IS YOUR CHOICE

Decisions about your breast cancer treatment and care are made with you and not made for you. It is important to know that you can take an active part in choosing the treatment that is right for you.

TALKING TO YOUR BREAST CANCER CARE TEAM

Speaking with your breast cancer care team can initially feel daunting, but it's a vital part of your journey. Effective communication with your care team not only helps you learn more about your diagnosis and treatment options but also empowers you in your care.

Being able to speak effectively with your breast cancer care team can:4

- Improve your quality of life
- Reduce your anxiety
- Help manage your symptoms
- Help you understand your cancer diagnosis and treatment options

Taking an active role in your conversations with your care team helps you feel more in control of your journey and empowers you to make informed decisions.

The checklist on the next two pages offers useful tips to guide these discussions, aiming to support you on your journey and enhance your experience with your care team.



Checklist to improve your discussions with your breast cancer care team⁵

O Download or order CBCN's <u>Breast Cancer and You</u> handbook.

In the first few pages, you will find the "Your Breast Cancer Diagnosis" and "Your Breast Cancer Treatment Plan" checklists that can help your cancer team tell you about the details of your cancer and your treatment plan.

• Get a notebook (or binder) to keep all of your health information in one place.

Record the names of every person on your cancer team such as your medical oncologist, radiation oncologist, surgeon, nurse, pharmacist, family doctor, family and caregivers.

Keep track of your symptoms and how you are feeling to let your cancer team know.

It can help to bring someone with you to your appointments.

A support person or a caregiver can help you navigate the logistics of your day like arranging for transportation and parking.

They can help you ask your questions, write down the answers, and remember events that you may have missed when talking to the team.

○ Make a list of questions for your breast cancer care team.

This will help to make sure you don't forget anything important. Try to make the questions specific and precise. Here are some questions you may have regarding your breast cancer and treatment:

- What are my treatment options?
- What type and subtype of cancer do I have, and what stage is it?
- How does my age impact my breast cancer type, subtype, and stage?
- What treatment do you recommend and why?

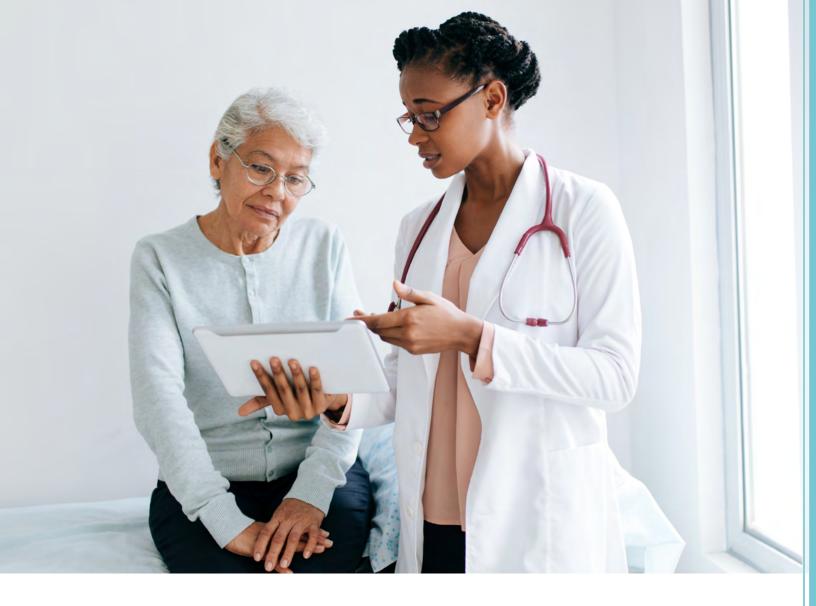
- Do I have a choice for the treatment of my cancer?
- What are the goals of my treatment (cure or pain and symptom management)?
- How often and for how long will I receive treatment?
- What is the impact of the treatment on my other health conditions and other medications?
- How do the benefits of the recommended treatments compare to the risks?
- What are the possible side effects? What can be done to manage the possible side effects of the treatment?
- What options are available for managing pain?
- How will I know if my treatment is working?
- Who is part of my treatment team? Who should I contact, and how, if I have a question or concern?
- Is there any information or resources available where I can read about this treatment or procedure?
- What questions would you ask if you were me?

