

Cancer Care Kenya

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Patient information leaflets

Treatment aftermath: A survivor's dilemma

Guidelines for cancer survivors, their families and friends

This booklet is intended as a general introduction to the topic: *treatment aftermath*. It should not be seen as a substitute for your doctor's advice. You can discuss issues raised in this booklet with your doctor.

If you are still receiving treatment or your doctor has told you that the cancer has advanced, this booklet may not be helpful.

Who is a cancer survivor?

A cancer survivor is one who has finished the active treatment for cancer. This term has different meanings for different people. For some, it's a strong positive label, but for some, its implication is just coping with the uncertain future. Some patients consider themselves as people living with cancer. This leaflet intends to help you to live life to the fullest after cancer treatment. The transition from patient to survivor is not an easy task. They perpetually ask themselves-what now?

A 'new normal' life?

A person embarks on a cancer journey with a feeling that his/her life is on hold. They do not know where they are heading to or where they are going to end up. But once they finish their treatment, they don't know how to re start as well. Once the treatment is over, survivors may think that their life will return to what it was like before the cancer diagnosis. Many of them will identify their state as a 'new normal' state. Infact the disease changes them. They may not look different outwardly, but inward changes are tremendous. They re-evaluate and change their values, goals, priorities and outlook on life.

How you feel and how you cope is purely subjective. It depends on the type of cancer and treatment you had, and what you're like as a person. 'I used to do many things in past', 'the way things used to be', 'I wasn't like this before', 'Ooops, I need to take rest for a while are some of the remarks of the patients who just completed the treatment .

Ongoing side effects of the treatment, general health status, other chronic illnesses also do matter for this 'new normal' state. Sometimes the after effects of treatment may make the daily life difficult.

Cancer as a life changing experience:

Cancer and its treatment gives people an opportunity to re-examine their life choices. They start re-defining their relationships. The priorities will be changed and goal setting will be more realistic. This is a gradual process, but has a positive effect on one's self.

Family as a support system:

Once you finish your cancer treatment, your family members will be relieved and try to cheer you up. They want you (also themselves) to forget the traumatic past. They forget the fact that you need to get more time to adjust with the new normal state. You have to explain them. Tell them that recovery is an ongoing process, and that you need time to think about what you've been through. You can't just 'get on with it' and move on as quickly as they might want you to. Don't feel pressured to make life changes if you don't want to, or if you are not prepared for it.

Some practical hints:

Ask yourself:

What things are important to me?

Am I doing the right things?

Am I doing things at my own pace?

Don't start any activities straight away. Take your own time to decide.

If you cannot go out alone confidently, seek the help of one of your beloved.

Be prepared for all kind of reactions.

If their reactions are not up to your expectation, don't feel upset.

Share your problems in support group gatherings or with your dear ones.

Talk to your doctor if you feel depressed.

Feelings of transition

Once the treatment is over, the feelings are different from individual to individual. It's normal to have many different feelings after treatment ends. Common feelings include relief, isolation, fear of the cancer coming back, uncertainty about the future, frustration with family and friends, anxiety about checkups, worry about side effects, lack of confidence and anger. These feelings can make it hard to accept that the cancer experience is over. Acknowledging and talking about how you're feeling may help you work through your feelings.

All survivors need more love and support to face this period of transition smoothly. They should never feel that they are alone in this cancer journey.

Fear of recurrence

The most common feeling of a cancer survivor is the fear of cancer coming back. The oncologists stress the importance of regular follow up, on account of the chance of cancer coming back. Survivors usually search the net and get the statistics. They feel as if the sword of Damocles is on their head. The first one year after completion is the most feared period, after that they tend to adjust with it. At times, they revert to this fear on some instances like their own birthday, festivals, anniversary dates, follow up appointments.

Whenever they hear about someone else's diagnosis or when they come across with a Harambee, this feeling will be ignited. Media reports may also trigger it. You feel as if your own body is betraying you. Risk of recurrence is different for each person. It depends on many factors including the type of cancer, stage at diagnosis, treatment and the time since treatment. For example, the same type of cancer can grow at different rates in different people. In general, the more one person enjoys a disease free state, the less chance of getting the disease back.

How to manage the fear of recurrence:

- Talk to a medical professional.
- Join a support group of cancer survivors.
- Seek the help of a professional counselor.

Follow- up care:

Regular follow up is extremely important in cancer care. It helps the doctor to assess the well being of patient, symptoms or signs of recurrence, side effects of treatment etc. The schedule for follow up are different for different types of cancers. Generally every 3 months for the first 2 years, every 6 months for next 3 years and yearly once thereafter is the follow up pattern recommended in our centre. Survivors will be very much anxious and apprehensive for the follow ups. Memories about the previous treatment fear that one would be told that the cancer has come back again, comments of others all make them vulnerable. Once you are through a follow up without any troubles, next time onwards, you will approach them with less concern and fear.

Remember to get a detailed summary from your oncologist, if not given, insist for one. It should contain all details of your disease and the treatment you got. Contact information of your oncologist and the treatment centre also must be mentioned in it. This is an important document which you need to carry to your GP.

