Life after Primary Gynecological Cancer Treatment: A Guide for Survivors and Caregivers



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This guide was created to help prepare gynecological cancer survivors and their informal caregivers for the transition out of first-line cancer treatment and into recovery and ongoing surveillance. Informal caregivers include the family members and close friends who support survivors throughout their recovery. The idea for this project started in late 2017 after we recognized a gap in support for gynecological cancer survivors in the southeastern Ontario region as they made this transition. These gaps led us to create a guide to support survivors and their caregivers during this period.

Gynecological cancer survivors include people diagnosed with cancer that begins in their ovaries, cervix, uterus, vagina, vulva, or fallopian tubes. In this guide, we identify the most common needs and concerns of gynecological cancer survivors when they complete primary cancer treatment. We also provide information and resources that may be helpful during this transition. The information in this guide is based on scientific evidence about gynecological cancer survivorship care and the expertise of clinicians and researchers. It has been reviewed by healthcare providers with a focus on gynecological cancer and tailored to feedback from gynecological cancer survivors and their caregivers.

This guide is intended to be used at various points in cancer recovery. As such, it is not necessary to read through the entire guide all at once. Chapters 1 to 6 each focus on one dimension of recovery. Chapter 7 includes a comprehensive list of resources. Survivors and caregivers should feel free to access any relevant information within this guide as needed.

INTRODUCTION FOR SURVIVORS

You have achieved a significant milestone in your cancer journey: you have completed primary cancer treatment. You may expect to return to your life as it was before your cancer diagnosis. But it is important to understand that "returning to normal" takes time and differs from person to person. You may still have physical and emotional effects from cancer and/or its treatment that can make it challenging for you to return to your former activities. Some of these side effects may disappear over time in the natural course of recovery. However, others may require medical treatment or additional strategies to help. Some may become chronic conditions and you may need to adapt your expectations for recovery.

Recovery after cancer treatment can be a slow process. Your cancer journey may have included surgery, chemotherapy, and/or radiation. You may continue to receive medications intended to prevent a recurrence. Your age may impact the type of issues you face, as young adult survivors (age 19–39) commonly face different issues than older adults (e.g., fertility issues). All of these things contribute to how long your recovery will take.

This guide highlights the most common issues you may face during your recovery. It can help you to be better prepared about what to expect after treatment and how to deal with any long-term effects. The guide has been designed to be used as a resource throughout your recovery, so feel free to reference specific chapters and resources as needed. You may find that every time you refer to this guide you find new information relevant for you (e.g., how to identify possible concerns to address at medical appointments). You may also find that some information does not apply to you (e.g., something specific to another age group).

This guide is for you—please use it however it suits you best.

[&]quot;I have now finished surgery, chemotherapy, and radiation; I'm done, according to the medical profession. But I don't really feel done. I think we survivors are never truly done. We just move from the quantifiable, treatable disease to the immeasurable uncertainty of survivorship. Believe me, the former is easier to deal with sometimes." ~ Cancer Survivor³

INTRODUCTION FOR CAREGIVERS

Having a loved one receive a cancer diagnosis and go through treatment can be as traumatic to the caregivers as it is for the patient. Although your loved one has finished primary cancer treatment, the cancer experience can still affect both of you. In fact, approximately half of caregivers report at least one unmet need during the recovery period after gynecological cancer. Caregivers also frequently report psychological distress related to this experience, and they want more information about how cancer and its treatment can affect survivors.

This guide highlights the most common ways cancer and its treatment can impact survivors during the recovery period. As a caregiver, you can use this information to better understand what your loved one is experiencing. But the cancer experience is challenging for everyone involved, *including you*. In <u>Chapter 7</u>, you will find a list of resources, some of which are specific to caregivers of cancer survivors. We hope you will use these resources not only to help you support your loved one, but also to take care of yourself.

[&]quot;I was confused [...]. I could not balance between care and other responsibilities. Due to lack of knowledge, I did not know what to do." ~ Cancer Survivor Caregiver²

[&]quot;It was just like a treadmill, everything was suddenly...happening...there were a lot of miscommunications along the line..." ~ Cancer Survivor Caregiver³

THE SIX DIMENSIONS OF RECOVERY

Gynecological cancer survivors have different needs and concerns after completing cancer treatment. These issues can vary widely, but the most common fall into six dimensions:

Physical Health: Many survivors may not be prepared for what could be the long-term physical consequences of cancer and its treatment, which can include changes in cognitive and bodily functioning. However, knowing what to expect can help you feel more prepared and understand how to manage your symptoms— it can also help you decide when you need support and where to find it.

Emotional and Psychological Well-Being: At the end of treatment, many cancer survivors experience emotional and psychological concerns and may not receive adequate support. Being aware of these concerns can make it easier for you to monitor your well-being and know when you need to get support.

<u>Sexual Health</u>: Many survivors have sexuality-related concerns after finishing treatment. Changes in sexual functioning may affect your relationships, level of intimacy, and quality of life. Your healthcare team can support you with any concerns you may have, just like with any other side effect of cancer and its treatment.

<u>Altered Self-Image</u>: Gynecological cancer treatments can result in body changes (e.g., how the body functions) that may leave survivors with an altered view of themselves. These altered self-images can be significant and challenging, so it is important that you receive attention and support for these concerns, if you have them.

Social Support: Cancer and its treatment may change how you interact with others, including your partner, family members, friends, and colleagues. Some cancer survivors report feeling abandoned by their existing social network after treatment is completed. You may find you want to connect with others who have had similar experiences as a way to help you through your journey

Return to Work: After completing cancer treatment, some people want to return to work for socialization, routine, or financial need. However, many people find that returning to work is more challenging than expected, so becoming aware of the possible issues is important to consider before taking this step.

The six dimensions of recovery can impact you in unique ways and influence your overall health outcome. The dimensions are also interconnected, so you will find some overlap between the sections of the guide.

In the next sections, we explore each of the six dimensions and provide strategies that can help you in your cancer recovery journey.

Before considering the specific elements that may impact the quality and length of your recovery, we'd like to encourage you to:

- Treat yourself with kindness and compassion.
- Reach out to others who may share your experiences and issues.
- Ask for help when you need it and accept the help that is offered.

