

*Reading  
this may help  
you understand  
the illness a bit  
better and what  
lies ahead.*

## Your Journey Through Cancers

A guide for cancer patients and their loved ones

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

# Your Journey Through Cancers

## A guide for cancer patients and their loved ones



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



## Content

Introduction	5
Step 1: Managing distress when coping with cancer	6
Step 2: Taking control of your treatment	10
Step 3: Be informed - Questions to ask your oncologist	12
Step 4: The impact of cancer on the family	13
Step 5: Tips for couples dealing with the cancer experience	14
Step 6: Helping children when a family member has cancer	15
Step 7: Tips on caring for your teenager	16
Step 8: Ways in which family and friends can help	17
Step 9: Know about resources	18



**The longest journey begins with a single step, or so an ancient Chinese proverb tells us. You have many steps ahead as you make your way through the coming months.**

## Introduction

Hearing the words “You have cancer” may be the most frightening words you’ve ever heard. You may feel scared, angry, crushed – or may keep hoping it has all been a big mistake. You probably won’t remember anything your physician told you and wonder how to begin dealing with this journey that feels so overwhelming.

Due to the domino effect that a cancer diagnosis may have on all aspects of the lives of patients and their loved ones, a professional counselling service is included in your treatment fees. At Cancercare, the oncology social workers form part of the multidisciplinary team approach as ...

**... we acknowledge and include the importance of body, mind and soul.**

The counsellors at Cancercare are oncology social workers by profession and are all experienced in assisting and guiding patients and families through a cancer journey. We encourage you to make use of the service as it provides a neutral space where you can ask questions, share concerns and deal with unexpected emotions. The counsellors are trained to provide psychosocial support services during your cancer journey and will refer you to a psychologist or psychiatrist if needed.

**Counselling** may include any one or a combination of the following interventions:

- Psychosocial assessment and drafting of a care plan
- Individual and family counselling
- Support in talking with your children about cancer
- Basic information on your treatment
- Emotional support and guidance
- Linking with community resources
- Discharge planning
- Arranging support for palliative care in the community
- Crisis and stress management
- Connecting with support groups and other community services



## Step 1

### Managing distress when coping with cancer

#### Definition of distress

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. Being exposed to distress when you have cancer is normal, but high levels of distress will impact your coping ability and may cause problems in many areas of your life. Being aware of the distress it is the first step you need to take to start implementing change and taking back your control of your life in this troubled time. The next step is learning to take action to lessen the distress, thus supporting your body, mind and spirit as you prepare for starting treatment.

The levels of distress will be different during different phases of your treatment and will coincide with emotions such as sadness, fear, anxiety, hopelessness and helplessness. This may impact your ability to cope with treatment, work, your relationships with family and friends, and it may even impact your spirituality. When you experience distress, it does not mean that you have a psychiatric illness. It is normal to feel sad, overwhelmed, anxious and worried when you start your journey with cancer. Everything is new and it takes time to adjust to the new reality in your life. Remember, distress not only touches and impacts the patient, but their family and friends as well.

See below some symptoms of distress according to the distress guideline of the National Comprehensive Cancer Network (NCCN) (<https://www.nccn.org/patients/guidelines/content/PDF/distress.pdf>)

#### Some symptoms of distress are:

- Sadness, fear and helplessness
- Anger, feeling out of control
- Questioning your faith, your purpose, the meaning of life
- Pulling away from too many people
- Concerns about illness
- Concerns about your social role (ie, as mother, father, caregiver)
- Poor sleep, appetite, or concentration
- Depression, anxiety, panic
- Frequent thoughts of illness and death

## **Times distress could become more prevalent**

Distress levels are often higher at certain junctions in the cancer journey. See the list below that indicates some stages when distress will increase acutely according to the NCCN distress guideline for patients. You can access the full document by clicking on this link: <https://www.nccn.org/patients/guidelines/content/PDF/distress.pdf>

### **You are more likely to become distressed if you:**

- Learn a symptom needs more testing
- Were just admitted to or discharged from the hospital
- Are being assessed for cancer
- Recently finished treatment
- Just learned the diagnosis
- Are in follow-up care
- Are undergoing genetic testing
- Learn treatment didn't work
- Are waiting for treatment
- Learn the cancer has returned or progressed
- Are starting another type of treatment
- Have advanced cancer
- Have a major treatment-related complications
- Are near to the end of life

We suggest you do baseline screening of your current distress levels and use this as a guide for seeking professional support from our team of oncology social workers or the the rest of your oncology team – sooner rather than later. They will provide counselling and assist you with developing coping strategies and assessing the support that you need most at the time.

