



*Just be gentle  
and give yourself  
time as this period  
is very stressful and  
filled with so much  
uncertainty.*

# Guide for Young Adults Diagnosed with Cancer

**Prepared by Oncology Social Work Team 2019**  
**CancerCare**

# Guide for Young Adults Diagnosed with Cancer



**Please be reminded  
to make use of the free oncology social work  
counselling and emotional support services at any time  
during your cancer journey.**



## Introduction

A cancer diagnosis between the ages of 18 and 28 years is often unexpected. A misconception makes us believe that cancer only happens to older people.

Young adulthood is a time when most people are focused on their education, career, dating, getting married and starting a family. However, as a young adult with cancer, you may feel as if your life has been suspended when life has just begun!

## Challenges when diagnosed

- Issues with not having adequate medical aid cover. Treatment can be expensive.
- Becoming financially dependent on your parents and moving back into the parental home can be a huge challenge for both sides.
- As a young adult, you may feel you are losing your independence at a time when you were just starting to gain it.
- Treatment schedules may interrupt studies or keeping up with the physical challenges of studying or work can be difficult.
- A compromised immune system may force you to stay away from big groups, which also means not attending classes or going to work.
- The effect of treatment or the cancer itself may limit your energy levels – which again affects work performance.
- On a social level, treatment can isolate you – one does not have the energy to socialise with friends. Friends and family may not understand what you are going through.
- Physical changes (hair loss, weight loss/gain) may affect one's motivation to be with others.
- Many cancer treatments affect fertility – which can cause huge fear and distress.
- A cancer diagnosis puts most people on a rollercoaster of emotions.
- Because cancer is relatively rare in young adults, there are few patients like you.
- Treatment may take you far from home, which is also difficult.
- A desire to be normal may keep you from sharing your cancer

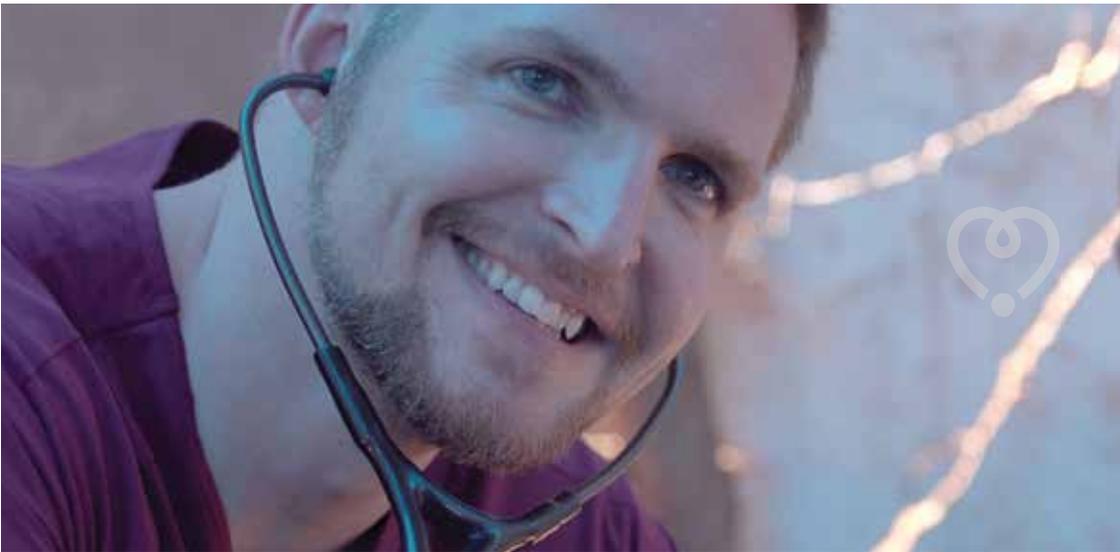
experience with your healthy peers, adding to a sense of isolation.

- There will be times when you experience anxiety about scans, procedures, or things happening in everyday life. This is normal. Anxiety can pop up when you least expect it, or it can occur for periods of time, but there are ways to cope with it.

## Working around the challenges

### Prepare for your medical appointments

- If you have questions for your doctor, write them down in advance.
- Write down your doctor's answers or bring someone with you to take notes or serve as a second set of ears.
- Ask if you can record the conversation using your cell phone. With the technology available, it is helpful to process the information later or listen to the information again with a friend or a family member.
- If you are a visual learner, ask to see the X-rays or slides.



### Be your own advocate

- You know yourself and your needs better than anyone. You may have to take the lead in bringing up certain topics, such as fertility preservation or how much your treatment will cost.
- Remember getting and 2<sup>nd</sup> opinion is your right.



## **Discuss your preferences**

- Your lifestyle and daily activities may influence treatment recommendations.
- Find out if treatment will interfere with your ability to continue working or going to school/college/university.
- If you have an important event coming up, ask if you can reschedule an appointment around treatment so you can attend.
- Scheduling adjustments may not always be possible, but you won't know unless you ask.



## **Help with your medical aid**

- Whether you are the primary medical aid member or a beneficiary, contact the medical aid and talk about any concerns you may have.
- Many medical aids will assign a case manager to help you clarify benefits and suggest ways to access other health services.
- You can also ask for help from an insurance broker or from the human resources division at your workplace.

## **Tips for taking control of your finances**

- Money may be the last thing you want to think about. But taking control of your finances from the start may be the best way to prevent a crisis later.

- Get a handle on your income and expenses and keep records.
- Stay on top of medical bills and save copies of every account, statement and payment you make or receive.