It is important for you to keep your healthcare team informed on your progress and up to date on any issues you experience as you move forward in your cancer recovery. The healthcare team is complex and the best professional to assist survivors may be different for each patient and/or issue. Your primary care provider may be the best person to help you manage some of your overall concerns, while your oncology team stays focused on cancer-specific issues. So it is essential that you have a discussion with your oncologist and/or your primary care provider about who is the best professional to support each challenge you face during your cancer recovery. To help you better understand the main healthcare professionals involved in your recovery process, refer to Figure 1.

Figure 1. The Healthcare Team



Note: In Chapter 7, you will find a <u>fillable version</u> of this figure where you can add the contact information of your healthcare team to use as a reference.



Cancer and its treatment affect your body in many ways. You may expect that you will have a total recovery and will return to the life you had before cancer, but this is not always the case. While most symptoms and side effects will disappear over time, some can last long after treatment is finished. Some of your side effects may even become chronic conditions. You may need to adapt to a "new normal" that does not include all the physical abilities you had before your cancer diagnosis. Any differences between what you expected after cancer and your reality may cause disappointment, anxiety, and even anger. Therefore, it is important that you know what to expect and learn how to manage any ongoing side effects.





"EIGHT IN TEN

people had physical challenges after their cancer treatment ended."⁴

"I don't think they can prepare you other than just saying you are having a life-changing treatment and you're not going to be the same person when you come out of this" ~ Cancer Survivor⁵

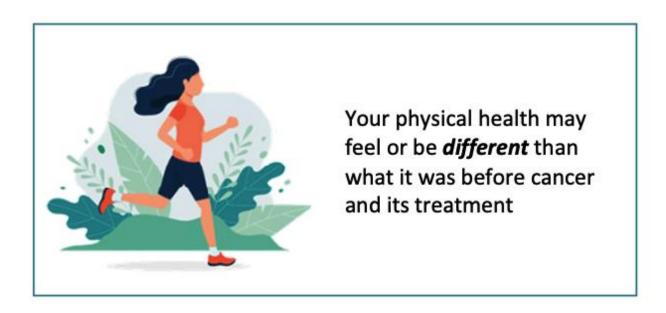
These are **some** of the physical side effects that you may experience from your cancer and/or its treatment:

- fatigue (which may be chronic)
- insomnia (e.g., difficulty falling and/or staying asleep)
- bowel dysfunction (e.g., diarrhea, constipation)
- gastrointestinal problems (e.g., nausea, vomiting)
- menopausal symptoms (e.g., hot flashes)
- neuropathy (e.g., tingling and/or painful sensations in your hands or feet)
- cognitive changes (e.g., chemo brain)
- changes to hair and skin condition (e.g., scarring, hair loss)

- changes to pulmonary functioning (e.g., changes in your lungs)
- urinary dysfunction (e.g., urinary leakage, retention)
- lymphedema (e.g., swelling in extremities)
- weight changes (e.g., weight gain or loss)
- joint and muscle discomfort
- loss of hearing and vision

Reflection

- Have you experienced any of these symptoms? How have they affected your quality of life?
- Have your symptoms become chronic (lasting more than three months and/or without any signs of improvement)? Are the symptoms worsening despite your efforts to address them?
- Have you talked with your healthcare team about these symptoms and how they are impacting you?



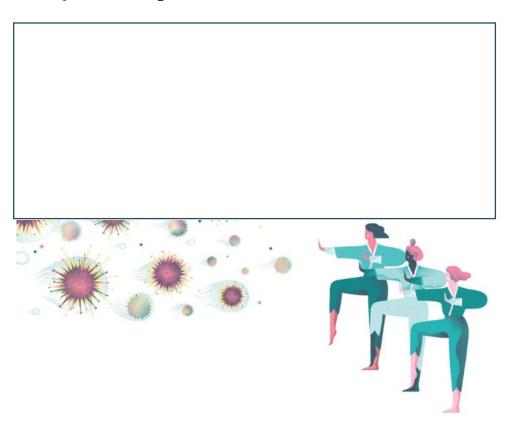
"It's an effort for me to get through the day. When I wake up in the morning, it is as if the night already falls." ~ Cancer Survivor⁶

Here are some strategies that may help you optimize your **physical health**:

- Be patient and monitor yourself. Recovery can be a long process. Many effects of treatment will disappear very quickly, while others may remain for months or years, sometimes becoming chronic conditions. Be patient, but monitor the issues that impact your quality of life.
- When issues come up, talk to your cancer care team. Your team is expert in treating cancer, but other professionals can help with any challenges you face after treatment. Ask who can best support you, and be prepared for referrals. You may be asked to contact your family physician, who may refer you to a specialist as needed.
 - For example, if you experience gastrointestinal issues, you can ask your healthcare team to arrange a referral to the nutritional team at the cancer centre or through your family doctor. They can assess your current eating habits and work with you to improve your gastrointestinal functioning and health.
 - Some physical symptoms may impact your daily functioning (e.g., your ability to go up and down stairs or dress without assistance). An occupational therapist can assess your situation and offer recommendations and aids to support you. Information about how to find an occupational therapist (and self-refer) can be found in the in Chapter 7 of this guide.
- Add physical activity to your day.
 - Daily exercise is considered a primary method to support recovery. You can start with a simple walk, then increase the time and intensity as you are able. Just being in the fresh air and moving will help strengthen your muscles and can help you feel better.
 - Aerobic and resistance exercises, such as biking, resistance training, walking, and using weights, can decrease tiredness, pain, shortness of breath, and insomnia.
 - Mindfulness-based strategies, such as yoga, art therapy, and meditation, can help to train your mind to be present in each moment. These practices can help reduce psychological distress, fear of cancer recurrence, fatigue, pain, and sleep disturbances.^{8, 9}

- The practice of Tai Chi, a Chinese martial art practice involving slow and controlled movements, can help reduce fatigue and improve sleep.¹⁰
- Include music in your recovery. Listening to a style of pre-recorded music that you enjoy can be useful to relieve symptoms and help with pain management .^{11, 12}

You can find more information and resources to support these physical health strategies in <u>Chapter 7</u> of this guide.



