

NAVIGATING THE ROLE OF CAREGIVING

Colorectal Cancer Canada



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INTRODUCTION:

When a loved one is diagnosed with cancer, it can be difficult for everyone who is close to them. Colorectal Cancer Canada is here for the whole family and friend system during the diagnosis, treatment, and everything in between and thereafter. Caregiving can be emotionally, financially, physically, and spiritually taxing – you are not alone in that. This resource will help validate some of the thoughts and feelings you experience and provide some coping strategies and tips for navigating the role of caregiving.



THE ROLE OF CAREGIVING:

A caregiver is someone who provides care to another individual; however, they are not paid. This may include several types of care such as emotional, physical, personal, spiritual, financial, to name a few. Being a caregiver for an individual who has cancer can be a difficult task as there are added responsibilities that are new to you. Some may be daunting, such as medical management and personal care, that you may not be trained in. While caregiving is not an easy task, it can be rewarding and bring you closer to the individual you are caring for – it may bring meaning and purpose to your life.

Whether you are brand new to caregiving or have been doing it for months/years, you may decide that caregiving is not for you or that you would like to seek support to avoid burn out. Having a direct conversation with your loved one with cancer about the responsibilities you are willing or not willing to take on is an important first step. Making a list of potential tasks with one of the patient's medical providers can be helpful in determining which tasks you are comfortable with. If you are not comfortable completing some of the tasks there are options available to you. Some options available to you may be:

- Seeking support from family or community members.
 - Communicate with your loved one with cancer about who they would like their main caregiver to be and whether they feel comfortable with additional caregivers to delegate some of the less personal tasks to. From there, a conversation with family and close community members can take place to determine who will assume each responsibility. It is important to discuss why you may require some additional support with caregiving for your loved one with cancer. They may be confused as to why you are wanting to delegate tasks to others. Being honest, authentic, and kind in your approach to this conversation is key.

Having a conversation around your needs and setting boundaries in the beginning can be much easier than trying to have a conversation later in the caregiving process for several reasons. You can practice role playing a conversation about needs and delegating tasks with a friend, family member, or a therapist. Another great option is to call or email Support at Colorectal Cancer Canada and we would be happy to support you with this conversation.



- Research home care options such as a nurse or personal support worker.
 - Sometimes partners, family members, and friends may feel uncomfortable with completing personal care tasks such as bathing, assisting with toileting, grooming, ostomy care, and others. There are agencies that will send personal support workers or nurses to your home and assist with the personal care duties. There will be a list of resources at the end of this toolkit with information regarding home care agencies.
 - Speak with the social worker at the hospital, Support at CCC, or your pivot nurse/nurse navigator about the resources available to you. There may be a program in your area with volunteers who provide respite, or other programs that would allow you to delegate tasks and take some time for self-care.
 - It is important to have a plan in place if you must be away from your loved one with cancer, whether it is an emergency you must attend to or a planned trip. It is a great idea to plan who will be present with your loved one, and to have a document that outlines all the essential information about care in your absence. Some individuals call this a care plan, and you can find templates for a care plan online or contact CCC and we will help you form a plan.



WHAT DO CAREGIVERS DO?

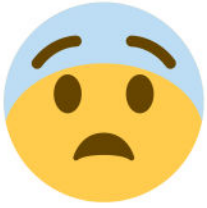
Caregiving includes many responsibilities in addition to those you already complete. What you do as a caregiver may change over time as the loved one's condition improves or worsens. During treatment, there may be added tasks; whereas, after treatment your loved one may begin taking on some tasks on their own, as they gain strength. Some potential caregiving responsibilities include:

- **Tracking and attending medical appointments with your loved one.**
- **Advocating on behalf of your loved one for quality care, second opinions, and other topics.**
- **Physical care such as mobility assistance, personal care, and assisting with incontinence products.**
- **Preparing meals and assisting with feeding.**
- **Medication tracking and ensuring that your loved one is taking the correct medications throughout the day.**
- **Emotional support as your loved one will also be experiencing a lot of change, fear, sadness, and other emotions.**
- **You may now be the primary financial source which may require additional coordination of finances. Colorectal Cancer Canada has a return-to-work guide for caregivers that can be found on our website.**
- **There are many more responsibilities in addition to those mentioned above – all of which can be difficult to juggle if you're the sole caregiver.**
- **The above responsibilities are on top of your regular day-to-day activities such as taking care of your children and animals, cleaning your home, laundry, grocery shopping, extracurriculars, and other chores that were on your to-do list prior to taking on the responsibility of caregiving.**

EMOTIONS:

