Planning ahead

hope
&hurdles

This booklet is for people who have been diagnosed with metastatic breast cancer (also known as advanced, secondary or stage IV breast cancer). It is designed to be read in conjunction with the *Hope & Hurdles Information Guide*.

It is confronting to think about what might happen in the future when facing a serious illness. This booklet provides information to help you work out what is most important to you to help you plan ahead, including:

- talking about the tough stuff
- supportive care available for you and your family
- advance care planning
- getting your affairs in order
- other resources that may be helpful.

This booklet is designed to help answer questions that can be difficult to think about. Planning ahead can help you to think about, and discuss with others, your values, experiences and preferences. It can also provide a sense of relief when it is done, as you can then focus on living life fully.

Thinking about the future – making choices

> *Metastatic breast cancer feels like you are living a 'double life' – trying to maintain hope, persistence, coping with treatment and side effects, and trying to be in control, all the while being aware of the reality of the situation and having to think about your own mortality.*

You may find that at times you are consumed by thoughts about the possibility of your disease progressing and facing the end of your life. This reality is something rarely disclosed to others – perhaps because they won't understand or may offer you platitudes about 'new treatments' and 'not giving up'. You may find that addressing these issues up front enables you to focus on living well.

Planning ahead can be difficult, but once your family starts talking about it, you may find it easier to speak about your wishes while you are well. Thinking about the future and making choices about your preferences for care can reassure you and your family that all your wishes are known and written down in case they are needed. This is the time to think about what matters most to you and those around you. You can take the lead by talking about this most difficult reality, even though it is very hard to do.

In doing so, you give others an opportunity to share, to say what needs to be said or to be silent and just 'be there'. There may still be sadness, tears and grief. However, there will also be relief that no words were left unspoken and that your wishes and preferred choices for care are known and respected by those around you.

You may find it helpful to read through this booklet in your own time and at your own pace. If you have any concerns with the information that you read, you can talk with your treating specialist or your GP. It is important that you seek support to address any concerns that you have.

Talking about the tough stuff

Most people find it hard to talk about death and dying – it's upsetting. It makes us uncomfortable. We often don't know what to say to people who are facing death or coping with grief. Advances in medical treatments have increased life expectancy, but they have also taken the care of sick people out of their homes and into hospitals. As a consequence, serious illness has become more remote, less familiar and perhaps more feared than it was in the past. The popular expressions about 'finding closure' or 'moving forward' after experiences of loss tend to stop us from talking about the sad realities of grief. We feel that we should 'put on a brave face'. However, it is important not to deny ourselves and loved ones the chance to talk.

> *Speaking openly about death can be very upsetting and frightening, but it is better than not discussing it at all.*
> – Nicola

Talking about dying and death is important for everyone involved, but it can be hard to know where to start. You might worry about finding the right time and the right words. Perhaps there is no 'right time' and there are no 'right words' – you just make a start and see how it goes. Remember that this is the beginning of what may be many conversations. You can adapt, modify and change what you say and who you say it to over time.

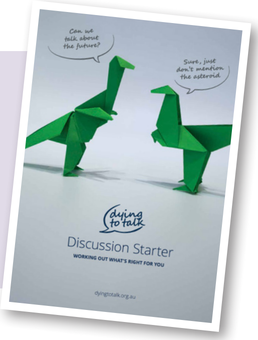
It may help you and those around you if you are able to give them some guidance on your feelings about talking about the end of life and how they could talk to you about dying and death.

This could mean explaining that:

- you have decided not to continue treatment and hope this decision will be respected
- you don't want people to avoid you, even if they find it hard to know what to say
- you feel able to discuss dying and death and would like them to feel that they can talk to you about it too
- there may be times when you don't feel like talking about it and you would like others to respect that
- people don't have to try to cheer you up – you just want them to listen and be there.