"I think it is twofold, it's not just about the exercise, it's about your mood and if you're exercising a little bit more, you're a bit more active, your mood will lift a bit more, and it also takes you out of thinking about it all the time and you feel like you're achieving something and it's like, for me, it was very important to feel like I was doing something to get myself well again." ~ Cancer Survivor¹³



You should always contact your **healthcare team** for advice on which strategies are best to support you in your journey. Your healthcare team can evaluate your needs and provide a referral to other professionals who can help. For more information on the healthcare team, refer to Figure 1 in the Introduction section of this guide.

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CHAPTER 2: EMOTIONAL AND PSYCHOLOGICAL WELL-BEING

Cancer and its treatment can affect your emotional, psychological, and spiritual well-being in different ways. Survivors describe some common issues they face as they transition out of primary cancer treatment: challenges with emotional well-being; a lack of support for follow-up care needs; and feelings of anxiety, fear, stress, and anger.





people reported having emotional concerns after their cancer treatment ended."⁴

Psychological well-being refers to your mental health and overall functioning related to your feelings.

Emotional well-being is your ability to process situations, handle stresses, adapt to changes, and produce positive emotions from those situations.

Spiritual well-being_can be defined as your capacity to integrate meaning and purpose into your life; this could include connectedness to nature and music, and even a sense of a power greater than your self.



If you fear a cancer recurrence, you are not alone. Fear of cancer coming back is one of the most common concerns reported by cancer survivors.

- It can start during the transition from cancer treatment to the surveillance period, which can leave some survivors feeling abandoned.
- It can generate stress and anxiety due to the uncertainty related to the future and constant worry about monitoring for symptoms that can be a sign of recurrence.

Additionally, the fear of cancer recurrence can be "triggered" in different situations:

- around the anniversary of cancer diagnosis
- when hearing about others' cancer experiences
- when attending healthcare appointments and medical tests

Fear of recurrence can also be an ongoing concern that significantly impacts your everyday life.

Signs of possible cancer recurrence are many and can vary according to the type of cancer. Some of the most common signs and symptoms are the persistent presence of:

[&]quot;It has been a constant fear and worry because I don't know when or whether the cancer will come back or not." ~ Cancer Survivor¹⁴

- abdominal bloating or pain
- pelvic pain
- pain during intercourse
- unusual vaginal discharge
- constipation or diarrhea



These are only **some** of the symptoms that may indicate a recurrence. You could also have these symptoms for reasons unrelated to a cancer recurrence.

If you have any of these symptoms and they persist, it is important to talk to your healthcare team about assessments and/or treatments. Knowing the possible signs of recurrence and who to contact if you experience them can provide some sense of relief for you and reduce your fears about recurrence.

"'We established a volunteer group and provide services at the gynecologic cancer clinic. We share our experiences with cancer. I told them that I was in Stage III, so don't be afraid. I have been living without recurrence for almost ten years. I want to give them confidence."

~ Cancer Survivor¹⁵

Feelings of fear and anxiety are common emotions of survivorship, and living with uncertainty is never easy. Some people find it helpful to acknowledge these emotions. You don't need to go through these feelings alone.

Besides the fear of cancer recurrence, you may encounter other post-treatment emotional and psychological experiences (there may be more not included here):

- Feelings of abandonment. It is common to feel abandoned as you transition out
 of active cancer treatment, where you had many appointments and different
 healthcare providers involved in your care, to cancer surveillance, where you
 may have fewer appointments and see fewer professionals. Many survivors find
 this process difficult as it can generate fear related to uncertainty about the
 future.
- Spiritual distress. Experiencing a serious illness like cancer may alter your sense
 of spirituality. Coping strategies can include spending time in nature,
 connecting with yourself through music or literature, or whatever helps you to
 connect with your sense of spirituality. Your sense of spirituality may or may not
 relate to religion.
- Expectations about returning to "normal." If your expectations are not met, it can generate uncertainty about how the future will be.

- Fear that ongoing side effects from cancer and its treatment will not disappear and may become chronic conditions.
- Concerns about the hereditary risks of cancer and how it may impact your children and other family members.
- Feelings of being a burden to family and friends.
- Feeling a loss of control over life and the future.
- Fear of death.

Reflection

- Have you ever reflected on if/how cancer may be impacting you and your life after finishing cancer treatment?
- What has helped you cope with any psychological challenges that you may have from cancer and/or its treatment?
- Have you considered whether some of these challenges may need professional help? Have you ever discussed your concerns with your healthcare team?

"I think once you allow yourself healing time, a few months, that after that you can do anything you want." ~ Cancer Survivor⁵

Here are some strategies that can help you manage your **psychological well-being**:

- Talk to your healthcare team.
 - Discuss possible side effects you could experience from cancer and the treatment you received.
 - o Confirm what an ongoing surveillance plan should include:
 - frequency of follow-up
 - tests to be done
 - what to look for as possible symptoms of recurrence
 - when and who to call to discuss health matters that may be related to cancer
 - when and who to call if side effects are not improving or are worsening

- Ask about genetic testing that might be available to determine any predisposition to gynecological cancer (e.g. risk of cancer for other family members).
- Let your healthcare team know about any emotional challenges you may be facing. Ask about possible referrals to a specialist, especially if your emotions are overtaking your daily enjoyment of life.
- Keep informed about new treatments and diagnosis developments in cancer. This knowledge can promote security and confidence about treatment effectiveness and new options.
- Practise Mindfulness. Mindfulness and other relaxation techniques can be helpful to cope with the emotional aspects of cancer, such as anxiety, depression, or stress.
- Find peer support. You may want to reach out to other survivors for encouragement and support. Shared experiences can help alleviate the feeling of being "the only one" and often provide solutions to managing difficulties (refer to Chapter 5—Social Support for more information).
- Use reflective strategies. Reflection can support improvements to your psychological well-being.
 - If you have feelings of uncertainty about the future, it can be helpful to realize that there are situations you can control and those you cannot.
 You may want to try to let go of things you can't control and save your emotional and physical energy for the things that you can control.
- Take action. If you experience feelings of anger, it can help to channel these
 feelings constructively. You could get involved in supporting others, raise funds
 for research, or participate in other activities that are meaningful and enjoyable
 to you.