You may be experiencing a variety of emotions, thoughts, and feelings which is completely normal whether you are new, in the middle of, or have been caregiving for years. Going from a partner, sibling, adult child, friend, or any member in the loved one's life to a caregiver can be a big, unexpected change that may make you feel unbalanced and overwhelmed. Given that a loved one has been diagnosed with cancer and that you are both trying to navigate this uncertain time, it is expected that big emotions, thoughts, and feelings will surface. It is important that you acknowledge your emotions, sit with them, and effectively process them to avoid repression, which can eventually lead to an outburst of anger and other emotions. Throughout the caregiving process you may experience a combination of the following:





FEAR:

This emotion can lead to a lot of “what if” questions and send you in a negative downward spiral of thoughts. You may be thinking: what will the kids and I do without my partner’s contributions? What if I do something wrong during personal care? What if the cancer progresses? What if I lose this person? What if the cancer comes back? These are all common thoughts, amongst others. Fear is to be expected as you are navigating unfamiliar circumstances. Fear is very common amongst cancer patients and their loved ones.



ANGER:

Maybe you had plans that you were passionate about and then the cancer diagnosis happened, which changed everything. You may think “what did I do to deserve this? Why me?”. Nobody deserves cancer, and you did not do anything wrong – you could not have prevented this on your own. It is ok to be angry that you now have caregiver responsibilities that put your plans on hold. Also note that anger is a secondary emotion most of the time – the sadness and other emotions you may not be processing may be showing up as anger. Emotions and showing your emotions are not bad – they send a message to you. Anger often means that you know that you deserve better than your current situation.



SADNESS:

A loved one has cancer, so it is completely reasonable that you are experiencing sadness – for yourself, your loved one, and other individuals close to the loved one with cancer. If you are caring for your partner and you have children, sadness will likely surface with your children as well. Caregivers are also more likely to experience depression; therefore, if you experience depression symptoms, please seek medical attention and/or therapy. Be sure to reach out to our support team if you feel that you need to be assessed for depression. We can refer you to the correct professional(s).



SURPRISED/SHOCK:

You may never have thought that you would become a caregiver. The cancer diagnosis of your loved one may have also been a shock. Feeling as though this situation must not be real can be a sign of shock which is completely normal. You may also feel like it is real one moment, and then not real the next.



LONELINESS:

Since taking on the role of caregiving you may feel isolated, the only one with the emotions and thoughts that come up for you, or maybe like your loved one is there but it is not the same as before. Despite feeling lonely, you are not alone in this. There are several supports for you, including CCC’s caregiver support group where you can share your emotions, thoughts, and experiences with others, and hear their similar experiences. Setting aside time to get together and socialize with your family and friends can help you feel less alone and prevent burnout.



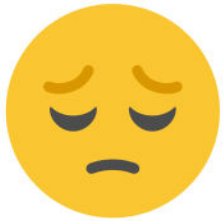
DISGUST:

Some responsibilities of caregiving can disgust you such as assistance with toileting, personal care/ grooming, vomit, incontinence, and many other components as a result of side effects from treatment or symptoms of colorectal cancer. Seeing your partner, parent, or sibling at their lowest point in the cancer process can make you feel disgust or resentment. It is completely ok to feel this way – you are not alone in feeling this. If the disgust becomes too much, you can refer back to the supports available in your community. Sometimes individuals need to omit the less desired responsibilities to maintain a positive relationship with the loved one with cancer.



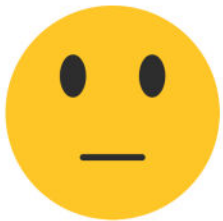
GRIEF:

It is normal to grieve the identity you held prior to caregiving. Uncertainty can leave you grieving a time when you were able to make plans and live life without wondering whether you could go through with the plans. Grief is not linear and giving yourself grace as you navigate grief is key.



GUILT:

Many caregivers report that they feel guilty that they cannot do more to help their loved one with cancer. You are likely doing the best that you can and it would be unreasonable to expect one person to complete all of the tasks in caregiving perfectly. Your feelings are valid, and you have to remember that you cannot wear yourself too thin as it puts you at risk for illness and burnout. You cannot care for your loved one unless you are well.



SHAME:

Feeling ashamed of some of the emotions you feel throughout caregiving is also a common theme. It is ok to feel any of the emotions as they communicate a message to you from your body. Anger is your biggest advocate and lets you know that you are not being cared for well enough. Fear protects you from dangerous things and supports you as you make difficult decisions. Sadness, and especially crying is a release of all the information, tension, and thoughts that are consuming you. Each emotion has a meaning attached to them that are helpful in determining what your next steps are and whether you need more care yourself.