Write down the answers in your notebook.

It is easy to forget something during one of these appointments. Writing it down can help you remember after the visit. Alternatively, you can also ask your support person to take detailed notes or ask your oncology team for a written treatment plan.

\bigcirc If you don't understand, let your cancer team know.

You are the most important person in making decisions about your health. If something is unclear, let your team know that "I don't understand...". Sometimes it can take a quick explanation that can help you learn what you need to choose the treatment that is right for you.



BEING AN ACTIVE PARTICIPANT IN YOUR BREAST CANCER TREATMENT DECISIONS

To guide your treatment path, your breast cancer care team will need to know some information about you to discuss your options. To help with these conversations, there is a checklist on the following pages that will provide your doctor with key information about you to help you make the best possible treatment decisions.

It is recommended that you take the completed checklist with you to your breast cancer appointments. This can help your cancer team focus on what is important to you.

The checklist is broken down into five key sections:



Your mind: Even though we commonly think of cancer as a physical condition, the mind and brain are very important when selecting cancer treatments.



Your movement: How you move and get around every day is very important. It can have an impact on your cancer treatment and getting to your appointments. Your movement and mobility can also be used to rate your overall health and fitness.



Your health: The older we get, the higher the risk of having many different conditions. These can include health conditions such as problems with the heart, lungs, or kidneys which may affect the different breast cancer treatments offered to you. You may also be concerned about how your breast cancer treatment may affect your other health conditions. If so, let your doctor know if this is important to you.



Your medications: Many older adults take several medications and supplements to treat or prevent other health conditions. Some medications and supplements may interact with your breast cancer treatments. It is important that you bring all your medications (even non-prescription ones) to a doctor's appointment. It is also important for the doctor to know if you have any problems remembering to take your medications.



Your goals and main concerns: You are the most important person on your breast cancer care team. While the doctor may make recommendations about treatment based on their knowledge, you are the only one who can let the doctor know what is most important to you. You can also ask what information you need to know to make a decision. This section will touch on considerations about your treatment goals and concerns.

TELL YOUR BREAST CANCER TEAM ABOUT **YOURSELF**

Tip: Your answers are very likely to change over the course of treatment and time. You are encouraged to complete this checklist regularly before each follow-up appointment/check-up.

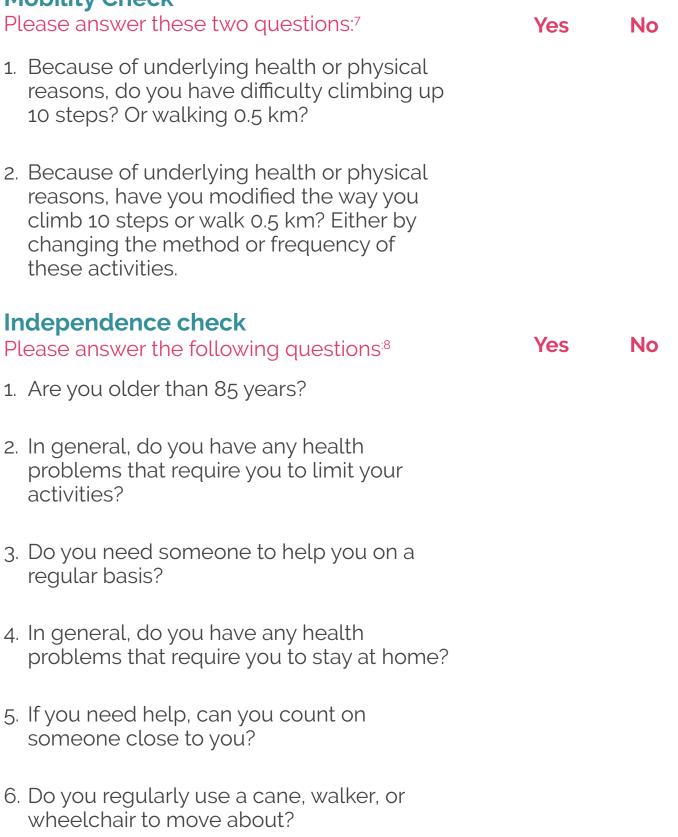
🕙 YOUR MIND **Healthy Aging** How do you maintain your overall mental health? Yes No 1. Meditate 2. Exercise 3. Read or listen to a book/audiobook 4. Listen to music or a podcast 5. Have one or more hobbies 6. Play an instrument 7 Watch TV or go to the movies 8. Other:

Memory Check		Q
Do you have any of the following symptoms? ⁶	Yes	No
 Memory changes that affect your day-to- day abilities 	0	0
2. Difficulty doing familiar tasks such as preparing a meal or getting dressed		
 Changes in communication such as forgetting words or using words that don't fit the conversation 		
 Confused on the day of the week or getting lost in a familiar place 		
5. Not recognizing something that can put your health and safety at risk		
6. Trouble understanding numbers and symbols such as having trouble paying bills		
7. Misplacing things and putting things in places they shouldn't be such as a shoe in the fridge		
8. Changes in mood or behaviour		
9. Losing interest in family, friends and favourite activities		
10. Having trouble seeing things correctly such as having trouble putting a glass on a table		

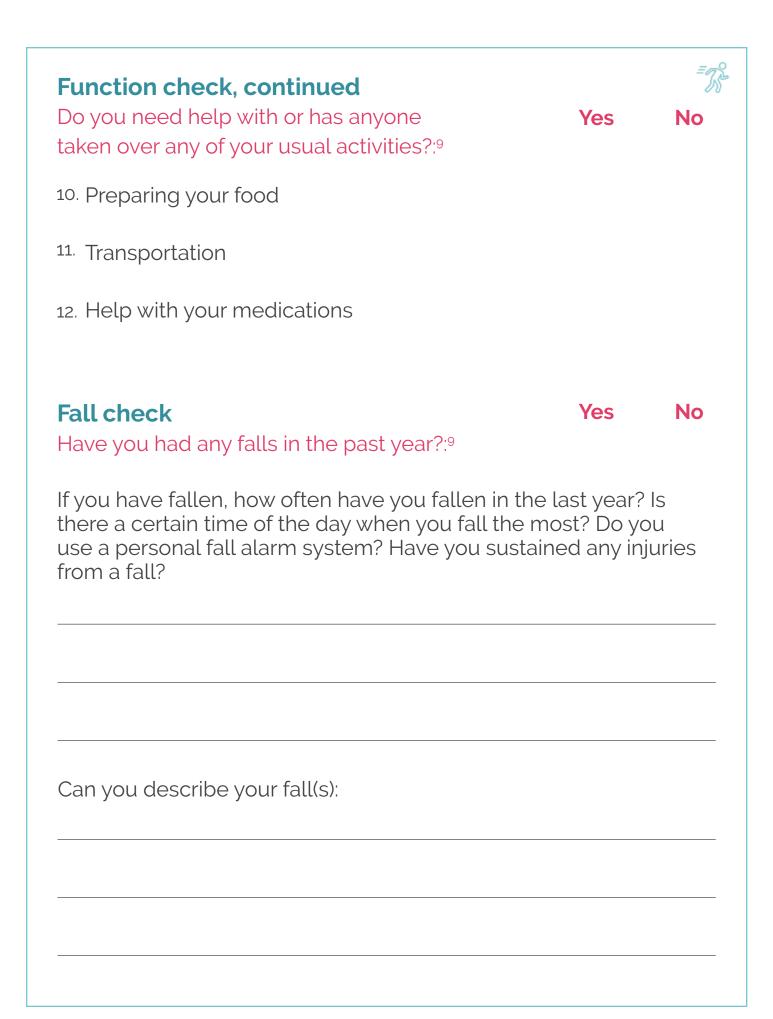
Mood and Anxiety Check				Q
Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days		every
Little interest or pleasure in doing things				
Feeling down, depressed or hopeless				
Feeling nervous, anxious or on edge				
Not being able to stop or contro worrying	l			
Diagnoses Check Have you ever been diagnosed v following:	with any o	f the	Yes	No
1. Depression				
2. Anxiety				
3. Bipolar disorder				
4. Schizophrenia				
5. Substance use disorder				
6. Post-traumatic stress disorder	r (PTSD)			
7. Dementia or Alzheimer's disea	ase			
8. Other:				

