

What to do after a cancer diagnosis – top tips to helping you navigate your cancer journey

A cancer diagnosis usually comes as a shock. It is a life-changing event and can cause chaos and anxiety for you, your family and friends. While there is no 'right' way in dealing with your diagnosis, here are some tips to help you manage this emotionally difficult and confusing time.

Here, Dr David Eedes, an Icon oncology advisor, shares his advice on what questions to ask your doctors and how to navigate the initial next steps of your cancer journey.

Start with a plan

Having a clear plan of action as soon as possible after the diagnosis of cancer has been made is useful in this initial period of shock and fear. Your treating specialists, whether a surgeon, oncologist or GP, are there to assist you in understanding the situation more clearly and planning further investigations and proposed treatment. This information assists by giving you some practical things to focus on. This helps in dealing with the emotions and confusion that are typical at this time of personal crisis.

Involve friends and family

When you see an oncologist for your initial consultation there is usually a lot of information passed on and this may be difficult to remember or understand. It is a good idea to ask a trusted friend or family member to accompany you. Not only will they be a source of support, but they can also help remember and decode what was said during the consultation and can possibly take notes for later reference. Feeling overwhelmed is common. This means you could forget to ask important questions: something that the person with you can possibly ask on your behalf. If you have questions that you want to ask and have thought of before your consultation, taking a list along is helpful.

Keep it simple

While you might be tempted to conduct your own research prior to meeting with your treating doctor, try to come for the first consultation with an open mind. Avoid arriving with a file full of information and a preference towards a certain kind of treatment. Remember you are consulting a specialist for their expert opinion and it is best to hear them out and give them space to follow standard consultation procedures. Allowing this will avoid important steps being missed or forgotten by the doctor. Once the time for discussion comes, then this is the time for questions to be asked and possible treatment options discussed. Your opinion or wishes can be mentioned at this point.

If needed, set a date for a follow-up consultation

The initial consultation – which generally will take an hour - is just that, a starting point. If you feel that your questions have not been adequately answered, or if you want the doctor to give you more detailed information, set a follow-up consultation. Often further tests are needed before the oncologist has a clear idea of your particular situation and then a more detailed discussion can follow. If you feel that the doctor you see initially is not a good personal fit, or you feel that the information you're given upfront is not answering your questions, you could seek a second opinion. Your GP or referring doctor could help with this.

Understanding your cancer type and stage

On confirming your initial diagnosis, the next step is to determine the exact type of cancer that you have, where it started and if it has possibly spread to any other parts of your body (metastasized). This might not be evident initially and more tests may be requested by your doctor.

Once all this information is collated, the oncologist will have a clearer idea of how advanced your cancer is. Cancers are staged according to how much they have spread from where they started initially and are referred to as Stage 1 - 4. In a common cancer like breast cancer as an example, spreading to the lymph glands under the armpit or to other parts of the body indicate what stage of cancer it is and allow the oncologist to give the patient the possible treatment option and possibly the longer term outlook or prognosis. This information is based on the oncologist's training and experience as well as data that comes from large international clinical trials collected over many years. However, each patient is unique, and treatment is tailored to them and their cancers as far as possible.

Preparing for treatment

Once you know what and where the cancer is, as well as what the probable prognosis is, the specialist will discuss what they believe the best treatment plan for you is. They may recommend specialised tests to determine your cancer's particular characteristics as this may help refine treatment choices. Depending on what has been done up to that point, a biopsy or operation to remove the cancer may be recommended. Specialised blood tests and radiology - X-rays, ultrasounds, MRIs or PET scans – may need to be done for further information.

Prior to going for one of these tests, it can be helpful to prepare by finding out what this procedure entails. Ask questions, do online research or, consider making the booking personally and find out what you need to do to get ready for the test.

Treatment

Once all the preliminary tests are completed, your oncologist will recommend a treatment plan that is unique to you. This choice of treatment will take into account your lifestyle, age, other illnesses, and your wishes, etc. So while you'll find plenty of literature online about different types of treatments, they are not always a good fit for you.

Your doctor will also explain why they believe the treatment plan they recommend is the right route to take. Your case might also be discussed and debated with a team of doctors at a multi-disciplinary clinic where various specialists will evaluate your case and make a recommendation. This is based on internationally accepted standards and guidelines.

While a particular treatment may be recommended, your opinion and wishes still matter; you might want to ask about other options and decide with the oncologist, based on your preferences, what treatment you would prefer. Remember, this may be a compromise and you need to be clear what the downsides of not taking the oncologist's advice might be. For some people quality vs quantity of life is more important and you need to clearly discuss with your oncologist. If you feel you are not being heard, possibly a further opinion would be best.

Side effects

Most cancer treatments have certain side-effects and your doctor should have explained these to you when discussing your treatment plan. Some patients want to know every detail while others prefer to know very little; the choice is yours of course but it is good to be prepared and know how to deal with them effectively and who to contact. To help you understand this information, it is advisable to acquire printed literature from your doctor, discuss the treatment with the practice nurse or to consult different websites. Make notes of any questions you may have as this material is often quite technical and you may want to ask more detailed questions from the team that are treating you. Things like hair loss are important for patients to know about. If it is going to fall out

you may want to ask when that will happen, how much will fall out and when it will grow back again, etc. With this insight you can plan ahead to see your hairdresser, get a wig made or find a lovely scarf or hat.

