



# cancercare<sup>®</sup>

by GVI Oncology

Your journey through cancer

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## INTRODUCTION

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

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 we have a holistic approach in treating our patients.

We acknowledge and include the importance of body, mind and soul.

The counsellors of Cancercare are oncology social workers by profession and are all experienced in assisting and guiding patients and families through a cancer journey. We suggest that you make use of the service as it provides a neutral space where you can ask questions, share concerns and deal with unexpected emotions.

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

- Psychosocial assessment and drafting of a care plan
- Individual and family counselling
- Basic information on your treatment
- Emotional support and guidance
- Linking with community resources
- Discharge planning
- Crisis & stress management
- Support groups

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

## STEP1: RECOGNISING THE REALITIES

- Take time to process the news.
- Tell your family and friends.
- Prepare to embrace life changes and to engage with the world.
- Get professionals to help you.
- Tend to your spirit.
- Life is never the same after having cancer. Work towards a level of acceptance.

## STEP 2: TAKING CONTROL OF YOUR TREATMENT

Patients are encouraged to become active members of their treatment team - 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 fight against cancer will improve the quality of their life and may enhance the possibility of their recovery "

### *How to do this?*

- Be well informed – gain information from your doctor about your diagnosis, treatment plan and side effects.
- It is helpful to keep track of all your medical treatment and emotional experiences in a file or journal, so that you have all your information together and can see your progress.
- Learn to express your needs and devise a plan to meet them.
- Develop a specific plan to deal with the physical and emotional side effects that you might experience.
- Remember your experience is unique and your body will react to your individual treatment differently to 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.
- Plan some fun-filled events.
- Surround yourself with the people you choose to be part of your team.
- Do not listen to all the stories that you are told.
- Eliminate people who are negative



Develop an action plan for your personal experience, by setting small achievable goals in all areas of your life, such as:

*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.
- Limiting caffeine, especially in the evening.
- Drinking water – at least 4-5 glasses a day.
- Eating a well-balanced diet.

*Managing hair loss:*

- Consult your hair stylist or visit a wig shop.
- Consider a short haircut before hair loss begins.
- Get hats, scarves or turbans.
- Protect yourself from exposure to the sun and cold.
- Be creative.

*Address pain immediately:*

- Pain affects quality of life and hope.
- Pain impacts on relationships.
- Pain does not mean advanced disease.
- Addiction to pain medication, in people with cancer, is rare.

*Dietary needs:*

- Take charge of your nutritional needs – this is one of the aspects you can assist your body with during your treatment.
- Consult a dietician and get sound advice. Do not listen to everybody and buy expensive supplements. Decide what you are comfortable with and then eat nutritious food in small portions.
- Increase your fluid (water) intake during treatment. It enables the body to discard damaged cells and assists in the rebuilding of normal cells.

*Other aspects to consider could include:*

- A diet action plan.
- An exercise plan.
- A spiritual plan.
- A plan for dealing with your emotions creatively.
- A plan for fun and family activities.
- A plan to achieve your personal goals.

*Having this kind of approach empowers you and moves you away from being a victim to becoming a survivor.*

### **STEP 3: BE INFORMED- QUESTIONS TO ASK YOUR ONCOLOGIST**

- Where is the cancer and what kind of cancer do/did I have?
- Has it spread? If so, where to?
- How fast or 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, can I take copies of test results and x-rays?
- Are any other tests required? If so, what are they and what would they be looking for? Will further tests hurt?
- What symptoms are likely to occur if the cancer progresses?
- What are the 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 minimized?
- How much will the treatment cost?
- What should I do or not do while having 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 be in charge of treatment?



*Bring a friend or family member with you to appointments to listen with you to the oncologist to increase your understanding.*

## **STEP 4: CHECKING YOUR EMOTIONS**

*Expect to take more than one ride on the emotional roller coaster as you move back and forth between a range of different feelings. This process definitely involves taking two steps forward and one step back. Over time, you will come to recognize when your emotional well-being is at risk:*

*Symptoms you have to look out for*

- I feel hopeless.
- Sleep disturbance for more than 2 weeks – sleep too much/little.
- I've gained/lost more than a few kilograms without reason.
- My thoughts race and I can't slow them down.
- I don't feel like being with anybody.
- I'm overly sensitive when anyone criticizes me.
- I'm more irritable with others than usual.
- I don't feel connected to anyone.
- Sometimes I can't make myself get out of bed.
- I don't do things for fun lately – I don't laugh anymore.
- I worry all the time.
- No one would miss me if I were dead.
- I don't see things getting any better in the future.

*Emotional distress*

- Emotional distress is often ignored. Don't ignore it.
- It can include anxiety, stress, depression, mood swings, irritability, insomnia, fear, isolation, denial, loss of hope.
- Speaking to a therapist in this regard can assist you in developing your own individualized action plan.
- Choose people you can share your feelings with and with whom you feel safe.
- Reach out to your loved ones – do not isolate yourself.
- Remember, tears have healing power – so make space for sadness but also plan or fun!

## STEP 5: 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 that 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 other issues and needs than a family with adolescents or a retired couple.*
- *Take note that existing marital or parenting problems 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 the emotional pressure on you while you are going through this cancer crisis.*

## STEP 6: TIPS FOR COUPLES DEALING WITH THE CANCER EXPERIENCE

- *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 – short and long term.*

### *Sexuality and cancer*

*Living with cancer can affect your sexuality, since cancer and treatment impacts on your hormones, body image, energy levels and emotions that often influence sexual-functioning.*

*It is of the utmost importance that you discuss these issues with your oncologist or social worker, as this matter can result in strain and cause problems in your relationship.*



## STEP 7: HELPING CHILDREN WHEN A 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 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 changes. 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 to keep all teachers and coaches up to date regarding your condition and how you'd like things to be handled regarding your children.