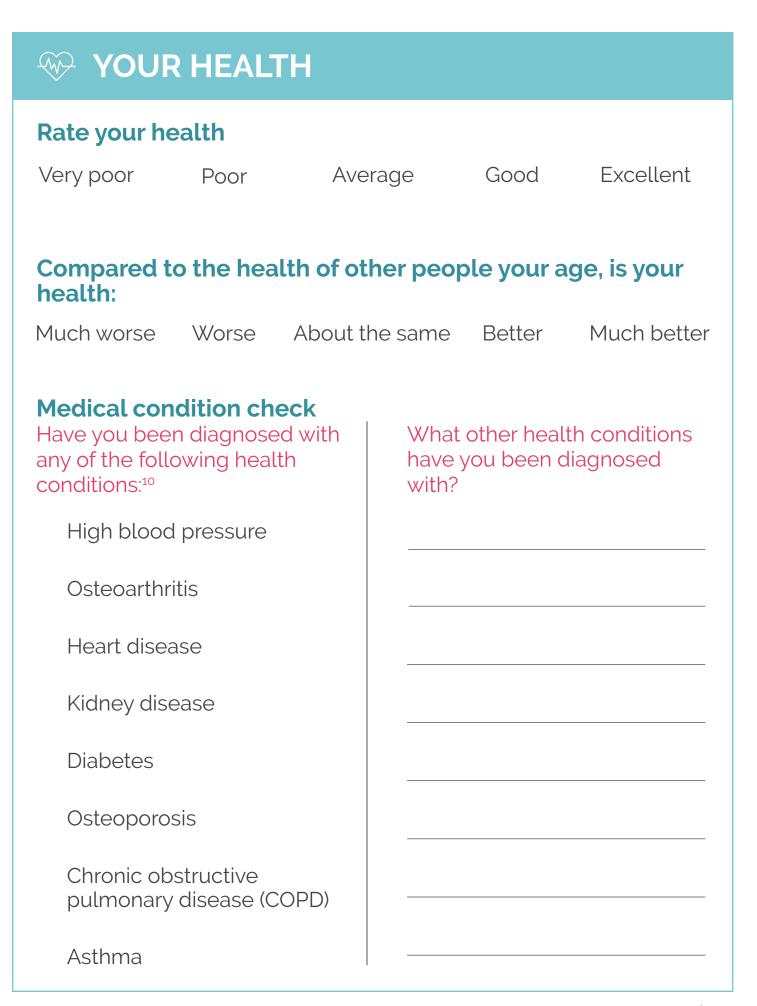
YOUR MOBILITY

Mobility Check



 Independence check, continued Please answer the following questions[®] 7. If you have stairs in your home, can you manage them independently? 8. Do you have other specialized equipment in your home such as grab bars, raised toilet seats, or a bath bench? 	Yes	F7€ No
Function check Do you need help with or has anyone taken over any of your usual activities?: ⁹	Yes	Νο
1. Dressing		
2. Eating		
3. Walking around		
4. Using the toilet		
5. Showering or bathing		
6. Other hygiene activities (for example, brushing teeth, hair care, etc.)		
7. Shopping		
8. Housework including laundry		
9. Paying your bills		





YOUR MEDICATIONS

Please list all the medications that you are currently taking. Please include all prescribed medications, any over-the-counter products, vitamins, herbs or supplements:

YOUR GOALS AND MAIN CONCERNS

When looking at your cancer treatment, what are your

main goals? (This could include things such as long life, living in my home, not being a burden to my family, low or no side effects, better quality of life, low or no pain, etc.)