HAPPINESS:

Some caregivers find their meaning and purpose in caregiving; others may have happy moments where they feel fulfillment in what they are doing for their loved one. In the same way that it is ok to be unhappy with your role as a caregiver, it is completely ok to be happy with the role as well; you may experience a blend of happiness and unhappiness throughout the process.

COPING STRATEGIES:

While sitting with your thoughts and emotions is important, it is equally important to have coping strategies to implement to ground yourself and avoid a crisis situation. Sometimes, we can find ourselves in a spiral of negative thoughts and having coping strategies to stabilize us in the present can be helpful. The following can be used individually and collectively to help you ground yourself:

MINDFULNESS:

To be mindful means to notice the thoughts and emotions that come up without judging them. Often, mindfulness and self-compassion are practiced together. For example: Maybe you are feeling angry because you have several tasks to do and there is not enough time to complete them. Practicing mindfulness would look like noticing the anger and feeling it wherever it is showing up in your body. You may acknowledge the anger by saying to yourself "I see you anger, and I feel you". From there, you will not allow yourself to judge your anger or why you are feeling it. You will treat yourself with compassion by saying something like "it is ok to feel anger, I am coping with uncertain times right now". This is one example; however, there are several ways to practice mindfulness. Please contact our support team to discuss them.

BREATHING EXERCISES:

Taking a deep breath can be very helpful in terms of helping you be calmer. If you find yourself feeling an emotion and you begin hyperventilating or the emotion is beginning to take over and become dominant – a breathing exercise may be the best place to start. First you will close your eyes (if you feel safe doing so) and take a deep breath in through your nose, pause for a second, and then release the breath through your mouth. Some individuals feel better if they put extra pressure on the exhale. You will repeat this process at least five times.

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MEDITATION:

There are studies that show major benefits of meditation as it relates to individuals reporting that they view their lives as happier and more meaningful. There are guided meditation videos on YouTube and other platforms that are geared toward specific issues such as sleep, anxiety, fear, pain, and several other common issues. Meditation is a combination of mindfulness and breathing as you sit or lay in a quiet area with peaceful music or nature sounds in the background and you take deep breaths several times while focusing on the present moment.

THE 5-SENSES GROUNDING METHOD:

Caregivers have many different responsibilities that can make you feel as though you are an observer on the outside of your body, looking in. Caregivers also experience an array of emotions that can become hard to control at times. A great exercise to explore when this happens is the 5-senses grounding method. You can practice this by following the below steps:

5: Acknowledge FIVE things you see around you.

4: Acknowledge FOUR things you can touch around you.

3: Acknowledge THREE things you hear.

2: Acknowledge TWO things you can smell.

1: Acknowledge ONE thing you can taste.

CEREMONIAL/SPIRITUAL TECHNIQUES:

Each culture have ways that make them feel better when they are experiencing a difficult time or big emotions. This will be determined by you and the culture you practice. Some examples may include smudging, sweat ceremonies, prayer, healing circles, and several other helpful traditions and techniques.

SUPPORTIVE SPACES:

Staying connected to others is important while navigating caregiving because staying in your own thoughts, especially if they are negative, can become a downward spiral that can leave you vulnerable to depression and other mental illnesses. Attending a support group, joining a Facebook group, attending community functions/meetings, or seeing a social worker can help you significantly as it keeps you connected to others. In these settings, you get to hear other experiences, receive empathy for your situation, and engage in activities that bring you joy.

COMPASSION FATIGUE:

Do you feel like you are too exhausted to care? Maybe you begin caring less about what your loved one with cancer feels or wants. It could be that you care less about your own wellbeing and engage in self-sabotaging behavior. It could be a wide variety of things; lack of care and compassion for self and others being the main theme. This may be an indicator that you are experiencing compassion fatigue. Caregivers who experience compassion fatigue may also be grieving the loss of their previous identity. Taking on the role of a caregiver means that your identity shifts to make room for caregiving and sometimes that was not a part of the plan. Some of the common signs of compassion fatigue is:

- **Lack of empathy or compassion.**
- **Feeling helpless or hopeless, like there is nothing that can make your situation better.**
- **Increased sadness, anger, anxiety, and other emotions.**
- **Difficulty sleeping or sleeping too much.**
- **Neglecting your own self-care.**
- **These are just a few signs/symptoms. If you believe you are experiencing compassion fatigue, reach out to a social worker or your medical provider. You can contact support services if you are unsure of who you can reach out to. .**



You may be able to reduce your chances of developing compassion fatigue by engaging in self care and delegating tasks to make sure you make room for your own joy, interests, and hobbies.

