Cancer Council

PRACTICAL SUPPORT fact sheet

Living with Incurable but Treatable Cancer

A guide for people affected by advanced and metastatic cancer

Living with incurable but treatable cancer can bring uncertainty, but many people continue to live well for years. This fact sheet explains what it can be like to live with cancer that can't be cured. It covers treatment, managing side effects, emotional wellbeing and practical support.

Finding out you have advanced or metastatic cancer that can't be cured can be a shock. However, treatment has changed significantly over the past 20 years.

New options (e.g. immunotherapy and targeted therapy) mean that some incurable cancers can now be managed and kept stable for a long time, often with fewer side effects.

These improvements in treatment mean many people now live with cancer as a long-term illness that is managed with ongoing treatment and support. Cancer may still be part of your life, but it does not have to be the main focus. Many people continue to work, travel, care for their family and do the things that matter to them.

"When I was first diagnosed, my advanced bowel cancer had already spread to my liver. I am now on targeted therapy and chemotherapy. I enjoy working part time, chasing after my busy toddler and planning holidays with family and friends. Cancer doesn't define my life." HELENA

What is metastatic survivorship?

Metastatic survivorship is when people are living with advanced cancer that most likely cannot be cured – and often while having ongoing treatment.

Cancer is called metastatic when it has spread from where it first started to another part of the body. It may also be called advanced cancer, secondary cancer, stage 4 cancer or "incurable but treatable cancer". It may not go away completely, but treatment may help control the cancer, ease symptoms and support your quality of life.

Ongoing treatment is often a normal part of life for people with metastatic cancer. It may also change over time, depending on how the cancer responds and how you are feeling.

Some people call metastatic survivorship "the long middle" – when treatment continues and life goes on, even though the cancer cannot be cured.

What to expect

Living with incurable but treatable cancer is different for everyone. There may be times when the cancer is stable, and times when the cancer changes, so treatment or symptoms also change. The uncertainty of living with incurable cancer can be hard, but over time, many people find ways to adjust and keep focusing on what matters most to them. Life with advanced or metastatic cancer may include:

Ongoing treatment

People with advanced or metastatic cancer usually have ongoing treatment to help keep the cancer under control. Treatment they may have includes chemotherapy, hormone therapy, targeted therapy, immunotherapy, surgery and radiation therapy.

Changes in your treatment over time

It is common for treatment to change. You might hear this called “lines of treatment”. This can happen if the cancer changes or treatment stops working. Changing treatment is a normal part of care of people with advanced or metastatic cancer.

Periods of stability and change

There may be times when the cancer is stable, and times when it grows or changes. These shifts are often checked with scans and tests and by how you are feeling. This up-and-down pattern can feel unsettling, but it is a common experience.

Planning around treatment

Many people having ongoing treatment plan activities, work or travel around appointments or the times when they have more energy and feel better. You may find it helpful to build flexibility into plans and routines where possible.

For a long time, people living with advanced or metastatic cancer were not included in cancer statistics. This is starting to change. The first national estimates are for metastatic breast cancer. These indicate that almost 21,000 people in Australia are living with metastatic breast cancer.

What are your goals of care?

Over time, what you want from your care may change. This depends on how you are feeling, what treatments can help, how the cancer responds and what matters most to you at the time.

Your goals – sometimes called your goals of care – might include:

- keeping the cancer stable and under control for as long as possible
- easing symptoms or side effects
- living as well as you can.

Your goals are personal, and they can change over time. Your healthcare team will talk with you about your goals and check in with you as things change. It can also help to talk with the people close to you about what is important to you. This is sometimes called advance care planning.

Planning for the future is not only for later in life – you can start at any time. It can mean talking about:

- what is important to you for your quality of life
- what treatments feel right for you
- where you would like to be cared for
- who you trust to make decisions if you can’t.

If you are a partner, family member or carer, these discussions can help you feel more prepared and confident in supporting the person you care about.

For more information, contact Advance Care Planning Australia on 1300 208 582 or visit advancecareplanning.org.au.

"What if" situations

Many people worry about what may happen if symptoms, results or treatments change. This is normal but if it becomes overwhelming, you can seek extra support. Sometimes thinking about possible situations ahead of time can help you feel more prepared.

