

# INTRODUCTION

## Purpose of *Life, Hope and Reality*

Progress in cancer screening and treatment have resulted in an increase in the number of people diagnosed with cancer and the number of people who live with it for longer periods of time. For some, following intense treatment, the cancer may be cured, whereas for others it can spread or come back. This means that some individuals live with the disease for many years.

The purpose of this booklet is to provide information about the needs that people with advanced cancer may be experiencing and key strategies to help in managing these. It also provides information about other resources and services for further support, if needed.

This booklet draws on the many information resources that already exist for people with advanced cancer, including those available from state based Cancer Councils. It aims to bring this information together into one resource and presents key take-home messages. This booklet integrates the most recent research evidence, as well as experiences of people with advanced cancer, their family, friends and health professionals. This may help you, and your family and friends, manage some of the challenges imposed by an advanced cancer. We hope that this information will assist you to live as well as possible.

Cancer comes in many different forms, with many different treatments and the same cancer can affect people differently. You will find responses to some common questions and concerns throughout this booklet and although no single answer will cover every need you may be experiencing, this booklet may help you identify your needs and provide some information about where you can go to obtain additional care and assistance.

**This booklet is not meant to replace the information given to you by your health care providers; rather it is designed to complement their advice and suggestions.**

## How to use *Life, Hope and Reality*

Depending on your needs, you may decide to read this booklet from start to finish or refer only to the sections that are most relevant to you.

Certain sections provide information that your family and friends may find useful as well.

In reading this booklet, you may uncover issues you may not have discussed with your health care team. **The Needs Assessment Tool – Patients & Families (NAT-P&F)** is a short guide included on pg 116 to help you and your family and friends identify some of these issues. It will guide you to where to find information in this booklet which may help, or allow you to flag the issues of concern to be raised with members of your health care team.

Feel at ease to complete **The Needs Assessment Tool – Patients & Families (NAT-P&F)** and take it to your health professionals. Together you will be able to discuss areas where you and your family may need help, and where to find that help.

Complete this Needs Assessment as often as you think is necessary. The health professionals you discuss these issues with may vary along your cancer journey; it may be a doctor (doctor or specialist), a nurse, a naturopath, a dietician, a social worker, a psychologist or others and these tools may help them identify what you need. Your symptoms and needs may also change over time, so it is important for you and your team of health professionals to reassess your needs regularly and adjust your care plan to ensure you are as well and as happy as you can be.

We have also included at the end of this booklet other assessment guides which are sometimes used by health care providers to better understand your needs and symptoms.

**Many are available and we have only included the following few:**

**Page 124:** Symptom Distress Scale may help you identify some of the physical symptoms you are experiencing.

**Page 126:** Fatigue Scale may help you to identify the level of fatigue you are experiencing.

**Page 130:** Pain Assessment Tool may help you better identify any pain you are experiencing.

**Page 133:** Emotion Thermometers may help you identify some of your emotional needs, including distress, anxiety, depression and anger.

**Page 135:**

Helpless/Hopeless and Fighting Spirit Scales may help you further identify some of your specific emotional needs, particularly if you feel like giving up or think nothing else can be done.

This booklet, including the assessment tools provided, recognise that your needs may not be limited to the disease itself and can include a broad range of issues such as emotional support or financial guidance.

This booklet also includes suggestions about where you or your health professional may find more information about available local services to meet your needs.

Throughout this booklet key points are emphasised in boxes labelled **Facts, Question and Answer (Q&A) and Tips**. These are meant to further explain important issues and provide strategies to help you manage.

As you read this booklet, if there is a word you do not understand, please consult the glossary on pg 140.

## Where to go for help

Your doctor or relevant members of your multidisciplinary health care team (your oncologist, surgeon, specialist, nurses, social workers or other health professionals) should be the first ones you call on for any concerns.

In general, specialists should be able to help with matters related to your cancer. You may find that the health professional you are closest to, such as the nurse or social worker, may be the best person to speak to about other personal and social concerns. If you are not sure, ask your doctor about where you might find the support you need.

If you are looking for further information on local support services, your community health centre may be able to help with suggestions and contacts.

Another helpful resource is the **Cancer Council Helpline** (phone 13 11 20 anywhere in Australia at the cost of a local call), where experienced professionals provide free confidential information and counselling and can put you in touch with other services.



The **Commonwealth Carelink Centres (Freecall 1800 052 222)** provide information for older people, people with disabilities and ill health as well as those who undertake a caregiver role. Further information on these services and others, is provided throughout this booklet.