Survivor's children:

Children might have seen you less often than they used to , while you were undergoing treatment. They may be worried that you may die. It is very hard for some children to adjust with treatment of cancer and its aftermath. They may remain worried why the life hasn't gone back to the state it used to be, even after completion of the treatment. Reactions of children varies according to their age. You have to try to remain as open as possible. Be honest with them.

Sexuality and intimacy

Anyone who had cancer treatment may have concerns related to their sexuality. This is especially true for those who are on ongoing anti hormonal therapy like in breast cancer, prostate cancer etc. Some patients with colon cancer or rectal cancer may have stoma on their belly. Women treated with cervical cancer will be afraid for having sex. Physical and emotional intimacy will be thwarted. Altered body image, following mutilating surgeries may make you less sexually appealing. You may not like to be seen undressed.

Some of the survivors even prefer to stay away from simple acts like kissing, hugging for fear of ending up it sex. This may embarrass the partner.

Talk to your partner. Tell them how you feel and why you don't want sex now. Reassure them that you love them and you want to be close with them. Most partners will happily adjust with you and wait patiently for you. Infertility secondary to cancer treatment also can cause problems in maintaining sexual relationship

Tips for coping with sexual problems:

- Try to spend more quality time with your spouse for e.g.: a week-end holidaying, walking together etc.
- Express affection by holding hands, touching, hugging, talking etc.
- Always discuss with your doctor all issues related to sexuality, ask for medical help in case you feel less sex drive, erectile difficulty, hot flushes etc.
- Some forms of treatment may bring menopause in women, either temporarily or permanently. You may get perimenopausal symptoms, which can be medically managed.
- Men may get andropausal symptoms after certain treatments like removal of testicles; hormone blockade etc. They may feel tiredness, mood swings and hot flushes. Discuss with doctor and get remedies if they are cumbersome.
- Remember that most of these symptoms are temporary; you will be okay in due course of time, perhaps after a year or two.
- There are moisturizing creams and lubricants for vagina available, get them with a prescription.
- Do not go for any OTC drugs or fake medicines.
- If you are on pain medication, take a break through medication half an hour before the sexual activity.
- Your partner has to spend more time to arouse you, as your sexual drive may be low, hence engage in more foreplay.
- During sex, attain your preferred position and posture.
- Shorter sessions are preferable for doing sex-because your energy levels may be low.
- A joint session with a therapist capable of dealing with issues related to sexuality is always desirable.

Complementary therapies after treatment:

Different types of complementary therapies are available in our centre, at the Faraja Cancer Support group. They include reflexology, massage therapy, relaxation exercises, meditation, yoga and nutrition. Please discuss with your doctor before starting them. Some therapies may not be appropriate for some survivors. Survivors using complementary therapies report that these therapies help them cope better with the treatment related side effects, relieving the stress, improving the mood.

Staying healthy after treatment:

Maintain a healthy body weight as per the guidelines. It reduces the risk of cancer recurrence; at the same time prevent a new cancer coming up. You can seek the advice of a dietician/nutritionist. If you have lost a lot of weight during treatment, you may have to regain it and thereafter maintain it carefully. Engage in good physical activity .It helps to protect against many cancers. There are many benefits to being active besides the possible protection from the cancer coming back. Talk to your doctor and find out whether engaging in exercise will help/hamper your recovery. Start physical activity slowly and increase gradually. Exercise can also boost energy levels, decrease fatigue, increase strength, relieve stress, reduce heart disease and lower anxiety and depression. Resume your normal work/duty once you feel confident.

Health tips

- Make fruit and vegetables, wholegrain breads, cereals, rice and other low-fat foods the basis of your diet.
- Choose lean cuts of meat and trim as much fat as possible before cooking.
- Remove the skin from chicken.
- Cook food in ways that use less fat – grill, steam, or bake.
- Use a nonstick fry pan or a spray of oil when pan-frying.
- Try low-fat varieties of milk, yoghurt and cheese.
- Use only a scrape of butter or margarine.
- Avoid high-fat snacks such as crisps and biscuits.
- Eat when you're hungry and stop eating when you're full.
- Dietary supplements like vitamins, herbal tablets etc are **not** a substitute for whole food.
- No need to give up meat. However eating too much red meat is not good.
- You can eat both raw and cooked vegetables, but remember that too much of boiling can reduce the amount of vitamins in vegetables.
- Making vegetables into juices may lose their fiber content. So it is preferable to eat them whole.
- Alcohol has to be avoided, if not possible, limit it to the minimum.
- Quit smoking if you haven't done so. Never restart it.

Seeking support:

Most of the cancer survivors need support after treatment finishes. The availability of services may vary depending on where you live. Some services are free, but others may have a cost. Joining a support group of people who had similar experience is a very good way to share your problems and it has a positive therapeutic effect. In these support settings, survivors can speak openly, share tips with others, and just be themselves. They probably feel comfortable talking about the diagnosis and treatment, relationships with friends and family hopes and fears about the future.

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