Once you have started the conversation, you may find that it is easier for some people to talk than you had expected. They might have been thinking about it, but not known how or when to raise the subject. They may be waiting for cues from you. You might find they feel relieved to talk.

Dying to Talk's discussion starter is a guide to help you start the conversation with family and friends on how you want to be cared for at the end of your life. Visit dyingtotalk.org.au to download a copy.



Your family and friends

> *I think one of the hardest things for me is knowing that my husband and children are really upset. Deep down they are really worried that I'm going to die, and that's a burden for me.* – Cecilia

It's often difficult to know how your family and friends will react to your news and whether or how they will continue to support you in the future. They will be dealing with their own emotions, fears and thoughts about death, which may or may not be helpful for you.

Often people don't know what to say. It's usually because they've never faced this situation before and worry about saying the wrong thing and upsetting you. Or they may simply feel uncomfortable talking about dying. Some people may avoid the situation and act as if nothing is different. Others may become over-protective of you.

Some people struggle to accept a loved one's decision to end treatment, saying things like 'You've got to keep fighting' or 'Don't give up'. Hearing such things can be difficult. People usually say these things because they are scared of the loss or because they don't know what else to say. You might find it helpful to explain that making the choice to stop treatment is a way of taking control and that you are comfortable with the decision.

Palliative Care Australia's brochure *How can I support my friend or family member?*
may be helpful to the people in your life.
Visit palliativecare.org.au to download a copy.

Your partner

> *After 40 years of marriage, I think I'm more worried about Bill than about me. He's not ready to talk about dying yet, but I hope he will be soon.* – Mary

For partners, facing the end of life of their loved one can be incredibly sad and confusing. It can be very difficult to accept that their hope for many more years together is no longer a reality.

You may worry about your partner's life after you're gone. Planning together can help both of you. Talking about your plans for the rest of your life, and for your partner's and family's lives, can help relieve worries. Facing the end of life often inspires couples and families to spend meaningful time together. Activities might include visiting a special place, taking a holiday, dining at a favourite restaurant, or looking through photo albums together and reminiscing. For many couples it is also important that they continue to share intimacy. Ensuring private time without visitors or interruptions can help. Sometimes you may have to be clear and even quite firm with people who may 'crowd' your space and make it hard to share time just with those closest to you. This is not the time to worry about hurting other people's feelings. This is the time to say what you want and need. The people who care about you will respect this.

Conflicts between couples can still occur during this time, particularly as emotions are raw. This is perfectly normal. It is helpful to remember that partners can find support through talking to friends, family members, others who have been in a similar situation, or health professionals such as a GP or counsellor.

For more information about partners see the 'Living well' chapter of the *Hope & Hurdles Information Guide*.

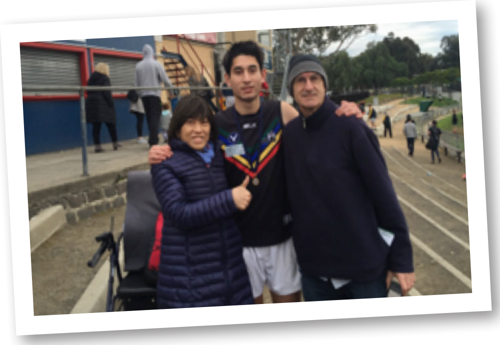
Children

Adults generally find it difficult to talk to children about dying and death. Our natural instinct is to protect them from sadness. However, avoiding discussions about dying may do more harm than good. No matter how good your motives, if children are not told the truth, they will almost certainly be angry and resentful. The truth can hurt – but secrets hurt more.

No matter what age they are, children will sense when something is wrong. What they need most is simple, honest explanations and answers to their questions. Remember that young children (aged 10 and under) will most commonly express their feelings through behaviour. Recognising 'naughty' behaviour as a sign that a child is worried is important. Reading storybooks about dying with young children can provide the opportunity for questions and encourage them to talk about their feelings.