Main concern check

Please check the top two concerns that you have when treating your breast cancer:

Treatment side effects – short-term

Treatment side effects – long-term

Emotional issues of being diagnosed with breast cancer

The impact of treatment on living in my own home

Impact of treatment on my quality of life

Survival

Other:_____

YOUR CAREGIVERS Getting support from the people that care for you

It may be difficult to ask for and accept help; however, every person with cancer will likely need some help or support from their family or friends at one point or another. These caregivers can offer a range of help like running a few errands to living with you to do everyday activities and being involved with every treatment decision. Caregiver support does not always need to come from loved ones. There are professionals or services that may be able to offer support to you as well. This could include transportation services, personal support workers, nursing care, or social workers.

Caregivers can be very important for older people with breast cancer. The next section will focus on your loved ones as caregivers and what you should know if you are the person with breast cancer or the caregiver to someone with breast cancer.





A good caregiver is important for many people with breast cancer. They may be the only person that knows everything about the person living with breast cancer and can share this with everyone on the cancer team.

What does a caregiver do?

Caregivers provide physical, practical, and emotional support, assisting with tasks that a person may need help with or finds challenging to manage on their own.¹¹ They may need to help with feeding, dressing, bathing, managing household chores, as well as taking over some of the day-to-day duties of the person they are supporting.¹¹ Caregivers may also be responsible for communicating directly to the cancer care team, getting to and from appointments, managing appointment schedules, and managing the post-treatment care and well-being.¹¹

Ideally, it would be great to have a few people that can be caregivers and support the person with cancer.

Why are caregivers so important?

Caregivers are a part of the cancer care team.¹¹ As part of this team, they could help to coordinate your care. They could help with tracking prescriptions and medication, reporting side effects, and maintaining and keeping track of paperwork.¹¹ The role of the caregiver can change along the cancer journey, depending on the treatment plan and the care needs of the person with cancer.

CARING FOR THE CAREGIVERS Taking care of yourself

What does it feel like to be a caregiver?

Whether you're younger or older, you may find yourself in a new role as a caregiver.¹² Despite the challenges of caring for a person with cancer, many people may find personal satisfaction in being a caregiver.¹¹ You might find that caregiving enriches your life.¹¹

Caregiving can also be frustrating and stressful.¹¹ Some caregivers can have trouble sleeping, are more anxious, and can be frustrated by the person's illness.¹¹ You might find it hard to balance taking care of a loved one or providing support from a professional capacity while managing your own responsibilities.¹² Whether you're caring for a parent, a friend, or your partner, it's also not uncommon to struggle with the potential role changes you may face.

It can be a lot of work caring for someone with cancer and it can take up a tremendous amount of time.

If you are caring for an older adult with breast cancer, you will need to work with the person you're supporting and the rest of the care team. They may be very comfortable making decisions about their care, or they may rely on you to help make these decisions. Every situation and relationship is unique. Ultimately, the person living with breast cancer is the driver along their journey, but some may benefit from having a caregiver to help them along the way.



To be successful as a caregiver, you also need to care for yourself. Here are a few tips that you can consider to help you with caregiving:¹¹

- Take a break and have time for yourself: Many caregivers find it difficult to take a break from their caregiving responsibilities. Caregiving all the time can be exhausting and cause other health problems for the caregiver. Even small breaks can help, like going for a walk, exercising, or reading. You can only help your loved one if you are well.
- Ask for help: See if there can be other friends or family that can help to support you or give you a break, even if it is just for a short time. Delegating some of your caregiver responsibilities can help tremendously.
- Your role may change: Some needs of the person you are caring for will improve while others may worsen. Their needs can change over time, which is normal. You may need to anticipate and adapt to these changes.
- Know your limitations: Caregiving can be overwhelming, and some caregivers feel they are all alone. Set realistic limits and let the person you are caring for know your boundaries of what you can and cannot do.
- Find support groups: If you want to talk to someone about the challenges of caregiving and being a caregiver, consider joining a support group. Some caregivers find it very helpful talking to others that are also caring for people with cancer. Ask the cancer care team and the social work department at the cancer centre if there are any groups or individuals you can connect with.