You can find more information and resources on how to support your psychological well-being in Chapter 7 of this guide.

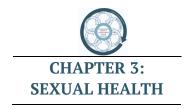
You may also find your own resources to support your psychological and emotional well-being. These can include reading books about other cancer survivors' experiences, going to workshops at cancer centres, or using information from reputable sources on the Internet. You may need to try a few resources before you find one that works for you. It is important that you are mindful of the quality and trustworthiness of the resources you are using, and you can always ask your healthcare provider's opinion.

"I didn't know when I signed up [that] mindfulness meditation was a huge part of it. I'm a huge cynic, if you told me that before, I probably wouldn't have signed up. Unequivocally the best thing I ever did." ~ Cancer Survivor¹⁶



You should always contact your **healthcare team** for advice on which strategies are best to support you in your journey. Your healthcare team can evaluate your needs and provide a referral to other professionals who can help. For more information on the healthcare team, refer to Figure 1 in the Introduction section of this guide.

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After gynecological cancer treatment, you may experience changes that affect your sexual relationships. Sexual-related concerns can negatively impact relationships and intimacy and, if not treated, can significantly influence your quality of life. No matter what type of sexual relationship you are in, sexual changes after cancer are important to discuss with your healthcare team, just like any other post-treatment side effects.



Sex is often defined as the act of having intercourse, but it can also include activities such as kissing, cuddling, and oral sex.

Sexuality encompasses your feelings, beliefs, and the ways you express yourself as a sexual being; it can include social, physical, spiritual, cultural, and emotional elements.

Intimacy involves your connectedness with another person, and it can involve physical affection, care, and love.

Every person's needs are unique, especially when considering sex, sexuality, and intimacy. You may find it helpful to consider your sexual life before and after cancer treatment so you can better understand how cancer may have affected your sexual health.¹⁷



"EIGHT IN TEN

As many as 85–90% of gynecological cancer survivors reported sexual disturbance after treatment ended."¹⁸

Here are **some** commonly reported sexual health concerns (**there may be others not included here**):

- painful sex
- vaginal dryness
- lack of interest in intercourse and intimacy
- decreased arousal
- vaginal shortening/narrowing
- reduced ability to achieve orgasm
- post-coital bleeding (bleeding after intercourse)
- fear and anxiety about sexual intercourse

Reflection

- When you compare your sexual activity now and before cancer, do you think cancer has affected your sexuality and/or intimacy?
- If cancer has affected your relationship and intimacy with your partner, have you discussed that with them?
- If cancer has affected your sexual health, have you discussed this with your healthcare team?
- What are your goals for your sexual health and intimacy?

Although sexual health concerns among cancer survivors are very common, they are frequently underdiagnosed and undertreated. There are different reasons for this:

- Some survivors may feel uncomfortable discussing this topic.
- Some survivors may not know how to start this conversation with their healthcare team.
- Some survivors may believe that these concerns are insignificant in comparison to others issues they are facing.
- Some survivors may expect their healthcare provider to ask them about their sexual health.

If you notice changes in your sexual life after cancer, it can be helpful to share these concerns with your healthcare team so they can support you during your recovery. If you find it difficult to talk about sexual matters, you are not alone! But there should be no embarrassment around these issues. **Sexual health concerns deserve attention just like any other side effects of cancer and its treatment**.

"I hardly want to have intercourse. I feel that my sexual desire is not only decreased but also lost. My husband touches and cares me, but I feel nothing. This situation also causes my husband to feel himself bad." ~ Cancer Survivor¹⁹

Before talking with your healthcare team, considering talking with your partner. What is important to both of you when it comes to intimacy and sexual health? Many people find it challenging to talk about sex with their partner--not just cancer survivors! You can find some tips to help you with these conversations in the strategies that follow.

Here are some strategies to help you manage your **sexual health** concerns:

- Complete a self-assessment. Think about how your sexual health was before cancer versus now, and consider if/how those changes may have impacted your sex, sexuality, and intimacy.
- Talk to your partner. You may want to start with what you each value about sex and why that is important for your relationship. If you feel uncomfortable talking about sex with your partner, you are not alone. Many cancer survivors find it challenging to talk about sex with others, including their partners.
 - If you haven't talked with your partner yet, but you want to, here are some questions you can use to start the conversation:
 - What do you value about sex?
 - What does our sexual relationship mean to you?
 - What do you enjoy most about our sex life?
 - What might be hard about trying new things?
 - How should we talk about what works and what doesn't work for us?¹⁷
 - When you and your partner understand what sexual well-being means to you and what you both value about sex, you are better able to identify concerns and come up with solutions.

- Talk to your healthcare team. If you still feel unprepared to have this conversation with your partner, you can ask for support from your healthcare team. They are well-positioned to help you to access any needed resources, especially because some of the concerns you are facing may need medical treatment. They can refer you to a sexual health clinic where you can receive one-on-one counselling.
 - It is normal if you don't feel comfortable beginning this conversation with your healthcare team. Here are some questions you can ask them:
 - When will I feel the desire to have sex again?
 - It hurts when I have sex, why?
 - What can be done about this pain?¹⁷
- Try supportive therapies. As part of your follow-up care, you may be referred to your family physician or a specialist who may offer the following supportive strategies:
 - The use of lubricants and moisturizers, physical therapy, or endocrinal medications.²⁰
 - Vaginal dilators, which may be used after primary treatment to gently stretch
 the vagina and prevent narrowing over time. You can find additional resources
 on the use of dilators in Chapter 7. Also, if the use of dilators is somehow
 negatively impacting your sexual health, you can always contact your
 healthcare team to adapt your treatment.
 - Sexual health therapy and education to improve your sexual health and reduce concerns about sex and intimacy after cancer treatment.²¹⁻²³
- Find peer support. If you feel comfortable sharing your feelings, a peer support group can provide a safe space to talk about your experiences and hear the experiences of others who may be facing similar issues.

You can find more information and resources related to sexual health in <u>Chapter 7</u> of this guide.

