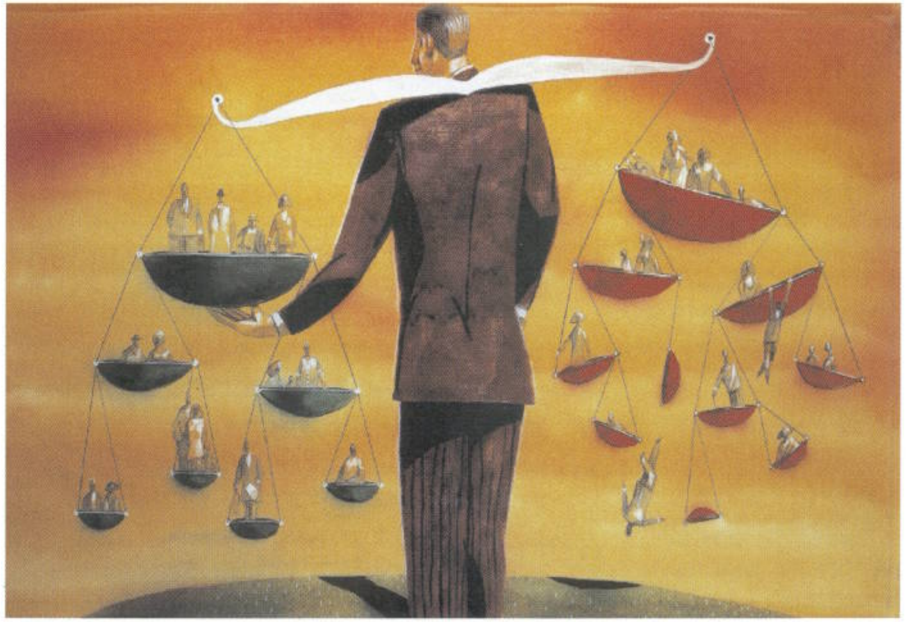
Living with Advanced Cancer



Your doctor has indicated that your cancer is at an advanced stage and it is often at this time that quality of life becomes an important part of cancer care. Quality of life care can include:

- Anti-cancer treatments
- Symptom management
- Psychological support for patients and their families
- Preparation for future care

Your doctor and the health care team will help you determine which treatments and services are most appropriate in your case and how they can be organised.

This pamphlet provides an introduction to some of the options that are available to you.

Communicating with the health care team

There are often barriers to having an effective discussion with the health care team about your health.

Talking to your doctor – It is natural to hold your doctor in high esteem, but this may prevent you from asking questions, expressing concerns, or telling the doctor when things are not going well. However, it is important to speak up, as your doctor needs this information to optimally co-ordinate your care.

Being embarrassed – Sometimes, people with cancer avoid bringing up issues because they do not want to seem ignorant or uninformed and they struggle with their concerns alone instead of getting help with them. No concern is too small or insignificant for discussion with your health care team. They can only deal with the issues that are bothering you if they know what they are.

Forgetting your questions – In stressful situations, it is natural to forget questions. Writing down a list before hand will help you to remember the questions you want to ask. You might also want to write notes during the visit, which you can look over when you get home.

Involving your family – Members of your family may have questions for your doctor. It may be useful to bring your family along to the appointment. The presence of family members can also help you to process and understand the information afterwards.

Medical Jargon – People with cancer may hold back from communicating if they are confused by medical jargon and terminology. Make sure you understand what you are being told, and if you don't understand the meaning of a word, ask your doctor. It may also be useful to repeat back to the doctor what you thought they said.

You might also like to ask your doctor if they would draw you a diagram or picture, especially if you think it would help you understand your illness better. You can also ask your doctor or any member of the health care team about where to obtain easy-to-read information booklets, which explain the issues and which you can refer to in your own time.

Be prepared – Often doctors need to look at your medical scans and/or reports from the last couple of years and will ask you to bring these along to your next appointment. If you are unsure about which test results to take with you – it is best to take all of them or otherwise phone up ahead of your appointment and find out which test results your doctor would like to review.

When your appointment is over, make sure you leave with a contact name and phone number. You may also want to consider bringing your diary with you so you can coordinate your appointments. It is also beneficial to allow some time before and after your appointment to calm and prepare yourself.

Anti-cancer treatments

Cancers can be treated in a number of ways including surgery, chemotherapy, radiotherapy and palliative care. In patients with advanced cancer, the latter two are most commonly used. It is best to discuss with your doctor what treatment options are available to you.

Side effects – Some anti-cancer treatments can have side effects, these may be subtle or more severe. Your doctor will discuss any significant side effects with you before commencing treatment but you may also want to ask questions. If you do experience any unexpected or painful side effects, you should immediately inform your doctor. Additionally, if you have any questions about combining medications, you should ring your doctor or chemist.

Symptom management

Many patients with advanced cancer are afraid of being in severe pain. Patients with advanced cancer can expect physical comfort and control of distressing symptoms such as pain, fatigue, nausea and shortness of breath. But in order to obtain this relief it is important to give your health care team feedback about these symptoms. Think about how often and when the symptoms occur, what treatments have been tried and which were effective.