For teenagers, facing the death of a loved one can be especially complex, as they are generally dealing with a lot of other changes in their lives. Girls often respond in a different way from boys. Some may feel they need to hide their feelings. Others may react with anger or seem not to care, but underneath they are hurting.

It is important to allow children and teenagers to talk about how they feel and to listen to their fears and concerns. They need to know that they can talk about anything related to dying and death. Family members and friends may be able to provide this support if your children do not feel comfortable speaking to you.



Things that may help you and your family support children during this time include:

- talking openly and honestly
- letting children talk, even about difficult things
- explaining to them it's not their fault
- explaining to them that they will always be safe and cared for, no matter what
- letting your children see that you are upset sometimes
- allowing others to give support
- letting the school, kindergarten, or childcare centre know about your situation
- maintaining structure and routine as much as possible e.g. encouraging them to participate in sport and normal activities.
- maintaining rules and consequences.

Things that probably won't help:

- rushing to reassure children
- keeping everything private
- letting discipline slip because of guilt
- pretending that everything is okay
- keeping secrets
- letting go of structure and rules
- telling children to 'be good for Mum/Dad'
- expecting children to spend all of their time at home 'because time together is precious'.

For more information about talking to children, see the 'Living well' chapter of the *Hope & Hurdles Information Guide*.

Support for you and your family

The complexity of living with metastatic breast cancer, sometimes for many years, means that you and your family may need additional support. The support you need may fluctuate over the course of your illness.

Supportive care is care that aims to optimise quality of life through all stages of life. Supportive care addresses information, physical, psychological, social, cultural and spiritual needs. Palliative care is an important part of this process.

Palliative care

> *My palliative care team has been amazing. They linked my family with services and support that would have been great to know about three years ago when I was first diagnosed with metastatic breast cancer.* – Terri

Palliative care can improve the quality of your life and help you manage issues, whether they are physical, emotional, spiritual or social. Palliative care services also provide support for your family and carers.

Palliative care services can complement your treatment and help you manage your illness, particularly pain and mobility, so you can continue to live life the best you can. The type of support provided is flexible and can change depending on your needs. For example you may be able to access spiritual support, financial planning or counselling for yourself and your loved ones through a palliative care service.

Your individual circumstances, culture, values, attitudes and beliefs will influence your supportive care needs. Palliative care

The Living Well with Metastatic Breast Cancer toolkit asks five questions to produce tailored information on how palliative care can improve quality life for you and your family.
Visit palliativecare.org.au.

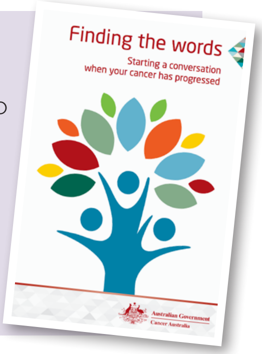
services will assist in planning your care according to your needs and help you make decisions for the future.

Depending on available services in your area and your needs, care can be provided in your home or as specialist in-patient care in a palliative care facility if preferred.

Palliative care can be accessed through a referral from your GP, medical oncologist or another health provider. Your doctor, breast care nurse or hospital social worker can provide more information or a referral. You can also contact a palliative care service directly (without a referral).

For more information about palliative care, see the ‘Treatment and side effects’ chapter of the *Hope & Hurdles Information Guide* or you can visit the Palliative Care Australia website at palliativecare.org.au.

Finding the words. Starting a conversation when your cancer has progressed is a guide developed to help people with cancer talk about how palliative care might help them live as well as possible. It can help you learn about what services are available should you need it. To download a copy visit canceraustralia.gov.au.



Advance care planning

> *As a family we have made plans for the future when I am no longer able to cope by myself. Strategies are in place. From time to time we revisit the plan to ensure that my needs are still being met.*
> – Barbara

We all have things that are important to us and this can be especially true at the end of life. You may have preferences about the care you will receive at the end of your life – things like where you would like to be, what sort of medication you do or don't want, and how much treatment you will accept. Thinking about and sharing these preferences and choices is called advance care planning. **Advance care planning** and **advance care directives** help people make plans for future health and personal care needs and end of life medical treatment.