See an example of the NCCN distress thermometer below. The guideline states that if you have marked six or more of the problems on the list, it is recommended that you make an appointment with the counsellor in the unit to discuss these concerns without delay. You don't have to do this alone – reach out and get help, as unmanaged distress may lead to depression and other more serious emotional problems. The CancerCare team is here to provide patient-centred, holistic care to all our patients and their family members.

NCCN Distress Thermometer



**Instructions:** Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today:



## Problem list

Please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

**Note: If you mark more than 6 items with yes you should consider getting Psychosocial support from a counselor**

Yes	No	Practical Problems	Yes	No	Physical Problems
		Childcare			Appearance
		Housing			Bathing/dressing
		Insurance/financial			Breathing
		Transportation			Changes in urination
		Work/School			Constipation
		Treatment decisions			Diarrhoea
					Eating
		<b>Family problems</b>			Feeling fatigue
		Dealing with children			Feeling swollen
		Dealing with partner			Fevers
		Ability to have children			Getting around
		Family health issues			Indigestion
					Memory/Concentration
		<b>Emotional Problems</b>			Mouth sores
		Depression			Nausea
		Fears			Nose dry/congested
		Nervousness			Pain
		Sadness			Sexual
		Worry			Skin dry/itchy
		Loss of interest in usual activities			Sleep
					Substance abuse
		<b>Spiritual / Religious concerns</b>			Tingling in hands/feet

Other problems:

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## Step 2

### Taking control of your treatment

Patients are encouraged to become active members of their treatment teams – engaging from the start with their oncologist regarding treatment decisions.

According to Dr Harold Benjamin, founder of The Wellness Community in the USA, “People with cancer who participate in their cancer treatment will improve the quality of their life and may enhance the possibility of their recovery”.

#### How do you do this?

- Be well informed – gain information from your doctor about your diagnosis, treatment plan and side effects. Keep a file with all your results and keep track of your blood results and learn what is important to watch out for. This empowers you and helps you become part of the healing process.
- It is useful to keep a journal of your emotional experiences. This allows you to fully express your emotions, without judgment, and helps with lessening anxiety. Learning about mindfulness and dealing with emotional issues that cause distress are core elements of your healing process. Emotions that are not expressed cause physical distress and can impact your immune system.

#### Read more about psychoneuroimmunology

*Being healed is much more than being cancer-free*

Psychoneuroimmunology (PNI) is the **study** of how the brain, nervous system and the immune system impact each other. Applications include how **stress** leads to **illness**.

Have a look at the Cancer Dojo App that was developed by a brain cancer survivor in Cape Town, South Africa! It will help you to become active in your own cancer treatment. *(It is not a free app, so if you cannot afford it, ask your team if they have vouchers to access the app.)*

<https://www.medicalnewstoday.com/articles/305921.php>

Cancer Dojo: <https://cancerdojo.com/>

<https://www.facebook.com/CancerDojo/>

- Learn to express your needs and devise a plan to meet those needs.
- Set small, achievable goals for every aspect of your life and develop an action plan for your personal experiences. This helps you focus and becomes the driving force of your healing process and will help you cope better with the side effects of treatment.
- Remember your experience is unique and your body will react to your individual treatment differently than those of others. The side effects described are general and your experience could be different.
- See your cancer treatment as one part of your strategy to deal with your cancer.
- Create a strong support system.
- Make a dream list that builds hope and helps you live one day at a time.
- Plan some fun-filled events.
- Be selective and do not listen to all the stories you are told. Make choices that you feel are needed as part of YOUR healing.
- Disregard people who are negative.
- Deal with baggage from your past, as the pain caused by emotional scars may hinder your healing process. Having cancer is a good opportunity to do a stock-take of what you need in your life at this time and will help you focus on being gentler on yourself in general.

**Conserve your energy by:**

- asking others to help you – delegate tasks.
- taking short naps.
- planning your activities with realistic goals.
- walking daily or developing an exercise routine.
- considering yoga or mindfulness practices.
- limiting caffeine, especially in the evening.
- drinking water – at least four to five glasses a day.
- maintaining a well-balanced diet.