What if you feel more tired than usual?
Feeling very tired (fatigue) is common. It can be caused by treatment, the cancer, stress or poor sleep. Let your healthcare team know – they can help find ways to manage it.

What if symptoms or side effects become harder to manage?
New or worsening symptoms don't always mean the cancer has spread. There are often ways to better manage symptoms, including medicines and changes to treatment.

What if you notice you have a new side effect or symptom?
New symptoms can be worrying. Tell your healthcare team about any new or changing symptoms. They can help work out what's going on and what to do next.

What if test or scan results change?
If this happens, your healthcare team will talk with you about your options and next steps. You will have time to ask questions and make decisions that feel right for you.

What if my partner or family is struggling?
Living with cancer can affect the people who are close to you as well. They can talk to your healthcare team or call Cancer Connect on 13 11 20 for information and support.

Understanding your feelings

Many people describe living with advanced or metastatic cancer as being in a "long middle" that is neither cure nor end of life. This can lead to many emotions – and they can change from day to day.

There is no right or wrong way to feel. Whatever feelings you have are understandable.

Some common emotions you – and people close to you – can feel include:

Anxious about tests – waiting for scan or test results can make you feel worried (sometimes called "scanxiety"). Some people notice changes in sleep, appetite or concentration. These reactions are common.

Pressure to stay positive – from others or yourself. While hope is important, so is letting yourself feel sad, angry, scared or tired.

Misunderstood – when you look well, people may not realise you could be managing pain, fatigue or worry.

Like a burden – worrying about the impact on your family and friends. These feelings can be painful, and talking about them can help.

Loss and grief – for your health, independence, routines, roles or plans for the future. It's natural to grieve these changes and to need time to adjust.

Loneliness – even if you have people around, you may feel like nobody understands what you are going through. Some people may have trouble coping with the diagnosis or distance themselves from you.

- Our booklet *Emotions and Cancer* can help you understand more about the emotional impact of cancer.

"I just have to live my life day by day. I can't predict my future, I can't plan things in the future. But what I can do is love every day and I truly do." ANNE

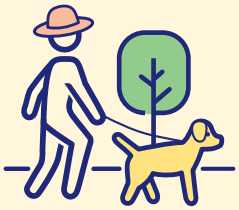
Living with uncertainty

Uncertainty is one of the hardest parts of living with advanced cancer. The following suggestions may help you manage this.

Take things one step at a time

Symptoms, treatment plans and day-to-day routines can change quickly. Focusing on the next day, week or appointment can feel more manageable than thinking too far ahead.

Create routines



Simple daily habits can bring a sense of stability, such as waking and going to bed at the same time every day, a short walk, a favourite show, or a regular phone call. Routines can help remind you that some things are still within your control.

Talk about how you're feeling

If you feel overwhelmed, it may help to talk to someone you feel comfortable with. This may be a trusted family member, a friend or a community leader. You can also call Cancer Connect on 13 11 20 to see if they can connect you with a support group.

Try complementary therapies

Meditation, relaxation, massage or art therapy may help reduce stress. You can listen to relaxation and meditation exercises in our *Finding Calm During Cancer* podcast series and read more in our *Understanding Complementary Therapies* booklet.

Find out more information

Understanding what to expect can help you feel more in control. Your treatment team can give you information and help you make plans. Cancer Council has many information resources. Call Cancer Connect on 13 11 20.

When to seek help for how you feel

Sometimes you might need to get extra help to manage your emotions. Talk to your GP or care team if you are:

- finding it hard to get through the day
- losing interest in things you usually enjoy
- feeling sad or anxious most of the time
- having trouble eating or sleeping
- having thoughts of hurting yourself.

Anxiety and low mood are common when living with cancer. Professional support – even for a short time – can help. This might be a counsellor, psychologist, social worker or psycho-oncologist.

Talk to your GP about whether professional support may help. You can also consider joining a support group. Many people find comfort in connecting with people in a similar situation. Cancer Connect can help you find this peer support. Call 13 11 20.

You can also call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. For crisis support, call Lifeline on 13 11 14. In an emergency call Triple Zero (000).

Looking after yourself

Living with advanced or metastatic cancer can affect your everyday life in different ways. Your energy, emotions and how you feel physically may change from day to day. Some days will feel easier than others.