Sometimes, your treating doctor will ask for assistance or advice from the palliative care team about managing your symptoms. Palliative care involves treatment to relieve, rather than cure, symptoms caused by cancer. It concentrates on your quality of life and that of your family. The focus of palliative care is controlling pain and other symptoms, and meeting a person's social, emotional and spiritual needs. Your doctor can refer you to the palliative care service.

Psychological care

Patients with advanced cancer often experience emotional distress as well as physical symptoms. The palliative care team can assist patients and their families in dealing with difficult emotions such as anger, fear, anxiety, grief and loss. Your doctor can also arrange for counselling and other psychological services that may be helpful for you and/or your family. You may also wish to speak to a representative of a particular church/religion; a member of your health care team can usually arrange this type of meeting.

Planning for the future

Some people prefer to plan for the future; others like to address issues as they arise. There are many issues that can come up for patients in the advanced stages of their illness:

Personal beliefs – Some people discover that their religious or spiritual beliefs change. They may also find themselves thinking about their life goals and reflecting on how ready they feel to approach the end of their life.

It is common to feel afraid of the unknown. People deal with feeling scared about what could happen to them in different ways. For some, it is important to talk with friends, family or members of the health care team about how they are feeling. Others may prefer to keep their feelings private and deal with them on their own.

Unresolved matters – People sometimes find that they have a strong desire to "tie up loose ends". This might mean making financial arrangements and planning for your family e.g. making a will. Sometimes, it means contacting someone with whom you've been out of touch for a while, or even saying certain things to the important people in your life.

Conveying your wishes – You may wish to talk with your family about your preferences for care, such as where you wish to be cared (e.g. home or alternative care). You might also want to think about someone in your life who could speak for you and relay your wishes, should you become too unwell to do this for yourself. If there is someone you trust to make decisions on your behalf, you may like to tell them this and make sure they know what your wishes are.

Hospital care decisions – In hospitals, emergency medical personnel are obliged to attempt to revive a person by administering CPR (Cardio-Pulmonary Resuscitation) if their heart has stopped or they have stopped breathing. CPR involves a number of procedures including pushing on the chest, external electric shock to the heart, administering drugs into the body by putting them through a vein, placing a tube into the throat to assist breathing and fitting a mask to the face which pushes oxygen into the lungs.

CPR is most effective for resuscitating patients after heart attacks and accidents, and if it is administered quickly about 40% of people can be revived. However, many patients do not recover fully and suffer long-term consequences such as brain damage.

People with advanced cancer often choose for resuscitation not to be attempted on the advice of their doctors. This decision is made for a number of reasons. Attempts to resuscitate people with advanced cancer are rarely successful. In these cases survival rates are less than 5% and those who are revived may suffer a further deterioration in their condition and quality of life. For those who are successfully resuscitated, few regain consciousness and almost none ever leave hospital. It can also be distressing for the family to see their loved one go through attempts of CPR procedures. Additionally, patients and their families commonly report that they have “suffered enough” and do not wish for their distress to be prolonged.

Decisions about your preference for resuscitation are deeply personal. If you need to make this type of decision, your feelings and beliefs (and perhaps those of your family or others close to you) are important to consider. You might also wish to ask your doctor what they think about CPR for you. If you decide that whilst in hospital you do not wish for resuscitation to be attempted, a formal note of this can be made, after discussion with your doctor. If your condition improves, or you change your mind, you can reverse the do-not-resuscitate order.

A do-not-resuscitate order does not actively bring a person’s life to an end; rather it gives permission to stop trying to extend the person’s life in ways that are intrusive and unlikely to be successful. A do-not-resuscitate order only specifies your preferences for CPR. It does not affect the quality of care, including symptom relief that you will receive.

People differ in how they cope with their cancer. Many people believe that an optimistic attitude is helpful. Some patients manage to remain positive by not thinking at all about their illness. Others try to remain hopeful by concentrating on new drug treatments and advancements in medical technology. It is important that people find ways that work for them to remain hopeful about the future.

Whilst we know that maintaining hope is important to patients and their families, they have also told us that there are some difficult issues which they would like more time to consider.

Patients who read this pamphlet are likely to be at different stages in their illness, this means that some of the information may not be relevant to you at this time.

We hope that the recommendations in this booklet might be helpful to you and your family, even though it is natural for material of this type to be distressing.

There are many ways in which we can help you cope with your illness and improve your quality of life. Please do not hesitate to ask any member of your health care team for further advice.

This pamphlet 'Living with advanced cancer' was originally developed for use in a research study on decision-making in patients living with advanced disease. The study was generously funded by the Patricia Ritchie Psycho-oncology Scholarship and the NSW Cancer Institute Research Scholar Award.

A number of individuals were involved in this research, including:

- Rhea Stein, School of Psychology, University of Sydney
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- Fran Boyle and Stewart Dunn, Pam McLean Cancer Communications Centre, University of Sydney

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