"My vagina had shortened; there was dryness as well. We could not have intercourse, after each time we tried, my husband felt bad, he got frustrated and angry. I was having therapy, the therapist wanted my husband to participate as well, but he did not come. Finally, he was persuaded. Now, that we have overcome the problems, my husband accepts the situation. We now try different positions. I also use climara (that is the name of the medicine with estrogen), and there is no dryness anymore." ~ Cancer Survivor 24

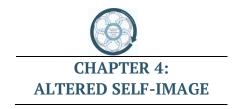
Fertility can be also be affected by cancer and its treatment, a problem that can be particularly distressing for younger survivors. Your healthcare provider may not be aware of your fertility concerns, so it is important to discuss these issues with them as soon as possible. Some cancer treatments may lead to infertility, but there options you can explore (e.g., adoption, surrogacy) if you want to be a parent. You can find more information about all the options by consulting with your healthcare team (e.g., social worker, family physician).

"I thought that my choice might have been taken away. That was it....at the time we weren't thinking we'd have another one [child] but I wanted it to be my choice." ~ Cancer Survivor²⁵



You should always contact your **healthcare team** for advice on which strategies are best to support you in your journey. Your healthcare team can evaluate your needs and provide a referral to other professionals who can help. For more information on the healthcare team, refer to Figure 1 in the Introduction section of this guide.

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After cancer, you may feel different and have a different relationship with your body, both in how you believe you appear to others and how your body functions. Some survivors may feel empty or incomplete because parts of their reproductive organs have been removed as part of their cancer treatment. Others may experience changes in their femininity, self-worth, and relationship with their partner.



"SIX IN TEN

As many as 58% of people reported having negative body image after their treatment ended."²⁶

Self-image can be defined as how you see your body and your ability to function. This "image" is influenced not only by the way you look, but also by your mental well-being, your body's functioning, and your interactions with your environment.

Self-identity is how you identify and define yourself, which can be influenced by your body image, but it can also involve broader aspects such as your abilities, social interactions, life experiences, and illnesses.

"There was life before cancer and life after cancer."

"It defines you because you are now viewing another dimension of your humanity."

~ Cancer Survivor²⁷

When survivors face disturbances related to their self-image and self-identity, it can be difficult for them to recognize themselves. For instance, if cancer and its treatment have affected your body functioning, you may not be able to do things that you did before. Or you may feel like you're not the same person you were before cancer. This is a shared feeling among some other survivors.

These are some of the post-treatment effects that may affect your self-image (**there may be others not included here**):

- loss of fertility
- hair loss
- weight gain/loss
- scarring
- skin changes (e.g., redness, sensitivity)
- disfigurement or loss of reproductive organs
- physical debilitation (e.g., loss of balance, muscle weakness)

Reflection

- Has cancer and its treatment affected your self-image or self-identity? Do you think these changes are affecting your quality of life?
- Have you tried any supportive resources to help?
- Have you asked your healthcare provider about what actions or resources you could for support?



"All organs related to my femininity were lost. I feel no longer as a woman. [...] I even avoid talking about femininity. It seems to me as if everyone watches me due to my incompleteness and so I always want to be alone."

~Cancer Survivor¹⁹

You may think body image and self-identity concerns are not important when compared to the rest of your cancer journey, but these can be real and need attention and support. If not addressed, they can have a negative effect on your relationships with yourself and others, as well as on your quality of life. It is important to be aware of some strategies that can help you manage your perceptions of body image and self-identity on your recovery journey.

If you have concerns about your **self-image and self-identity** during your recovery, here are some strategies that may help:

- Complete a self-assessment. It can be challenging to identify whether or not you have an altered self-image and/or identity, but doing a self-assessment may help you identify potential concerns. Think about how you felt before cancer and its treatment versus now. Consider your relationship with your body and your sense of yourself as a human being. Have these changed? Have they changed in a positive or negative way? Are any changes impacting the way you feel and the way you live your life?
- Talk to your healthcare team. Once you have a better idea about possible concerns related to your sense of self, you can look for support and resources from your healthcare team. You may notice that you are not able to specify what your concerns are because issues related to body image and self-identity are subjective and difficult to describe. But once you know that something is different or not feeling right, your healthcare team may be able to help you pinpoint the concern and support you (e.g., referral to a specialist).
 - Your healthcare team may be able to refer you to a sexual health clinic (refer to the Resources section in Chapter 7 for more information). The staff in these clinics offer individual counselling to help you deal with body image disturbances after cancer and its treatment.

• Try psychotherapy.

- Cognitive behavioural therapy can help you understand why you see yourself the way you do and help you find new ways to think about yourself.
 Participating in this type of therapy may help improve your sense of body image and how you feel about your body.
- Psychosexual therapy is specific counselling that can help you address sexual concerns with your partner. It may also improve your perception of your body image and sexual satisfaction.²⁸
- Add physical activity to your day. Participating in exercise programs (e.g., gym classes, running) may contribute to feeling healthy and improve your self-confidence.²⁹

You can find more information and resources related to self-image in <u>Chapter 7</u> of this guide.



You should always contact your **healthcare team** for advice on which strategies are best to support you in your journey. Your healthcare team can evaluate your needs and provide a referral to other professionals who can help. For more information on the healthcare team, refer to Figure 1 in the Introduction section of this guide.

Notes:			



Cancer and its treatment may change your interactions with others. This can include interactions with your partner, family members, friends, colleagues, and others. When going through cancer treatment, some people distance themselves from others so that they can focus on their treatment and health needs. However, when treatment is finished and they don't need to attend as many appointments, some survivors experience a feeling of emptiness or loneliness and may find it difficult to restore their interactions with others.



"I thought I would feel happy about finally reaching the end of treatment, but instead, I was sobbing. [...] I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned."

~ Cancer Survivor³

These are some changes you may experience around social support (**there may be others not included here**):

- the amount of emotional support you receive, such as conversations and expressions of love, spending time with friends or family, and receiving care and empathy
- the amount of help you receive from people, which may include help with daily activities, cleaning the house, and child care
- the amount and/or frequency of information you receive, such as advice and suggestions from people who are close to you and your healthcare team (e.g., related to side effects)

These changes can be either positive or negative. Some survivors believe that cancer has negatively impacted their relationships by decreasing their communication and contact with others. Other survivors believe that cancer has increased the strength of their relationships and the amount of support they receive from others. The end of treatment, when survivors are "cured" and do not need as many healthcare services as before, may also generate feelings of emptiness and abandonment.