Your doctor and community health centre should have information on local palliative care services (for definition of “palliative care” see Glossary on pg 140). In Chapter 8 of this booklet, you will find details about palliative care and how palliative care services can support you and your family.



### FACT

It is a common misconception that palliative care is the “last stop” for people with advanced cancer. In fact, palliative care staff and specialists can help you and your family at any stage of your illness after curative treatment, especially given their training and experience in helping people with a wide range of needs and concerns.

## About cancer

### What is cancer?

Cancer is the abnormal growth of the body’s cells, caused by damage to the genes that control the cells’ growth and regeneration. This damage may be environmental, inherited or both.

Abnormal cells may grow into a lump called a tumour which may be benign (localised and non-cancerous) or malignant (cancerous and capable of spreading to other parts of the body).

Cancer usually starts as a tumour at a “primary” site (main tumour site). It may be contained there, or it may spread to surrounding tissue via the lymphatic system or blood stream. Cells that move to other parts of body and grow into new tumours are said to have metastasised, creating “secondary” cancers.

In some cases, a new cancer may appear after a primary cancer is cured.

Cancer is said to be “advanced” when it reaches the point where treatment is unlikely to eradicate the abnormal cells. At this stage, the disease may progress, or it may be controlled but chronic. People can live for many years with advanced cancer.

## Types of cancer

Cancers are named after the part of the body where they start. A secondary cancer is still labelled as the original cancer, even though it has moved to a different spot.

- Bone
- Breast
- Central nervous system (brain, meninges, spinal cord)
- Gynaecological (ovaries, cervix, uterus, vulva, vagina, endometrium)
- Head and neck (tongue, mouth, salivary glands, oropharynx, nasopharynx, nasal cavity and larynx)
- Leukaemia (bone marrow)
- Lower gastro-intestinal (colorectal or bowel)
- Lung
- Lymphoma (lymphatic system)
- Prostate
- Renal and urinary tract (kidney, bladder, urethra, renal pelvis)
- Skin
- Testicular
- Unknown primary site
- Upper gastro-intestinal (oesophagus, stomach, small intestine, liver, gallbladder and pancreas)

The five most common cancer sites in Australia are: prostate, colorectal, breast, melanoma and lung cancer.

## Tests for cancer

Cancer can be detected and monitored using a combination of tests, including:

- **Visual monitoring** – changes to the body, such as lumps, irregular discharges or bleeding, pain or soreness, skin changes, unexplained weight changes.
- **Blood and/or urine tests** – looking for indicators that something abnormal is happening in the body. For instance, a Prostate Specific Antigen (PSA) blood test can be used to screen for and monitor the progression of prostate cancer.
- **X-rays or ultrasound** – may reveal tumours in certain parts of the body.

- **Biopsy** – tissue samples taken from “suspicious” lumps (using surgery, fine needles or scopes) and tested for cancer.
- **MRI (Magnetic Resonance Imaging)** – a magnetic field and radio waves used to get images of inside the body that x-rays cannot capture (eg. soft tissue).
- **CT (Computerised Tomography) scan** – medical imaging using x-rays and computer technology to create multi-dimensional “photographs” of structures inside the body.
- **PET (Positron Emission Tomography) scan** – medical imaging involving the injection of small amounts of radioactive material, which shows areas of fast cell growth.

## Treatments

Cancer can be treated using several conventional therapies. Non-mainstream or complementary therapies are also available, depending on the progression of the disease, these treatments may focus on curing or relieving symptoms.

### Conventional medical therapies include:

- **Surgery** – to remove or reduce tumours.
- **Radiotherapy** – using x-rays to destroy cancer cells.
- **Chemotherapy** – using drugs (taken orally or intravenously) to destroy cancer cells.
- **Hormone therapy** – decreasing or increasing hormones that affect cell growth.
- **Immunotherapy** – using substances to encourage the immune system to fight cancer cells.

Complementary therapies, such as massage or herbal medicine, may also be used to treat cancer. Often these are used in tandem with conventional treatments. Some people also choose to try alternative methods (eg. microwave therapy), which tend to be less orthodox.



### FACT

It is very important that you discuss any complementary or alternative therapies you are using with your health professional, as some of these are known to negatively interact with conventional therapies.

Sources: Cancer Australia, NSW Cancer Council, Better Health Channel (Victorian Government)

## Personal Notes

A series of horizontal dotted lines for writing notes.

A series of horizontal dotted lines for writing notes.