TALKING TO YOUR FAMILY AND FRIENDS ABOUT YOUR DIAGNOSIS

Finding out you have cancer can be overwhelming for you as well as your friends and family. People often don't know how to approach the subject with their loved ones and in turn, their loved ones don't know what to say or how to respond.¹³

While these conversations can be difficult, talking about your diagnosis with people close to you can provide much-needed support. Having the support of someone who cares and is there for you can help reassure you that you are not going through difficult times alone. Moreover, many studies have shown that those who feel supported have reported better quality of life and wellbeing.¹⁴ The table below has some tips for how you can talk to your family, friends and caregivers.

Telling family, friends and caregivers about your cancer diagnosis^{11, 13, 15}

Who do you want to tell about your cancer diagnosis?	Being diagnosed with cancer is a major event in your life. Some people will want to share their diagnosis with everyone, while others would prefer to only let people very close to them know. Whichever choice you go with is okay, and completely up to you.
Determine what you are going to tell them	This can be very hard because you may not have all the answers when you first tell them about your breast cancer diagnosis. It is important to tell them what you know and what you don't know. You can decide how much information or how little information you want to share.

Remember everyone will handle this differently	 There are a wide range of reactions when you talk to someone about a cancer diagnosis. Some will not know what to say and become very quiet. Other people might be confused, shocked, angry, or sad. This is okay. Everyone copes with this type of news in different ways. Let people know that the best thing they can do for you is to be themselves and feel at ease with you.
Tell them how you are feeling about your diagnosis and treatment	 You may already have some thoughts on your diagnosis and the different treatments you may take or may not take. Letting them know can help to make sure they know your wishes about how you want to treat your breast cancer.
Ask them how they feel about the diagnosis	 You can ask them about how they are feeling about your diagnosis. You can ask why they feel this way. You can also consider providing them with pamphlets or websites so they can read more about breast cancer.
Talk to them about the need for help and support	 Even if you are feeling well today, there may be times where you need extra help. Many family members, friends, and caregivers will want to know what they can do to help you. You can explain what you think you may need today and what you may need in the future.

Talk to them about the need for help and support (cont'd)	 Many are eager to help. Try to delegate specific tasks like rides to the hospital, grocery shopping, or getting your medications at the pharmacy.
Remind them to keep talking	 Cancer changes over time and you may feel different over time. It is important that you and your family/ caregivers have an open dialogue about any of these changes.
What not to do	 Don't ignore or neglect a friend or relative who may need to open up and talk with you. However, communicate with your loved ones if you are not feeling up to talking on a particular day. Don't ignore your own needs to talk with someone.
	 Don't set up a "happy face" if you don't really feel that way. While you might tend to try to protect your loved ones by acting as cheerful as possible, it will help you and them more if you share your true feelings.
	• Don't feel that there's a perfect way to talk with others. You'll find that there are times when you feel great about talking and sharing, and other times when you feel that communication is not going very well. Realize that you – and others – are doing the best you can most of the time. And that's good enough.

PLANNING FOR THE FUTURE The importance of advance care planning

It is important to document and communicate your wishes for present and future healthcare treatment, regardless of your age or cancer stage.¹⁶

Advance care planning can help lower the financial, legal, logistical, and emotional burden on your family.¹⁶ It can also ensure that your voice is heard and that you continue to have a say in your future care in case you are unable to speak for yourself. Advance care planning is not just for individuals nearing death and can be considered at the beginning of a breast cancer treatment.¹⁷

Thinking about the future can be stressful. However, the discussions and decisions in these plans will outline the type of care you want to receive, your wishes for different treatments, how you want your cancer symptoms managed, and any religious, spiritual, or cultural considerations. You may never need your advance care plan, but if you do, you'll be glad that it's there.