*If you are unsure whether your children are okay, get advice from a professional person.*

## STEP 8: TIPS ON CARING FOR YOUR TEENAGER

- *Teenagers can be unpredictable.* Recognize 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* regarding 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 upon their inner thoughts.* Encourage your teenagers to find creative ways to process their feelings and energy, such as athletics, writing in their journal or other creative activities.
- *Teenagers who want to contribute to care giving* should be allowed to participate in tasks that respect 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 in control about how your medical care is provided.
- *Teenagers need consistency.* Ensure that they still attend 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: HYPERLINK “<http://www.re-mission.net>” <http://www.re-mission.net>



## STEP 9: WAYS FOR FAMILY AND FRIENDS TO 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 child care, 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 10: KNOW ABOUT RESOURCES

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

*Recommended Internet sites:*

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

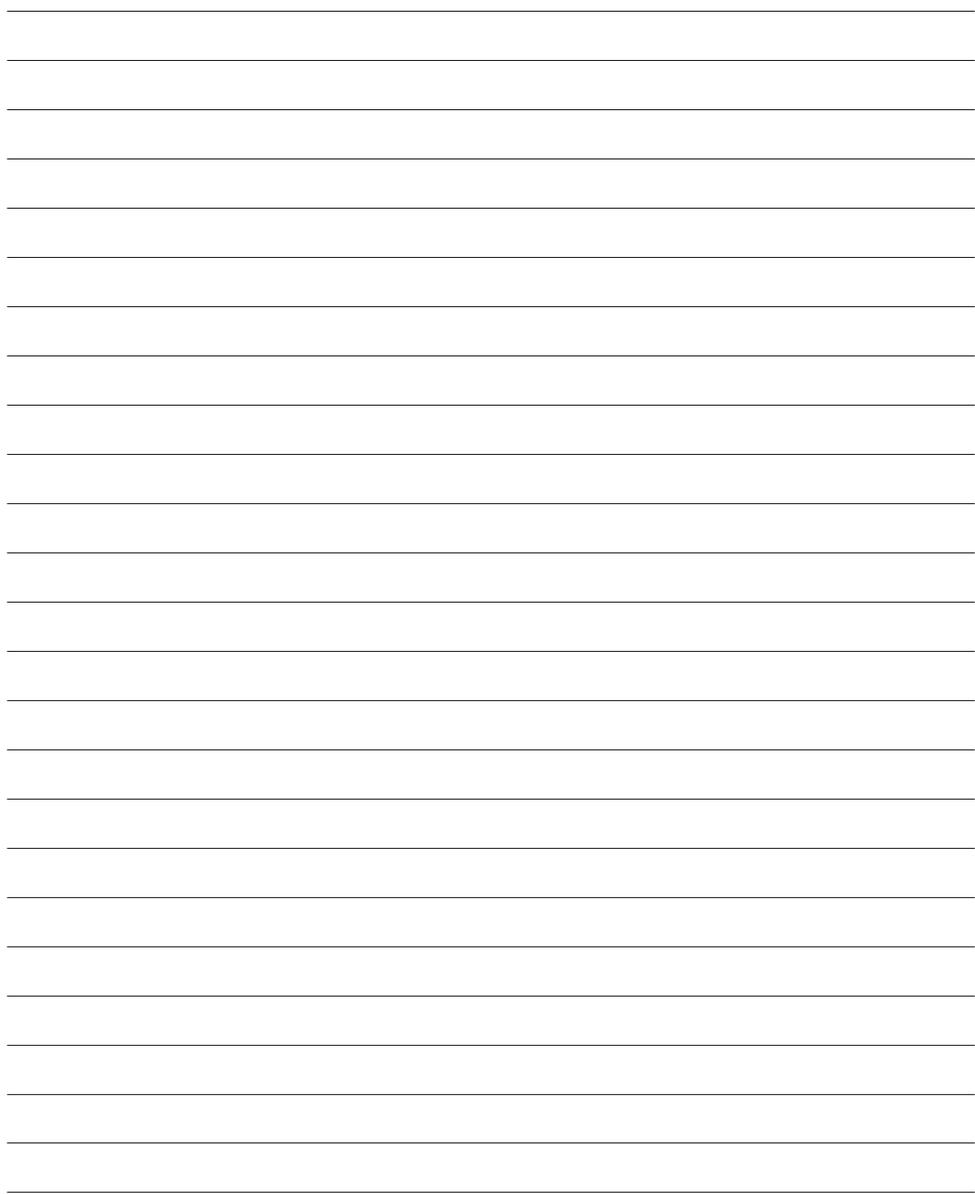
- [www.cancercare.co.za](http://www.cancercare.co.za)
- [www.cancer.org](http://www.cancer.org)
- <http://nci.nih.gov>
- <http://plwc.org.za>
- <http://www.cancer.net/portal/site/patient>
- [www.macmillan.org.uk/Cancerinformation/Cancerinformation.aspx](http://www.macmillan.org.uk/Cancerinformation/Cancerinformation.aspx)

- [www.livestrongcareplan.org](http://www.livestrongcareplan.org)
- [www.oncolink.upenn.edu](http://www.oncolink.upenn.edu)
- <http://www.plwc.org.za>
- <http://reach4recovery.org.za>
- <http://nccn.com>

*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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\*These units have clinical research units on site