**With this kind of approach, you are empowered to move away from being a victim to becoming a survivor or learning to live with the cancer differently!**



## Step 3

### Be informed - Questions to ask your oncologist

- Where is the cancer and what kind of cancer do/did I have?
- Has my cancer spread? If so, where to and what does it mean for my cancer journey?
- How will this impact the outcome of my treatment?
- How fast or how slow is this cancer growing?
- What symptoms will the cancer cause?
- Is there any room for doubt regarding the test results and diagnosis?
- If I seek a second opinion, may I take copies of test results and X-rays? (Remember you have a right to a second opinion, so don't get stressed by this. It may help you in making treatment decisions.)
- **You choose who will treat you, not your surgeon. It is important to trust your team, so take time to choose them/your doctor. Ask them about their experience with your type of cancer. Ask them how many patients they have treated.**
- Are any further tests required? If so, what are these tests and what is sought to be gained from it? Will further tests hurt?
- What symptoms are likely to occur if the cancer progresses?
- What are my treatment options?
- What treatment do you recommend and why?
- How often is the treatment necessary?
- What are the benefits versus risks of the treatment?
- Is the treatment aimed at a cure, remission (control) or a response?
- What are the likely side effects of the treatment?
- How can these be minimised?
- How much will the treatment cost? (Ask about genetic testing, if applicable, and its value in your case.)
- What should I do or not do while undergoing treatment?
- How long will it be before I know if the treatment is working?
- How severe will the pain be and how can I manage the pain?
- What are the long-term side effects of treatment/medication?
- Who will oversee treatment?
- What can I read on this topic? (Feel free to ask questions about medical terms and their meaning.)

Write down your questions before you see your doctor so that you are prepared prior to your consultation. **Take a family member or friend with to your appointments for support and to listen and help you remember facts/discussions.** Record the session with your oncologist to listen to later (inform and ask permission from the doctor before doing this).



## Step 4

### The impact of cancer on the family

Individuals who are diagnosed with cancer are not alone in this experience; it also affects their families and loved ones. It is important to talk about changes in feelings, roles, needs and expectations during this period.

Remember, the issues that are important will differ for all families, depending on the life stage of the family and the children. Families with young children will have different issues and needs than a family with adolescents or a retired couple.

Take note that marital or parenting problems that exist prior to the diagnosis can be aggravated by the added pressure of the illness. Consider contacting the oncology social worker when you experience problems – it is important to alleviate your emotional pressure while you are going through the cancer crisis.



## Step 5

### Tips for couples dealing with the cancer

- Open and honest sharing is key to navigating this experience.
- Don't try to protect each other – share the good and the bad.
- The supporting partner needs to realise he/she cannot fix this.
- Keep talking although it may be hard – even about the difficult issues.
- It is okay to cry together.
- Allow each other alone time.
- Each person's reaction to cancer is unique – there is no right or wrong.
- Clarify expectations and set goals together – over the short and long term.

#### Sexuality and cancer

- Living with cancer can affect your sexuality, as cancer and the treatment thereof impact on your hormones, body image, energy levels and emotions, which often influence sexual functioning.
- It is of the utmost importance that you discuss these issues with your oncologist or the social worker, as this matter can result in strain and cause problems in your relationship.



## Step 6

### Helping children when family member has cancer

When cancer has entered your life, there is no way to protect your children from the fact that it has entered their lives too. If they are included in the management of the crisis, they can be guided towards accurate, healthy and hopeful interpretations of the events, while learning adaptive coping skills.



#### What to tell young children

- If possible, tell your children the news yourself. Children know when something serious is going on, even when nobody says anything to them.
- Keep in mind the age and past experiences of each child – **keep it simple**.
- Tell each child enough to deal with in his/her world and to satisfy his/her need for information.
- Expect to review the same information over and over.
- Use the word ‘cancer’.
- Teach them that cancer is not contagious.
- Prepare them for expected changes in a life-enhancing way.
- Help them to adjust to change. Find a healthy balance between maintaining routines and making necessary exceptions.
- Empower your children to contribute to your comfort in a way that is appropriate for their age.
- Continue keeping all teachers and coaches up to date regarding your condition and how you would like things to be handled regarding your children.
- If you are unsure whether your children are okay, get advice from a professional person.