Overall, survivors report the continued need for social support throughout their cancer recovery and want to connect with others who understand their experiences. This support can be received from different people, in different ways:

- peer support (support from people who share similar life experiences, such as other cancer survivors)
- professional support (support from professionals who help meet your needs, such as nurses, social workers, and financial advisors)
- group support (support from people who share a common interest or concern, such as group support for fear of cancer recurrence among survivors)
- family support (support received from family members, such as a partner)

Cancer survivors who have better social support usually have better health outcomes,³⁰ so it is important to manage any changes after cancer treatment. You don't need to go through this alone!

Reflection

- What impact has cancer and its treatment had on your social interactions?
- Who has been your greatest source of support throughout your cancer journey? What aspects of their support have you found most helpful?
- Are there any activities that you are comfortable doing to improve your social support?
- Have you asked your cancer team to connect you with local support groups and other resources? What is available at your cancer centre or in your community?

Here are some strategies that may help you to maintain or expand your **social support**:

- Acknowledge your boundaries. Cancer can be an extremely stressful experience, and you should have a safe place to share your feelings, experiences, and challenges. Sometimes you may feel uncomfortable talking about your cancer journey, so it is important that you share it within your comfort level and with people you trust who care about your well-being. If you do not feel comfortable sharing information about your cancer journey with someone, that is okay! You can let them know that you will only share information if and when you feel it is the appropriate time.
- Choose your support network. Friends and family members can be a great source of support during your cancer journey. Even though some of your relationships may have changed after cancer, restoring those that are important to you can help you regain a sense of normalcy. Friends and family members can help you maintain emotional stability if you go through any post-treatment challenges.
 - You may need to balance your expectations with the people around you.
 Don't be afraid to talk to your friends and family about what you need from them. Many times, you may just want someone to listen to your concerns and not fix them for you. It is okay to let people know this.
- Find peer support. Connecting with others who have experienced similar issues can be a great source of support and information. It can be comforting to know you are not alone. Being part of a peer support program (locally or online) can give you a safe space to share your story with others who have faced a similar journey, and it can be a great social support for people living with and beyond cancer.³¹

You can find more information and resources related to social support in <u>Chapter 7</u> of this guide.

"To hear somebody else who was a survivor have the same feeling that you have just solidifies that your feelings are not abnormal... that you are not alone... that there's others that are the same" ~ Cancer Survivor¹⁶

"When life is difficult, a companion who shows concern is good help. An arm and a hug are better than any words." ~ Cancer Survivor 32



You should always contact your **healthcare team** for advice on which strategies are best to support you in your journey. Your healthcare team can evaluate your needs and provide a referral to other professionals who can help. For more information on the healthcare team, refer to Figure 1 in the Introduction section of this guide.

Notes:			



The effects of cancer and its treatment can be demanding and so you may have decided to stop working for a time. But now that you have finished active treatment, you—like many other survivors—may be looking forward to returning to work. There are several reasons you may want to return to work:

- social interaction
- personal fulfillment
- financial need or reward
- increased self-esteem
- a sense of normalcy following cancer
- other reasons



"FOUR IN TEN

people reported having practical challenges after their cancer treatment ended [e.g., returning to work]."4

Going back to work can create unique and individual challenges. The way your cancer and treatment have affected your body may leave you unable to work as much or as effectively as you did before.

There are some commons aspects that make it challenging for cancer survivors to return to work are (**there may be others not included here**):

- fatigue
- difficulty concentrating
- reduced confidence
- physical limitations (e.g., lymphedema, neuropathy)
- cognitive impairment (e.g., chemo fog)
- fear of disclosing diagnosis
- fear of stigma

Reflection

- How has cancer and its treatment affected your ability to work?
- What are some positive things about returning to work? What are some negative things about returning to work?
- If you want to return to work, when do you think would be a good time? What resources do you need to support you? Have you asked your healthcare team or employer how to get these supports in place?
- If you won't be returning to work, have you considered what supports you will need (e.g., emotional, financial)? Have you asked your healthcare team or social worker about how you can access these supports?



"I definitely think going out every day, whether it is hard or not hard, definitely gives you a purpose and it gives you a sense of, you know, how it was before. It just gets everything back into perspective and back to living a proper life, otherwise, you'd just be living in what you've had done and what you're going through." ~ Cancer Survivor

Returning to work can be a very important and empowering step for some survivors, but the physical, cognitive, emotional, and psychological consequences of cancer and treatment can make this process difficult. However, with preparation, planning, and support, you can overcome these obstacles and facilitate your return to work.

It is important that you work with your employer and healthcare team to create an effective and manageable return-to-work plan. Here are some strategies to help you if and when you **return to work**:

- Talk to your employer. It is important to discuss any workplace accommodations to help you with your specific needs. 34, 36 These could include the following:
 - You may need to work reduced hours and/or arrange a flexible schedule with your manager to reduce fatigue.³⁴
 - You may consider gradually increasing the number and intensity of workrelated activities. You may find that working from home is more helpful and achievable as you return to work.³⁵
- Talk to your healthcare provider. Returning to work can be a long process, so talk with your healthcare team to find the best way to make this transition as smooth as possible. You may need to manage your expectations and not put too much pressure on yourself as you transition back to work.

You can find more information and resources related to return to work in <u>Chapter 7</u> of this guide.

You may also feel that **you don't want to return to work, and that is okay**. You need to find out what works best for you. Consult with your healthcare team, social worker, and/or financial advisor for advice and support as you make your decision. If you decide that returning to work is not what you need or want, contact your employer for information about retirement and/or financial support. You can also consider volunteer positions to help provide professional fulfillment and different ways to spend your time (e.g., opportunities are available within Cancer Care Ontario for cancer survivors to volunteer by helping other patients navigate the system).

Different types of work (e.g., full-time, part-time, self-employment) have different resources for support, but overall, the following people can provide information and support for your return to work:

- Healthcare team. Your healthcare team knows your needs and any cancer- or treatment-related barriers you may experience. As such, it is important that you contact them beforehand so they can help you develop an action plan for your return to work. For more information regarding the healthcare team, refer to Figure 1 in the Introduction section.
- Social worker. The social work team can connect you to resources that are specific to your situation.