If you haven't decided on the type of care you would like at the end of your life it is important for you to consider your options, make choices and let those around you know your preferences. You may have some questions about what your options are. There are people who can help you understand what your choices are. This includes health professionals within your medical team such as your GP, medical oncologist, a social worker or palliative care team.

> *It is okay to say 'I am scared' and wonder 'Will I die with dignity or pain?'.* – Judy

Advance care planning is a process to help you plan and write down your future health care preferences.

Advance care directive is sometimes referred to as a 'living will'. It is a legal document about your health care preferences if you are no longer able to make decisions for yourself because of illness or incapacity.

It is natural for most people facing the end of life to want to die in comfort, without suffering or pain. It is important to talk to your doctor about any specific concerns you have. Everyone is different. Your care at the end of life will be tailored to your symptoms and concerns.

You might also like to think about:

- Where do you want to die? At home? Or would you feel more comfortable in a specialist in-patient palliative care facility?
- What are your goals for care?
- Who and what do you want around you? Particular people? Pets? Smells such as scented candles? Music?
- What don't you want?

> *I couldn't talk about death and dying with my husband – he just finds it so difficult. I'm scared of deteriorating before I die, and where I'm going to die. I know my husband wouldn't want me to die at home, but I don't want to die in a hospital. I can't discuss this with my family, but my support group is a safe place to talk about the options, such as in-patient palliative care options.* – Cheryl

Advance care planning can include legal documents, such as an advance care directive and an **enduring power of attorney**, where your preferences are recorded. These forms may be called something else depending on which state you are in. Writing down your preferences in a legal document and letting others know where you have kept this is important so there is a clear record of your choices. As your treatment changes, your choices may also change. It is important to revisit your advance care plan and share any changes with your loved ones. Updating any documents is also a good idea.

Enduring power of attorney (or similar term) is the legal document about who you want to make health care decisions for you if you become too unwell to communicate those decisions yourself.

Each state and territory has different names for the legal documents you can use to make an advanced care plan, so it is a good idea to ask for help. To find out about the relevant documents for your state or territory visit advancecareplanning.org.au.

Appointing someone to make decisions on your behalf

Advance care planning also involves appointing someone to make decisions on your behalf in the event you become unable to make decisions for yourself. This person is called a substitute decision-maker, or a medical decision-maker, depending on the state you are in. The person you appoint can make decisions for you in regards to your financial and legal affairs, medical treatment or personal affairs.

Your substitute decision-maker doesn't have to be a family member. They could be a friend, an unpaid carer, or even a neighbour. Depending on your state/territory, you may be able to appoint more than one substitute decision-maker.

For more information and to download the forms you will need to complete, visit australia.gov.au and search 'powers of attorney'. Your hospital social worker should also be able to help you to find the information that you need.

In every state and territory, a power of attorney or appointment of enduring guardian is a legal document appointing someone to make certain decisions on your behalf when you are not able to do so. Before you appoint someone, it is important to discuss with them the kinds of decisions they might be asked to make. For instance, if they're medical decisions, the person needs a clear understanding of your views and preferences for your treatment. This is where advance care planning can be helpful.

When you appoint a power of attorney or enduring guardian you need to be able to understand the implications and consequences of what you are doing, otherwise the appointment will not be valid. This means that you need to be of sound mind at the time of making these decisions and signing the documents. This is why it is important to discuss these matters and make decisions earlier rather than later. The best person to choose is someone you trust, who knows you well and who can be objective enough to make decisions that are best for you.