SELF CARE:

You may be rolling your eyes as most do when self-care is mentioned. Many believe that self-care must be a big commitment that includes hiking, spa days, and other extravagant things. It can certainly be those things for some individuals; however, many caregivers may not have the time to regularly schedule these commitments into their schedule. The self-care that will be discussed here are activities that are necessary in order to live a healthy lifestyle and ensure that you are being cared for in the same way that you are caring for your loved one. It may be helpful to write or type a plan and post it somewhere visible to remind you that your own wellbeing is equally important. Some examples of self-care activities that you may include in your plan are:



SLEEP:

In general, the recommendations for sleep is 7-9 hours per day. If you have issues with sleep you could discuss this with your doctor and/or try a meditation specific for sleep. In the resource section an article will be included that discusses the importance of sleep and how one might be able to get better sleep.



MOVEMENT:

Many caregivers do not have the time to implement a specific exercise plan; however, any type of movement is a great start. Movement of your body is shown to have several benefits, including mental clarity and feeling great overall. This may include walking around your block for 10 minutes, twice a day. It can be marching in place while you complete a household chore. You can be as creative as you would like with this activity.



NUTRITION:

Firstly, you must eat! Many caregivers report that they forget to eat which is not great for your health. Having nutritious grab-and-go type foods is important to ensure that you are fueling your body for the amount of additional work you are completing as a caregiver. You may have a pack of nuts, fruit, and vegetables ready to pack and eat at any time, as an example.

JOY:

As a caregiver, many previous joys, hobbies, and social events may be replaced with care. It is important to schedule in activities that you enjoy. Making a list may be helpful to determine which interests you can still partake in while you are caregiving, that bring you joy. This may be coloring adult coloring books, reading, planting flowers that are visually pleasing, listening to your favorite music, having someone come in for respite while you enjoy a coffee with your friends. It can be many things depending on what brings you pleasure.



SCHEDULED BREAKS:



Throughout the day, take micro-breaks so that you can take a few deep breaths, eat, hydrate, and relax for a moment. If you tend to forget to take these breaks, schedule them into your phone and make reminder alarms as they are super important for your wellbeing. If there are times where you feel overwhelmed and you do not have a break scheduled, take some time away anyway and practice some coping strategies to ground yourself and then return to your caregiving duties once you feel better.

LIFE AFTER CAREGIVING:

The time may have come where you are no longer required to be a caregiver. Whether this means that your loved one has recovered and are able to care for themselves, or that your loved one passed away – navigating life after caregiving can be equally as daunting as becoming a caregiver. For some caregivers, caregiving is their meaning and purpose for a long time, and they are unsure about how to navigate life after caregiving. For others, processing the grief of losing their loved one and not having caregiving duties to complete is extremely difficult. Even if caregiving was not enjoyable for you, you may be lost as it relates to filling the empty space with other activities. Caregivers who do not engage in active self-care and participate in activities that bring them joy may feel like they are navigating a brand-new phenomena in their lives. Life after caregiving is a new season that will take some adaptation before it feels comfortable again – you may always miss some aspects of caregiving. Some things you can do to help navigate this new season is:

- **Let yourself grieve and feel all the emotions. This is your time to process what just happened for the duration of caregiving. There is no right or wrong way of grieving and processing emotions – it will not be linear.**
- **Attend therapy and discuss your thoughts, emotions, and experience with a licensed professional.**
- **Re-implement hobbies and activities you enjoyed prior to caregiving that you could not engage in during caregiving.**
- **Get outside and enjoy activities and friends that may not have been a possibility during the time you were a caregiver.**
- **Explore new hobbies and try new things.**

Caregiving is a different experience for each person depending on their experience, stage of cancer, and other determinators. It is important to navigate the role of caregiving with self-compassion, self-love, and grace. You will make mistakes and that is completely ok – acknowledge your mistake and move forward with an abundance of compassion, love, and grace for yourself.

If you are struggling or you would like someone to talk with, please reach out to a Patient Support Specialist at Colorectal Cancer Canada. They can provide emotional support, resources, and education for any topic you are inquiring about.

Email support at support@colorectalcancercanada.com

IF YOU REQUIRE ANY OF THE FOLLOWING RESOURCES OR RESOURCES OUTSIDE OF THOSE LISTED BELOW, PLEASE CONTACT US AT SUPPORT@COLORECTALCANCERCANADA.COM

RESOURCES:

- Depression self assessment/Anxiety self-assessment
- Caregiver associations for each province
- RTW Caregiver toolkit
- Intimacy and Sexuality toolkit
- Homecare/respite care for each province.
- Breathing/meditation exercises
- Sleep Support
- Exercise Recommendations
- Self Care Plan Template
- Referral Support

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