- Employer. Your employer can support you with workplace adjustments so you can find what works best for you (e.g., working from home, modified work activities).
 - Human resources can help you make any adjustments to support your return to work (e.g., work reduced hours, change from full-time to part-time).
 - Your employer's insurance provider can provide information on how to access insurance services, benefits, and other resources.
- Personal financial advisor: A financial advisor can help you assess your financial situation so you can decide whether you need to return to work and when it is best to do so. This advisor can help you identify your financial needs and plan your expenses for short- and long-term situations.



You should always contact your **healthcare team** for advice on which strategies are best to support you in your journey. Your healthcare team can evaluate your needs and provide a referral to other professionals who can help. For more information on the healthcare team, refer to Figure 1 in the Introduction section of this guide.

Notes:			



CHAPTER 7: RESOURCES

In this guide, we have addressed some of the concerns gynecological cancer survivors face after they complete first-line treatment. You may have experienced a few of these issues, all of them, or perhaps none at all. Whatever your level of need, always remember that you are not alone.

It can be challenging to find the right support as you recover from cancer. The strategies and resources in this guide (and those found in your social networks, cancer centres, and communities) can help you manage some of your concerns. However, every cancer survivor's journey is unique, and what may work for someone else may not work for you. You should always talk to your healthcare team about your needs—they often know the best way for you to receive support and find your "new normal" after cancer.



Some issues may require a specialized intervention from a healthcare provider, so always ensure that your team knows your health concerns so that they can connect you with the correct support. Consider the information provided in Figure 1 in the Information section. At the end of this Resource section you will find Figure 2, which is a fillable version of Figure 1. Please feel free to add information about your own healthcare team and refer to Figure 2 as needed.

Pharmacist Nurse Name: Name: Contact: Contact: **Psychologist Physiotherapist** Name: Name: Contact: Contact: **Family Physician Occupational Therapist** Name: Contact: Name: Contact: **Oncologist** Dietitian Name: Contact: Name: Contact: Social Worker **Psychiatrist** Name: Name: Contact: Contact: Healthcare These are some of the healthcare providers that can help you in your journey, but there are other professionals that may be able to support you and are not listed

Figure 2. My HealthCare Team

The following pages list **some** resources that may help you, but you may find others not included here. If you find a resource on your own, make sure to check that the information is reliable. Asking these questions will help: Who is the author and what is their expertise in this topic? What is the purpose of the content? Who published the content? Give preference for resources from reputable organizations (e.g., Canadian Cancer Society and Ovarian Cancer Canada).

The resources are organized by category according to the goal of the resource (e.g., social support, return to work). Each resource includes links and QR codes to access websites.

How to use QR codes: (1) Open the camera app on your smartphone; (2) point the camera at the QR code; (3) make sure the QR code is centred on your smartphone; (4) wait for the code to scan; (5) open the QR code by clicking the link below the image (on Android phone) or by clicking in the Safari notification at the top of the screen (on iPhone).

PHYSICAL HEALTH RESOURCES

At-Home	Home and Community Care Support Services
Support	Access to health care or personal support in your home, including
Services	occupational therapy, physiotherapy, and personal support. You can self-refer or have someone else refer for you (e.g., a health care professional).
	https://healthcareathome.ca/home-care/

Physical	There are several free online services that can help you to keep
activity tools	active after cancer treatment.
	ActiveMatch is a service that helps women diagnosed with cancer find a local exercise partner. https://activematch.ca/
	There are also a variety of apps that promote physical activity. In
	your app store, search for cancer exercise apps.

MENTAL HEALTH RESOURCES

Managing	Anxiety Canada	
your anxiety	Exercises on mindful breathing and information about how that can help you manage your anxiety and where you can find professional support. https://www.anxietycanada.com/articles/mindfulness-mindful-breathing/	
	Cancer Care Ontario A guide to help you manage your anxiety and links to additional resources. https://www.cancercareontario.ca/en/symptom-management/3981	

Mindfulnessbased strategies

Canadian Mental Health Association

Information on what mindfulness is, how it can help, and where to find mindfulness programs and sessions.

https://cmha.ca/documents/mindfulness



Relaxation techniques

Cancer Care

Information about relaxation techniques and mindfulness practices to help you cope with cancer.

https://www.cancercare.org/publications/54relaxation_techniques_and_mindfulness_practic es_coping_with_cancer



Managing depression

Cancer Care Ontario

A guide to help you manage depression and links to additional resources.

https://www.cancercareontario.ca/en/symptom-management/3986



Coping techniques

Coping with Cancer

Interactive website to help cancer survivors and caregivers cope with cancer and find support.

https://www.copingwithcancer.ca/#intro 1-416-968-0207



Psychosocial support	Psychosocial Oncology Laboratory Resources in a variety of formats (e.g., videos, webinars, podcasts) related to fear of cancer recurrence, living with uncertainty, and anxiety. https://socialsciences.uottawa.ca/psychosocial-oncology-laboratory/resources	
Emotional	Information about feelings you may encounter	TELEVISION TELEVISION

Emotional health	Information about feelings you may encounter throughout your cancer journey and how to cope. https://www.cancer.gov/about-cancer/coping/feelings	
Mental health	Stupid Cancer	国際教育の国
and wellness	Information specific to adolescent and young adult (age 15–39) cancer survivors on many topics, such as mental health, relationships, college and career issues, and finances. https://stupidcancer.org/resources/	

SEXUAL HEALTH RESOURCES

Resources on sex, intimacy, and cancer

Canadian Cancer Society

This booklet provides information about common challenges to sexual well-being and possible solutions to help you manage them.

https://cancer.ca/en/cancerinformation/resources/publications/sexintimacy-and-cancer



Information on how to manage sexual problems, including the use of lubricants, vaginal dilators, relaxation, and exercises.

https://cancer.ca/en/treatments/sideeffects/sexual-problems-female-sex-organs



Groups are also available on a variety of topics, including sexuality and cancer.

https://cancerconnection.ca/groups

Vaginal dilator information guide

SunnyBrook: Odette Cancer Centre

Educational resource to help patients use and understand the purpose of vaginal dilators after radiation treatment.