After you have completed the relevant forms you will need to give a copy to the person or people you have appointed. Keep a copy for yourself. You will need two witnesses (one must be a medical practitioner or an authorised witness) to witness your signature. You can end the arrangement at any time by completing a revocation of enduring power of attorney form and signing it in front of two witnesses (one must be a medical practitioner or an authorised witness) and then notifying your attorney that you have revoked their power to act.

The power of attorney (and the role of the attorney) ceases when you die. The executor named in your will then takes over the responsibility of administering your estate.

Advance Care Planning Australia has a telephone advisory service that you can call for more information or advice on these matters on 1300 208 582. The service operates between 9.00 am and 5.00 pm (AEST) Monday to Friday.

Getting your affairs in order – the practicalities

Many people at all stages of life find it comforting to know that they are organised and that their affairs are in order. This is not a sign of giving up – instead, it's a sign of you continuing to make choices about how you want things to be.

Getting your affairs in order may be a question of reviewing arrangements you already have in place. If you don't have arrangements in place, you may find the process tiring and emotionally demanding. Consider breaking things down into small tasks, rather than trying to do it all in one day.

Getting your affairs in order can include everything from sorting your finances and writing a will to planning your funeral or other celebration of your life. You may also like to take time to think about how you would like your family and friends to remember you, and what special memories or thoughts, if any, you would like to leave for them.

Creating memories – Leaving your 'thumb print'

> *I started scrapbooking my son's life, such as baby photos and favourite foods – information that only I know as a mother and might not be able to tell him when he's older. I'm now scrapbooking my own life for my son. – Bev*

It isn't easy to think about life going on without you, but when you give consideration to how you would like to be remembered, you have an opportunity to go on providing inspiration and comfort to those you love.

> *I have always been the photographer in the family and I realised there were no photos of me and my daughters, so I got professional photos done, just to be prepared.* – Mavis

> *I miss her voice – I wish we had recorded something before she died.* – Mark

You might want to leave something for your loved ones after your death. This could be a letter, photo album, audio or visual record, book of thoughts and memories that you want to share, diary, or 'time capsule'. If it is to be opened on a special occasion – for example, a child's wedding or a particular birthday – make sure that your executor is aware of this and knows where to find it.

> *Our mum never spoke to us about her impending death. Mum did not leave any instructions or wishes for her funeral, or write anything personal that we could keep in her memory. When my sister was diagnosed with metastatic breast cancer, this drove our discussions, ideas and plans for how she might keep her memory alive for her children.* – Julie

Making a will

> *Making a will was really hard because I didn't want to think about dying. Once I started it was quite liberating – it gave me a little bit of control saying I want my niece to have my favourite necklace because I know she loves it.* – Hilda

A will is a legal document that sets out how you would like your personal assets and belongings to be distributed when you die. Everyone should have a will and update it whenever their circumstances change (e.g. marriage or divorce, selling or purchasing a major asset like a house).

A solicitor will be able to help you prepare your will. Alternatively, you can buy a 'do-it-yourself' will kit from a newsagent or online.

In making your will, you can appoint one or more people to carry out your instructions. The people you appoint are called *executors* and are usually family members or close friends. Being an executor comes with responsibilities, so it is important to discuss these with the person you'd like to appoint before naming them in your will. You do not have to disclose the contents of your will to anyone at any time.

If you die without having made a valid will, the law decides who gets your assets.

This is called ‘dying intestate’. Dying intestate means that your wishes are not considered when dividing up your estate. In most instances, your estate will be shared between your partner and/or children. However, a will lets you decides how you want your estate to be distributed to ensure that the important people in your life are protected after your death. For example, a will allows you to appoint guardians of any children you have under 18 years of age and provides an opportunity for you to provide for any stepchildren or other dependents.

Bequests

Many people want to leave a bequest as a part of their legacy. There are many charities, including BCNA, that rely in part on bequests to fund their operations.

BCNA has been privileged to receive bequests from members and supporters. However, if BCNA doesn’t learn about a bequest until after the person’s death, the organisation is not able to thank the supporter during their lifetime.