Looking after yourself is often about finding small, manageable ways to support your wellbeing and doing what feels right for you.

Staying socially connected

Cancer can sometimes feel isolating, especially if treatment or fatigue makes it harder to socialise. Staying connected with people who matter to you can help you cope better.

How you connect with others may look different at different times. Some days you may enjoy seeing friends or family in person. On other days, a phone call or text message may feel like enough. It is okay to set boundaries and let people know what support feels helpful for you.

Eating well

Eating healthily can become more challenging for people with advanced or metastatic cancer. Appetite loss, taste changes, nausea and fatigue may affect what and how much you can eat. Some treatments can also cause mouth and throat soreness, which can make it uncomfortable to eat.

Choose foods you enjoy and that help you maintain strength and feel as well as possible. Some people find it easier to:

- eat smaller meals more often
- keep easy-to-prepare foods available
- focus on nourishing foods when appetite is low
- drink enough fluids throughout the day.

A dietitian can provide advice if eating becomes difficult. To find an accredited practising dietitian, contact Dietitians Australia on 1800 812 942 or visit member.dietitiansaustralia.org.au/faapd.

▸ See our *Nutrition for People Living with Cancer* booklet.

Keeping active

Exercise can help improve energy, mood, sleep and overall wellbeing for many people living with cancer. Even small amounts of exercise (e.g. short walks, light stretching) can help. What is safe for you will depend on your health, symptoms and treatment.

A physiotherapist or exercise physiologist can create an exercise plan tailored to you. You can find a physiotherapist near you through the Australian Physiotherapy Association's online directory – visit choose.physio/find-a-physio. To find an accredited exercise physiologist near you, visit essa.org.au.

▸ See our *Exercise for People Living with Cancer* booklet.

Ask your GP if you're eligible for a chronic condition management plan. This may help cover some of the costs of up to 5 visits each year to allied health professionals such as physiotherapists, dietitians or exercise physiologists.

Managing symptoms and side effects

People living with advanced or metastatic cancer can have a range of symptoms, which may change over time. Some symptoms are caused by the cancer itself, while others are related to treatment. There are many ways to manage symptoms and improve quality of life. Your cancer team can support you, and you may also see health professionals who specialise in pain and symptom control. They are called the palliative or supportive care team.

Side effect	What it is	Cancer Council resource
Fatigue	feeling very tired, even after rest	▸ *Understanding Fatigue and Cancer*
Brain fog	trouble concentrating or remembering things	▸ *Understanding Changes in Thinking and Memory*
Peripheral neuropathy	tingling, numbness or pain in the hands or feet	▸ *Understanding Peripheral Neuropathy*
Lymphoedema	swelling caused by a build-up of fluid	▸ *Understanding Lymphoedema*
Pain	new or ongoing pain	▸ *Understanding Cancer Pain*
Eating changes	discomfort eating or drinking; problems with taste and smell	▸ *Understanding Mouth Health and Cancer Treatment; Understanding Taste and Smell Changes*
Mood changes	feeling low, anxious, or emotionally different	▸ *Emotions and Cancer*
Fertility issues	temporary or permanent infertility (unable to conceive a child)	▸ *Fertility and Cancer*

Let your healthcare team know about any changes — even small ones. Getting support early can make a difference.

Your healthcare team

Getting the care and support you need for incurable but treatable cancer can feel overwhelming. You don't have to manage it on your own.

Your GP can be one of the central health professionals in your team. They can be your main point of contact between specialist appointments. Your GP can:

- help you manage your overall health and wellbeing, including other health conditions
- refer you to other health professionals, such as physiotherapists, dietitians or psychologists
- support you between hospital visits.

Your cancer care team (e.g. oncologists and cancer nurses) can sometimes provide this type of support too, but they will often focus mainly on your cancer treatment. Together with your GP, they work as a team around you.

Care can look different depending on where you live. Some people receive most of their care through a hospital, while others are supported by a mix of hospital and local services. If you are unsure who to contact about symptoms, appointments or support services, ask your cancer care team.

Some hospitals and treatment centres have health professionals called cancer care coordinators, nurse navigators or specialist nurses. These health professionals can coordinate appointments, explain treatment plans, connect you with support services and answer questions between visits. Ask your healthcare team if this type of support is available.