## Step 7

### Tips on caring for your teenager

- **Teenagers can be unpredictable.** Recognise the variety of responses that teenagers may have. They may be uncomfortable with some of their feelings and thoughts about your cancer.
- **Teenagers want detailed information** on diagnosis and treatment. They may seek further information on their own.
- **Teenagers need to know the truth** and may feel particularly sensitive to information they feel is incomplete or inaccurate. Teenagers need privacy. They may or may not want to talk about the experience – but ensure they know there are people available when they are ready to talk.
- **Teenagers often write about and reflect on their inner thoughts.** Encourage your teenagers to find creative ways to process their feelings and energy, such as athletics, writing in their journal or participating in other creative activities.
- **Teenagers who want to contribute to care giving** should be allowed to share in tasks, with acknowledgement of the fact that they are not yet adults but also no longer young children.
- **Encourage your teenager** if he or she wants to accompany you to treatment. This can help them feel more involved in how your medical care is provided.
- **Teenagers need consistency.** Ensure that they continue attending normal activities and social events.
- **Teenagers are often self-conscious.** To help your teenagers understand that there are other people going through a similar experience, you might suggest that they participate in a support group, peer-to-peer network or online chat room.

#### Special note

Please visit the following website for a great interactive PC game: Re-mission. It is aimed at children of cancer patients and was written to help them cope through a medium they are very familiar with. Please see: <http://www.re-mission.net>

## Step 8

### Ways in which family and friends can help

- **Acknowledge** that the patient has cancer and don't ignore it in conversations.
- **Give the patient time** to accept the diagnosis.
- **Talk about cancer.** Share your feelings on how cancer is affecting you both. Listen and acknowledge each other's feelings.
- **Be sensitive** to the patient's feelings and thoughts.
- **Encourage** the family to seek emotional help when needed.
- **Be natural.** The person you see is the same person they were before they got cancer – don't treat them any different.
- **Maintain regular contact with the patient and the family.**
- **Share success stories** about people beating cancer. Don't tell cancer horror stories and other people's bad experiences – **they do not want or need to hear them.**
- **Focus on encouragement and hope** – no pity allowed.
- **Practical support is vital** – such as childcare, assisting with transport or cooking a meal.
- **Celebrate important days.** Don't forget birthdays, anniversaries and other important milestones such as the completion of chemotherapy.



## Step 9

### Know about resources

For any information on cancer and resources available in your community, contact the oncology social worker.

The sites suggested below will provide some general understanding of a diagnosis and treatment options. It is still best to liaise with your oncologist regarding your specific diagnosis and prognosis.

Cancercare	<a href="http://www.cancercare.co.za">http://www.cancercare.co.za</a>
American Cancer Society	<a href="http://www.cancer.org">http://www.cancer.org</a>
Cancer Care	<a href="http://www.cancercare.org">http://www.cancercare.org</a>
National Cancer Institute	<a href="http://nci.nih.gov">http://nci.nih.gov</a>
ASCO patient information	<a href="http://www.cancer.net/portal/site/patient">http://www.cancer.net/portal/site/patient</a>
Macmillan cancer support	<a href="http://www.macmillan.org.uk/Cancerinformation/Cancerinformation.aspx">http://www.macmillan.org.uk/Cancerinformation/Cancerinformation.aspx</a>
Survivorship plans – Live Strong Care Plan	<a href="http://www.livestrongcareplan.org/">http://www.livestrongcareplan.org/</a>
Oncolink	<a href="http://www.oncolink.upenn.edu">http://www.oncolink.upenn.edu</a>
Reach for Recovery	<a href="http://reach4recovery.org.za">http://reach4recovery.org.za</a>
National comprehensive cancer network	<a href="http://nccn.com">http://nccn.com</a>
Cancer Alliance of South Africa	<a href="https://www.canceralliance.co.za">https://www.canceralliance.co.za</a>
Cansa	<a href="https://www.cansa.org.za/category/recent-posts/cope-with-cancer/stories-of-hope/">https://www.cansa.org.za/category/recent-posts/cope-with-cancer/stories-of-hope/</a>

<p>The Belong App</p> <p>“Belong” group is a great encouragement for people who travel the journey called “cancer”! I am elated that I found this resource because many questions and feelings were answered.</p>	<p><a href="https://play.google.com/store/apps/details?id=com.belong&amp;hl=en">https://play.google.com/store/apps/details?id=com.belong&amp;hl=en</a></p> <p>or</p> <p><a href="https://apps.apple.com/au/app/belong/id929905619">https://apps.apple.com/au/app/belong/id929905619</a></p>
<p>Cancer Dojo App</p>	<p><a href="https://www.medicalnewstoday.com/articles/305921.php">https://www.medicalnewstoday.com/articles/305921.php</a></p> <p>Cancer Dojo: <a href="https://cancerdojo.com/">https://cancerdojo.com/</a></p> <p><a href="https://www.facebook.com/CancerDojo/">https://www.facebook.com/CancerDojo/</a></p>



**Time flies. It always has.  
But after cancer you treasure the time you have  
and carefully make the most of it.**



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