People who advise that they have included BCNA in their will are invited to join the Pink Lady Bequest Society. Members are invited to gatherings to hear firsthand how bequests are making a difference and some of the exciting developments BCNA is planning for the future.

Pink Lady
Bequest Society

If you would like more information about leaving a bequest to BCNA, visit bcna.org.au or call 1800 500 258.

Thinking about finances

> *I've organised my financial and other business matters to ensure all my family members are aware of my wishes.* – Marion

For many people, ensuring financial affairs are in order can lead to fewer worries about what may happen down the track. Doing what you can to sort out your finances while you are in a position to make decisions can help avoid problems later on and may provide you with greater peace of mind.

Securely recording your important financial information

> *I keep details of all my financial and legal information on a USB stick. That way I can update it easily if anything changes. I've made sure my children know about the USB and where to find it.* – Jane

Having all of your financial information kept securely in one place will make life easier and less stressful for you, your family and friends.

Information you might want to put together includes:

- bank accounts, including any PINs and/or passwords
- tax file number (TFN)
- the names and contact details of your accountant, financial adviser and solicitor
- superannuation funds and account numbers, and any investments such as shares or property
- any rental or leasing agreements
- insurance policies
- mortgage papers/certificates of ownership
- any other relevant PINs or passwords for accounts where you are the primary contact, e.g. your telephone or internet company.

It would also be helpful to include a copy of your birth certificate and documentation relating to your parents, spouse and children, along with your will and any instructions for your funeral. If you have a fireproof safe, you can keep the file at home and give a key or the combination to someone you trust. Otherwise, your solicitor or bank can store the file for you. Your executor should have a sealed copy of the documentation and know where to find the originals. Having this information in one place will make life much easier for your family or carers.

It is important information is kept secure. Therefore, it is not recommended that you keep passwords and other access information in a file on your computer.

> *I keep details of all my financial and legal information on a USB stick. That way I can update it easily if anything changes. I've made sure my children know about the USB and where to find it.* – Jane

It is sometimes hard to know where to start when you look at bringing together important information about things such as your financial affairs. You may also worry about how you keep this information secure.

LifeBank is a tool that provides a safe option to store all your details in one place. LifeBank is secure software that records and manages all personal and family details, including health information, investments, insurance policies, and your wishes in one place and makes you the sole guardian of the information. It also allows you to share data with a trusted person when you wish to. It is downloadable to a computer/laptop or can be delivered on a secure encrypted data key.
For more information visit lifebanksystems.com.

Superannuation and insurance

To ensure that your superannuation benefit (which is comprised of both your contributions to your superfund and any insurance benefits to which you are entitled) goes to the people that you want it to, you may want to update your beneficiaries with your superannuation provider.

Superannuation benefits, generally (some exceptions apply), do not form part of your personal estate. This means that your superannuation benefit cannot be distributed to the people you choose in your will, and are instead controlled by the trustee of your nominated superfund.

Many people are unaware that when they die the trustee of their superannuation fund may decide on the dependents who receive their superannuation benefits. This means that your entire superannuation and perhaps other insurance benefits, such as any life insurance or disability insurance attached to your superannuation, may be divided up and distributed among the dependents you leave behind in a way that you may not have wanted them to be. Even if you have specified the way in which you would like your superannuation benefits to be distributed in your will, the trustee may still make decisions on your behalf.

In order to avoid this, you may be able to make a binding death benefit nomination through your superfund. This ensures that your superannuation is paid to who you want after your death. There are restrictions on who you can nominate (it must be a financial dependent) and the form will likely need to be updated every few years. To find out if you are able to make a binding death benefit nomination, contact your superannuation fund.

Accessing superannuation funds early

The law that governs superannuation funds allows superannuation money to be accessed early and tax-free on the grounds of a terminal illness. Two doctors (including at least one specialist) must sign a certificate that states that the individual has 24 months or less to live because of illness.