Financial and practical concerns

Living with advanced or metastatic cancer can put pressure on many areas of your life, including finances, work and everyday responsibilities. Managing cancer over a long period of time can mean ongoing costs and changes to your income.

Care for advanced and metastatic cancer is often ongoing. You will probably need treatment, scans and appointments over months or years. Even if you have treatment in a public hospital, there may still be out-of-pocket costs.

Changes to work and income

Cancer and treatment can affect your ability to work, depending on how well you feel and the type of work you do. Some people can adjust their hours or work arrangements, or take extended leave, while others may decide to stop working or retire.

Fatigue, other side effects, and uncertainty about treatment schedules can make it difficult to make longer-term decisions about work. Whether you can continue working may depend on the support and flexibility of your employer.

These challenges can be especially difficult for casual workers, farmers and people who are self-employed or in caring roles.

LiveWorkCancer is an organisation that helps people affected by cancer navigate work and cancer. Visit liveworkcancer.org.au for more information.

Who can help with finances

When cancer affects your finances, seeing a qualified professional for advice can help. Your local Cancer Council may be able to provide financial counselling or connect you with a financial planner. Call Cancer Connect on 13 11 20 to find out more.

Other professionals who can help include:

Social workers – help you better understand the assistance you may be entitled to.

Financial counsellors – provide free and confidential advice about managing bills and debt, accessing hardship support and negotiating payment plans. To talk to a financial counsellor, phone the National Debt Helpline on 1800 007 007 or visit ndh.org.au.

Financial advisers – help you manage your money, assets and financial affairs to meet your personal and financial goals. Financial advisers must hold an Australian Financial Services (AFS) licence, or work for a business that holds one. They usually charge fees. To find a financial adviser, visit moneysmart.gov.au and search the financial advisers register.

Other areas to look at that could provide financial assistance are:

Centrelink and government support – Some people may be eligible for income support payments, carer payments or other government assistance. Visit servicesaustralia.gov.au and search for the payment and service finder to see what payments you may be able to get.

Superannuation and insurance – Talk to your superannuation or insurance providers to find out if you are able to access:

- superannuation (super) on compassionate or medical grounds
- income protection insurance (sometimes through your superannuation fund)
- total and permanent disability (TPD) insurance.

▸ See our *Cancer, Work and You* and *Cancer and Your Finances* booklets.

Relationships and family

Living with advanced or metastatic cancer can affect your relationships in many ways. It may change how you connect with your partner, family, friends and others around you. Some relationships may grow stronger, while others may feel more complicated at times.

Talking to others

Many people find it hard to know what to say after a diagnosis of advanced cancer. You may feel pressure to explain your situation, answer questions or reassure others.

You can decide what you want to share, who you want to tell and how much detail feels right for you. Some people prefer open conversations, while others share information only with close family and friends.

When you don't feel like talking

There may be times when you do not feel like talking about your health. This is okay. Some ways to deal with this include:

- let people know when you need space
- use text messages to avoid repeating information
- ask someone you trust to share updates
- change the subject when you need a break.

Dealing with unwanted advice

It may seem difficult dealing with unwanted advice from friends and family. People may try to help by offering advice or suggesting so-called "miracle cures". You can tell them that you are making decisions based on discussions with your medical team and prefer not to receive advice. You can let them know other ways to support you, such as cooking a meal, helping with daily tasks, or spending time together.

Parenting and family life

If you have children or teenagers, you may worry about how cancer is affecting them. Many parents find it hard to know what to say.

Children often cope better when communication is honest, age-appropriate and ongoing. Giving them opportunities to ask questions can help them feel more secure.

It's also common to feel sadness, guilt or grief about changes in your role or family life.

▸ See our *Talking to Kids About Cancer* booklet.

Sex and intimacy

You may lose interest in sex, or feel that any visible changes make you less attractive, or worry others will reject you. Fatigue and stress can all affect relationships and interest in sex.

These concerns may feel difficult to talk about. You may find talking with your healthcare team, GP, psychologist or counsellor helpful.

▸ See our *Sex, Intimacy and Cancer* booklet.