If you are a younger patient, fertility could be of concern. It's key to first establish what the risk is and then to look at your options. Sperm banking for men or egg preservation for women needs to be discussed before the treatment starts.

Understanding the side effects could also assist you in planning ahead for when you'd need time off work or if you can exercise, etc. This is also helpful for making practical family and professional arrangements.

Alternative treatment routes

For some patients conventional cancer treatment – surgery, chemotherapy or radiotherapy – is not something they wish to embark on. Some may consider alternative or complementary therapy options as being more attractive. This is a personal choice and it is important to understand what the pros and cons of doing this are. If you are considering this route, it is best to inform your oncologist about your decision. If you are planning to do this in conjunction with conventional cancer therapy, complementary treatments could interfere, counteract or negate your anti-cancer treatment and this needs to be discussed openly. Most oncologists will support you in this as long as they are informed and feel it will not compromise your outlook.

Covering the cost of cancer

The diagnosis of cancer may have an impact on your financial situation and so managing your finances from the beginning is very important. It is advised that once you have been diagnosed you contact your medical scheme to find out exactly what scheme option you are on and what its oncology benefits are. They can also inform you of processes to register on their oncology programme, give details of its authorisation processes and advise if there are any restrictions about which hospital or treatment centre you might go to. It is also an opportunity to find out about upgrading your medical scheme option in order to be able to access more expensive treatments that your current option may not cover.

Also consult your insurance broker as you may have a life insurance policy with a dread disease cover or gap cover insurance. This will come in handy if there are shortfalls in costs associated with your treatments or restrictions on your ability to generate an income.

In certain circumstances your medical scheme oncology benefits may not cover the full cost of the treatment recommended to you by your oncologist. Some patients opt to fund the treatment themselves or look into upgrading their medical scheme option as mentioned before. It is also important to find out from your oncologist if there is the possibility of accessing a clinical trial that might have new treatment options not yet available locally.

Sources of support

After your diagnosis, or while undergoing treatment, it is common that you or a family member may feel anxious or depressed enough to consider seeking emotional and psychological support. Do not feel ashamed of this and rather deal with it early on. Management of anxiety and depression has been shown to have a positive impact on your cancer outcome and your quality of life during and after your treatment. Support can be from a counselor or psychologist for talk therapy, or, in some cases, a psychiatrist to discuss medication to deal with the depression and anxiety.

Talking to people who have been through a similar experience may be helpful and connecting with a support group can be useful. The Icon practice counselor, CANSA <https://www.cansa.org.za/> or your local hospice are good places to find out about these groups. They too offer support for cancer patients and their families. The Icon website also has details of organisations that can be approached for this sort of information.

There is plenty of literature online, but it is important to find sites that are solid and are not fronts for commercial promotion of various treatments. Any of the UK NHS (National Health Services) sites are reputable <https://www.nhs.uk/conditions/Cancer/>, as are the US NHI (National Health Institution) sites <https://www.cancer.gov/resources-for/patients>

The diagnosis of cancer is a life-altering event for any person and their family. It is a time of emotional turmoil, physical changes and many ups and downs; this is never an easy time. Being informed, being prepared and making sure that certain of the recommendations given here are dealt with early on will help to alleviate some of the challenges that a patient faces on their journey through treatment. Following some of these tips will help smooth the way and prevent unnecessary and avoidable distractions. This will allow the focus to be kept on the important things such as achieving goals and treatment milestones.

What is Icon

Icon is a countrywide network of oncologists, representing over 80% of the all oncologists in private practice in South Africa. Icon was started 10 years ago to ensure and advocate for the highest standards of care for cancer patients. Certain medical schemes are contracted with Icon and you need to check on this.

All Icon oncologists are listed on the Icon website – <http://iconsa.co.za/> - and you can find an Icon accredited oncologist nearest to you on this site. Icon accredited oncologists work together to offer patients the best quality of care while aiming to minimise personal financial strain. Icon has strict accreditation processes and all of its units are accredited using internationally and locally accepted quality standards.

One of the many benefits of using an Icon network oncologist is the Icon pre-authorisation software which links directly to medical aids and allows permissions / authorisations to often be immediate. This means that you can get started on your treatment promptly.

Icon Oncology has developed its treatment protocols taking into account patient needs and looking for the best outcomes for each patient. By following a value-based care approach it aims to deliver affordable cancer treatment options without compromising quality. The model was developed to ensure the right treatment for the right patient that would be given by the right specialist. The standardised protocols are aimed at reducing waste or depleting resources. This was with the aim of trying to ensure that your medical aid oncology benefits are spent in your best interests but without compromising standards.

These protocolised treatments are approved by the contracted medical schemes and mean that there is less delay in getting treatment authorised. Icon also has a medicine formulary of locally registered cancer medicines that will be paid for by the scheme generally without co-payments. This takes some of the stress out of a cancer patient's experience.

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