2SLGBTQIA+ resources	Cancer's Margins Information and stories specific to the 2SLGBTQIA+ community living with and beyond cancer. https://www.lgbtcancer.ca/sexuality-and- cancer/	
	Canadian Cancer Survivor Network Resources and information specific to the 2SLGBTQIA+ community living with and beyond cancer. https://survivornet.ca/cancer-type/all-cancers/cancer-survivorship/lgbtq-information/	

Fertility	Information about fertility for young cancer survivors, including options for conception after treatment.	
	https://www.canada.ca/en/public- health/services/fertility/cancer-fertility.html	

SELF-IMAGE RESOURCES

Body image support and services

Look Good Feel Better

Various resources (e.g., workshops, beauty tips, survivors' stories) to help you feel like yourself again.



https://lgfb.ca/en/

1-800-914-5665

Canadian Cancer Society

Information and helpful tips about how to cope with body image and self-esteem challenges.



https://www.cancer.ca/en/cancerinformation/living-with-cancer/youremotions-and-cancer/coping-with-bodyimage-and-self-esteem/?region=on

University Health Network

Booklet on how to manage body image concerns after cancer treatment.



https://www.uhn.ca/PatientsFamilies/Health_I nformation/Health_Topics/Documents/Managi ng_body_image_problems_after_cancer_treatm ent.pdf

Access to free wigs

Canadian Cancer Society

All Canadian cancer survivors, regardless of where they live, have access to free wigs.





1-888-939-3333 (toll free)

SOCIAL SUPPORT RESOURCES

Support groups for ovarian cancer (in person)	Ovarian Cancer Canada In-person support groups specific to ovarian cancer survivors (organized by region). https://ovariancanada.org/Living-with-Ovarian-Cancer/Find-Local-Support-Groups	
	OVdialogue A national online support group of approximately 1,000 members. It operates 24/7 with discussion boards and a live online chat every Thursday at 1 p.m. Eastern time. https://ovdialogue.ovariancanada.org	

Support groups for all types of cancer (in person and online)

CancerConnection.ca

An online community where people affected by cancer can discuss their experiences, share information, and get support. Access is open 24 hours a day and membership is free. You can indicate "gynecological cancers" to reach that specific community.



https://cancerconnection.ca/home#-featuredcontent-

Canadian Cancer Society

People living with cancer or their caregivers are matched with a trained volunteer who has gone through a similar cancer experience.



https://cancerconnection.ca/peersupport

Phone: +1(888)939-3333

For information on local support groups, contact your regional Canadian Cancer Society office.

RETURN-TO-WORK RESOURCES

Resources and interactive tools

Cancer and Work

Up-to-date information, resources, and interactive tools that can help you assess your work abilities, identify steps to return to work after cancer.



https://www.cancerandwork.ca/

ADDITIONAL RESOURCES

Resources for Cancer Survivors

Cancer	National Coalition for Cancer Survivors	
survival	In this audio program, you can learn how to	国际政策部
toolbox	manage your cancer through a variety of resources.	多数数
	https://canceradvocacy.org/resources/cancer- survival-toolbox/	
Survivorship	National Coalition for Cancer Survivors	
checklist	Use this checklist to actively engage with and take control of your care.	回然為微固
	https://canceradvocacy.org/resources/survivorship- checklist/	
Self-	Self-management program	
management	Online support and health coaching on how to	国際総合国
program	manage some of the chronic conditions you may	
	experience after cancer treatment.	
	https://selfmanagementontario.ca/	
	1-844-301-6389 (toll free)	同性系統的
Educational	Foundation for Women's Cancer	
resources for	Educational material on different types of cancer	回的数据数据回
gynecological	that affect women; resources on sexuality,	不是的特别
cancer	survivorship, and other issues.	
	https://www.foundationforwomenscancer.org/	16363611 EV
	gynecologic-cancers/educational-materials/	自然思想想

Resources for all types of cancer

Canadian Cancer Society

Information about research, services available to those living with cancer, and booklets for different stages and types of cancer. You can also chat with a trained cancer specialist, join discussions, get peer support, and help others.



https://action.cancer.ca/en/living-withcancer/how-we-can-help 1-888-939-3333 (toll free)

You can also find specific resources for life after treatment.

https://cancer.ca/en/living-with-cancer/lifeafter-treatment



Canadian Cancer Survivor Network

This network was created by a group of Canadians concerned about cancer and survivorship issues. Find information related to support, events, where to seek support, and other issues.



https://survivornet.ca 1-613-898-1871

Resources for ovarian cancer	Ovarian Cancer Canada Information about research, resources, patient stories, events, and educational programs. https://ovariancanada.org/ 1-877-413-7970 (toll free)	
Webinars on a variety of topics	Wellspring: Be Well Talks Online modules and programs on a variety of topics, including coping skills, meditation, body image, nutrition, fear of cancer recurrence, sexual health, and caregiver support. https://wellspring.ca/online-programs/ 1-877-499-9904 (toll free)	

Resources for Caregivers

Caregiver experience	American Cancer Society Resource to help caregivers better understand the cancer experience, including information on the disease process and what can be expected. https://www.cancer.org/treatment/caregivers/what-a-caregiver-does/treatment-timeline.html	
Caregiver support	National Cancer Institute Support for caregivers of cancer patients and survivors, as well as information on how to best cope with the role of a caregiver. https://www.cancer.gov/about-cancer/coping/caregiver-support	

Resources for young survivors

Additional	Heather's Hangout	同時の変数回
resources	A blog post for young cancer survivors with	
	resources on hair loss, fertility, and mental	
	health.	1992 Sept.
		220000000000000000000000000000000000000
	https://heathershangout.com/resources-for-	国家教育者民
	young-adult-cancer-survivors/	
	Journal Control Dury 1 (1010)	

These are only some of the many resources you can access. Other tools and programs may be recommended for managing issues you face. You should always contact your healthcare team for advice on which strategies are best to support you in your journey. Your healthcare team can evaluate your needs and provide a referral to other professionals who can help, which may include a dietitian, occupational therapist, pharmacist, physiatrist, physiotherapist, psychiatrist, psychologist, recreational therapist, rehabilitation nurse, or social worker.

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