### **Bring up fertility preservation concerns**

- Cancer treatment can have a variety of long-term and short-term side effects on a person's ability to conceive or carry a baby to term.
- Discuss fertility concerns with your doctor before, during and after treatment.
- If family planning is a priority, make sure your healthcare team is aware of this.
- Your healthcare team may refer you to a fertility preservation specialist so that you can explore options such as sperm or egg harvesting (storing for later use).

### **Organising your health information**

Keeping your records together in one binder/folder can help you stay organised and feel in control of your treatment schedule and appointments.

### **Information you may want to collect**

- A contact list of medical providers
- Dates of appointments and any discussion notes
- Medications you are taking
- Accounts and account enquiries
- Medical aid information
- Copies of medical records

### **Seek professional support**

- Oncology social workers are licensed professionals who counsel people affected by cancer, providing emotional support and helping people access practical assistance.
- Individual counselling gives you the opportunity to address how cancer may affect your life in respect of relationships, career goals and life priorities, etc.
- Cancercare provides some free counselling sessions you may make use of.



## **Support groups**

Attending a support group allows you to compare your experiences and solutions with other young adults. However, in South Africa groups are limited but online groups can be just as effective.

## **Studies and work**

- You may be required to adjust education- or career-related goals.
- You may be able to continue with work or studies by adjusting routines and schedules.
- Your lecturers and colleagues may prove to be excellent sources of guidance and support, should you choose to disclose your diagnosis.
- You may return to the workplace during or after treatment, but it may be necessary to tell your doctor about your typical workday so that he or she can determine whether you can return to work during treatment or thereafter.

## **Know your rights**

- A cancer diagnosis does not automatically disqualify you from employment, insurance or healthcare.
- It is important to know your rights and how to protect them.
- Many legal resources are available to answer questions and help advocate on your behalf for access to benefits and services. The oncology social worker in the unit can also assist or direct you to the applicable resources.
- You have the right to a second opinion, should that make you feel safer.

## **Reach out to family and friends**

Your family and friends are part of your support team, but they may need more information about cancer to help them understand your situation. Others may have different reactions and views about cancer than you do, but education, communication and understanding can help them to support you.

Most cancer patients have probably had a moment where they've wanted to say, "I can't believe you just asked me that". You don't need to share any information that makes you uncomfortable, and you don't need to feel guilty about not answering a question.

A good answer is: "Today is a good day, thanks for asking" and "My

doctors are taking excellent care of me, and I'm taking things one day at a time".

### **Parents**

Be honest about your need for privacy. Share your feelings and emotions with them. You may find them to be a strong source of emotional and practical support.



### **Siblings**

Watching a brother or sister face a cancer diagnosis is difficult for siblings of any age. They may want to help you in practical ways such as providing transportation to and from treatment or helping with household tasks. Encourage your siblings to talk openly with you. Let them know that they can support you by just taking the time to listen. Spend time together talking about subjects other than cancer.

### **Friends**

You will often find that friends and peers do not know how to respond to your cancer diagnosis. Take the lead in reaching out to them. Be honest about what you need and what you feel like discussing. Ask them to help you in specific ways such as running errands, providing transportation, or preparing meals. Focus on the friends who can listen to you and support you.



## **Spouses and partners**

The thought and fear of losing a loved one can be overwhelming. Sometimes this fear can drive an emotional wedge between partners and negatively affect communication. Talk openly and honestly to each other about thoughts, feelings and fears. Day-to-day topics can help bring back a sense of normalcy to your lives. The social worker can offer guidance to couples.

## **Intimacy in relationships**

Cancer changes sexuality. The side effects of treatment and surgery may cause a decrease in self-esteem and sexual libido. Discussing



sexuality with your partner may feel uncomfortable at first, but it can lead to a greater sense of emotional intimacy. Be honest with each other about feelings and sexuality. Communication will be important to make the relationship grow.

## **Talking to your children**

Parents want to protect children by not sharing. However, speaking honestly to your children can help them feel safe and secure. Give accurate, age-appropriate information. Explain your treatment plan and how it may affect their lives. Encourage them to share their feelings, even those that are uncomfortable. You may also want to speak to an

oncology social worker. More tips for communicating with your children can be found in CancerCare's Connect booklet, "Helping Children When a Family Member has Cancer".

## After treatment

- You may worry that cancer will return.
- You may struggle to get used to new routines. Some young people enter this new phase feeling stronger, whereas others are more fragile.
- While most of the side effects that you had during treatment will go away, long-term side effects such as fatigue may take a while to disappear. Other side effects, called late effects, may not occur until months or even years after treatment.
- Follow-up care is important for all survivors. These check-ups can both reassure you and help prevent and/or treat medical and psychological problems.

## Resources

1. <https://www.nccn.org/patients/guidelines/aya/index.html>
2. <https://www.cancer./types/aya>
3. <https://www.cancercare.org/>
4. <https://cancerdojo.com>
5. <https://www.youtube.com/watch?v=KovNSrBYiF0> (Fertility issues)
6. <https://ulmanfoundation.org/>
7. <https://www.livestrong.org/we-can-help/just-diagnosed/young-adults-with-cancer>
8. <https://www.cancer.org/cancer/cancer-in-young-adults/cancers-in-young-adults.html>
9. <https://www.youngsurvival.org/who-we-are>
10. <http://www.hope4yawc.org/>
11. <https://stupidcancer.org/get-help/resource-directories/young-adult-organizations/>



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