Advance care planning can seem very stressful but if done correctly it can make it easier for your loved ones and care team to make decisions on your behalf.

There are 5 steps when building your advance care plan. These include:17

- Think about what's right for you: What you value, your wishes, beliefs, and understanding about your care and specific medical treatments.
- Learn about medical procedures: Some may improve your quality of life and others may only keep you alive longer.
- Decide on who is going to make decisions on your behalf if you are unable to speak for yourself: Choose someone who would honour and follow your wishes if you can't speak for yourself.

- Talk about your wishes: It is important that your family and care team know them.
- Record your wishes: Write down or make a video recording of your wishes.

It is important to let your family and caregiver know your wishes about these options and when you would like to consider them. To learn more, visit **Advance Care Planning Canada** (<u>www.advancecareplanning.ca</u>).

Palliative Care, Hospice Care, and Medical Assistance in Dying

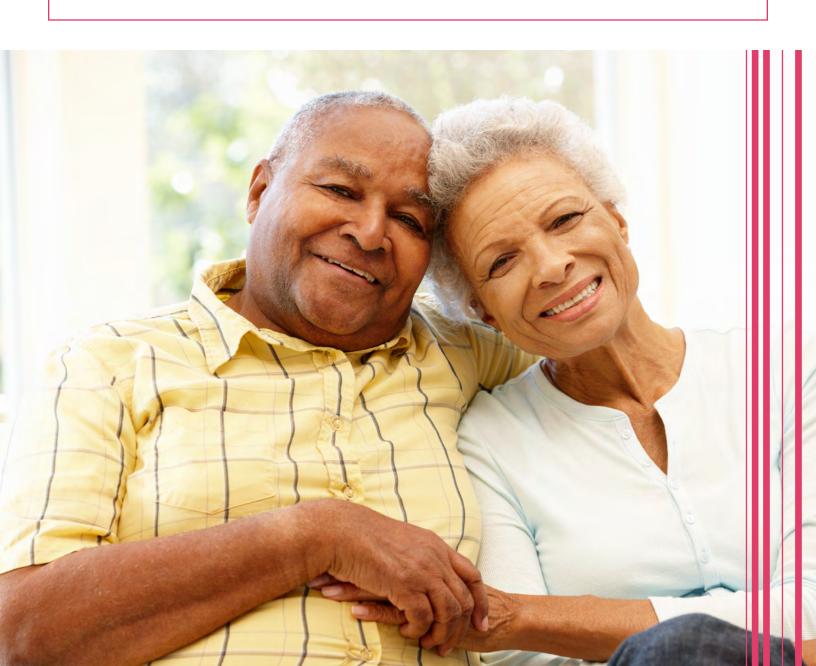
In addition to advance care planning, you can also plan for palliative and hospice care. Palliative care is specialized medical care for people living with a serious illness, like cancer. The goal of palliative care is to improve quality of life, reduce and manage symptoms, and provide holistic support for the individual, their caregiver, and their support network. It can be incorporated into your treatment plan at any time, not just at the end of life.

Hospice care begins when a person is entering the final stages of life. It is designed to relieve discomfort at the end of life. Hospice care can be provided at home or at a hospice facility.

Medical Assistance in Dying (MAiD) is an additional option for some living with a life-limiting illness to consider. This decision is not easy and may not be an option for everyone. If you want to learn more about MAiD, talk to your cancer care team for more information.

To learn more about these options, download **CBCN's Breast Cancer: Talking Palliative Care** (<u>www.cbcn.ca/en/publications-and-</u><u>resources#talking-palliative-care</u>). Being diagnosed with breast cancer, regardless of your age, can cause a rush of emotions and questions.

This resource was designed to help empower you as you navigate your breast cancer diagnosis at an older age. Coping with breast cancer begins with knowing what to ask to get the answers that are relevant to your cancer care journey. The more you understand about your diagnosis, your treatment options, and what you can expect, the more you will be able to participate in your care and make informed decisions about your health.