Support for carers and family

Family members and close friends of people with advanced or metastatic cancer may also be dealing with their own emotions and challenges. They may feel worried, tired, scared or unsure how to help.

If you are a carer, it's important to look after your own wellbeing too. Support might include counselling, support groups, practical help, or taking a break when needed.

▸ See our *Caring for Someone with Cancer* booklet.

Questions to ask your health professionals

This list may be helpful when thinking about questions to ask.

- What is the treatment goal? To control the cancer, or to relieve symptoms?
- What does my prognosis mean?
- What side effects or symptoms should I expect from the treatment? How can I manage them?
- How often will I need to have treatment?
- Are there any side effects or symptoms I should look out for and tell someone about?
- Are there any clinical trials I could join?
- What happens if the treatment stops working?
- Who can I contact between appointments?
- Can you refer me to a palliative or supportive care team?
- Are there support services that may help me?
- Can you refer me to a psychologist or counsellor to help me cope with the uncertainty?
- How can I connect with other people in a similar situation?
- Can you help me talk to my family about this?

"I'd like people with advanced cancer to know that there are a myriad of services. You only have to ask; you are not alone." PAT

Where to get help and information

Call Cancer Connect on 13 11 20 or visit the website for more information about cancer and health care. Qualified professionals can listen to your concerns, put you in touch with local services and send you free copies of our booklets. You can also visit your local Cancer Council website.

Cancer Connect	**cancerconnect.org.au**
ACT	**actcancer.org**
NSW	**cancercouncil.com.au**
NT	**cancer.org.au/nt**
QLD	**cancerqld.org.au**
SA	**cancersa.org.au**
TAS	**cancer.org.au/tas**
VIC	**cancervic.org.au**
WA	**cancerwa.asn.au**
Australia	**cancer.org.au**

Other useful websites

Palliative Care Australia	**palliativecare.org.au**
MBC Action Australia Information and Support hub	**mbchub.au**
Peter MacCallum Cancer Centre	**petermac.org (search "living with cancer")**

Acknowledgements
This information was reviewed by: Professor Bogda Koczwara AM, Director, Australian Research Centre for Cancer Survivorship, (a UNSW partnership with Cancer Council NSW); Dr Andrea Smith, Senior Research Fellow, The Daffodil Centre, Sydney, NSW; Dr Ashley Bigaran, Accredited Exercise Physiologist, Olivia Newton-John Cancer and Wellness Centre, Austin Health, VIC; Jill Carland, Consumer, MBC Action Australia; Jenny Gilchrist, Nurse Practitioner – Breast Oncology, Macquarie University Hospital, NSW; Prof Nicolas Hart, NHMRC Investigator Fellow (Cancer Survivorship) and Program Director (Clinical Exercise Physiology), INSIGHT Research Institute, UTS, NSW; Prof Michael Jefford, Consultant Medical Oncologist and Director, Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, VIC; Helana Kelly, Manager, Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, VIC; Braxton Laine, Consumer; Dr Toni Lindsay, Senior Clinical Psychologist and Psychosocial Services Manager, Chris O'Brien Lifehouse; Romy Pham, Senior Advisor, 13 11 20, NSW; Prof Jane Phillips, Head of the School of Nursing, Queensland University of Technology and Emerita Professor at IMPACCT (Improving Palliative, Aged and Chronic Care through Clinical Research and Translation), University of Technology Sydney (UTS), NSW; Dr Kathy Pope, Radiation Oncologist, Peter MacCallum Cancer Centre, Melbourne, VIC; Marco Salvador, Consumer; Peter Spolc, Consumer; Dr Monica Tang, Medical Oncologist and Staff Specialist in Cancer Survivorship, Nelune Comprehensive Cancer Centre, Prince of Wales Hospital, NSW; Dr Elysia Thornton-Benko, Specialist GP/ Primary Care and Cancer Survivorship Physician, NSW; Janelle Ward, Oncology Social Worker, Wollongong Hospital, NSW; Jayne Watson, Clinical Nurse Consultant, Peter MacCallum Cancer Centre, VIC.

Note to reader
Always consult your doctor about matters that affect your health. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this fact sheet.

This fact sheet is funded through the generosity of the people of Australia. To support Cancer Council, call 13 11 20 or visit cancerconnect.org.au.

Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past and present.

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