ADDITIONAL RESOURCES AND INFORMATION

Finding credible resources and relevant information is crucial when dealing with breast cancer. It's important that you have access to safe and accurate information. Below is a list of some recommended websites to consider.

Canadian Breast Cancer Network Resources



Breast Cancer and You: A guide for people living with breast cancer, Seventh Edition <u>www.cbcn.ca/breast-cancer-and-you</u>



Senior Women with Breast Cancer www.cbcn.ca/senior_women



Metastatic Breast Cancer Handbook: A guide for individuals living with stage IV breast cancer www.cbcn.ca/mbc-newly-diagnosedguide



Tips, Advice, and Guidance for the Newly and Recently Diagnosed www.cbcn.ca/publications-andresources#tips-advice-guidance



Breast Cancer: Complementary therapies series www.cbcn.ca/publications-andresources#complementary-therapies-series



Breast Cancer: Side effect management Series www.cbcn.ca/publications-andresources#side-effect-management-series



Advocacy Guide: Palliative care in Canada www.cbcn.ca/advocacy-guides



Breast Cancer: Talking palliative care www.cbcn.ca/publications-andresources#talking-palliative-care



Breast cancer and bone health: What you need to know www.cbcn.ca/breast-cancer-and-bonehealth



End of Life Care www.cbcn.ca/mbc_end_of_life

Other Resources

Canadian Cancer Society

www.cancer.ca

- **Community services locator:** A directory that helps cancer patients, caregivers, and healthcare providers find the services they need such as emotional support programs, homecare, cancer treatment transportation, and more. (<u>https://csl.cancer.ca/</u>)
- Your Emotions and Cancer: (https://cancer.ca/en/living-with-cancer/coping-with-changes/youremotions-and-cancer)

Canadian Coalition for Seniors' Mental Health

www.ccsmh.ca

The CCSMH is committed to improving the quality of care and support for older adults throughout Canada by bridging gaps in knowledge and practice, ensuring that mental health receives the attention it deserves within the realm of aging.

After Breast Cancer

www.afterbreastcancer.ca

Breast cancer can impact body image. This resource provides access to basic needs such as mastectomy bras, mastectomy camisoles, and breast prostheses to women who don't have insurance or are financially challenged.

Advance Care Planning Canada

www.advancecareplanning.ca

Provides assistance with establishing legal authority to manage money, property, and estate on a patient's behalf.

Canadian Virtual Hospice

www.virtualhospice.ca

Provides support and tailored information about advanced illness, palliative care, loss, and grief to people living with illness, their family and caregivers, healthcare provides, educators, and researchers.

Palliative Care Coalition of Canada

www.pallium.ca/palliative-care-coalition-of-canada-pccc

Provides resources to support healthcare professionals in being able to provide a palliative care approach to patients and families.

APPENDIX I - ABOUT CBCN'S 2022 SURVEY

Overall, the survey findings indicate that there are opportunities to improve disseminating information about breast cancer treatment options and care for older adults (aged 65 years and older) who have been diagnosed with breast cancer, particularly in applying the lens of age-related needs and differences from younger patients.

Below are some key findings.

- Survival and long-term side effects were the biggest concerns.
 - Survival (23.8%) and long-term treatment side effects (17.8%) are the top concerns when diagnosed with breast cancer.
 - Family/children (15.8%) and emotional and psychological (16.1%) issues were also major concerns when they were diagnosed.
- Many women, age 65 and older, didn't bring up their concerns to their cancer care team.
 - Only about half of respondents (56.9%) brought up their concerns with the cancer team.
- Improving communication with the cancer care team was a high priority.
 - About half of the respondents were very interested in learning more about how to communicate with their doctor and healthcare team.

Most older women want more information when diagnosed.

- Only about 1 in 3 respondents (36.3%) rated the information they received at diagnosis as very good.
- When asked if they felt they were provided with information needed to make treatment decisions, close to 20% (19.8%) said "no".
- About half of respondents were very interested in learning more about current breast cancer treatment options, new treatments, and latest research.
- About half of respondents were very interested in learning more about the long-term effects of treatment on their health.

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