People who are terminally ill may also be entitled to a terminal illness insurance benefit (which is usually the early payment of the benefit that would be paid on death). At the moment, most life insurance policies attached to superannuation accounts are only payable if a person's life expectancy is one year or less. This means that if a person withdraws all of their superannuation contributions (often called their account balance or preserved amount) on the basis of a two-year life expectancy, it could cause insurance policies connected to their superannuation to lapse. It may be advisable to leave some money in your superannuation account to cover the cost of the insurance premiums.

If you are interested in accessing superannuation early and are unsure about what benefits you may be entitled to, you should seek legal advice before applying to your superfund. Cancer Council has a program that provides free legal, financial and workplace assistance to people affected by cancer who cannot afford to pay for advice.
Call 13 11 20.

You can also find out more about accessing superannuation under the terminal illness provision from BCNA's fact sheet *Superannuation and insurance payments for people with a terminal illness*, available from our website bcna.org.au.

Debts

Many people worry about what might happen to their debts after death. What happens to your debt will depend on whether there are any assets in your estate, such as money or property, whether your assets are in your name or joint names (i.e. with another person) and whether other people may have acted as guarantor for your debt.

When a person dies, outstanding debts are paid out using any money or property left behind in their estate. After all the debts of the estate are paid, the executor of the will divides up the estate and distributes the assets to the beneficiaries.

If you can afford to, you may choose to pay off any unsecured debts, like credit cards and loans, which are not secured against your assets. This can make things easier for your executor and means that the money and personal gifts you want to leave won't be delayed in getting to the people you choose.

You may have insurance on some of your debts, such as mortgage insurance or credit card insurance, which means that your debt may be able to be wiped after death. Talk to your bank if you are unsure what insurances you have.

Cancer Council has a free information fact sheet called *What happens to debts after death*. You can call your state or territory Cancer Council on 13 11 20 to ask for a copy of this fact sheet or visit cancercouncil.com.au.

Legal and financial assistance

Cancer Council has a program that provides free legal, financial and workplace assistance to people affected by cancer who cannot afford to pay for advice. If you would like to know more about this program call Cancer Council on 13 11 20.

Online accounts

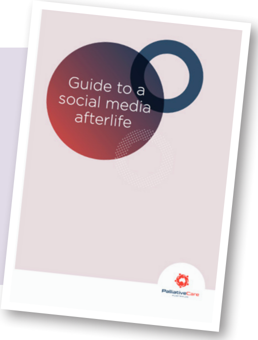
It is a good idea to consider what will happen to any online accounts that you have – email, Facebook, Twitter, Instagram, online dating sites, LinkedIn, Tumblr, BCNA online network or other social media. Planning ahead also involves leaving instructions and passwords to somebody you trust so that they are able to carry out your wishes for your social media accounts.

Most social media platforms have an option for you to nominate a 'legacy contact' – a trusted family member or friend – to take over managing your account when you die. Other platforms will only delete your account when notified of your death.

There are a range of options for your online presence after you die. If you have any strong wishes about what you do and don't want to happen with your online presence, you should make these clear to someone you trust who can make arrangements for you.

Visit the information page of your social media platform to find out about your options. Each social media platform will have its own rules regarding deletion of your account.

Palliative Care Australia's *Guide to a social media afterlife* provides information to help you or your loved ones manage your social media accounts. Visit palliativecare.org.au.



Planning your funeral or celebration of life

A funeral can be a celebration of your life. Aside from traditional religious services the options for funeral celebrations are endless. They can be held indoors or outdoors and can be led by a religious leader, celebrant, family member or good friend. The service can include whatever you choose – songs, hymns, verses, stories, video footage or any other way you would like to be remembered and celebrated. It is important to know there are many options now available to you and the choice is yours.

Some people find planning their own funeral rewarding. Choosing the venue, funeral director, celebrant, music, readings and flowers can bring a sense of control and involvement. Others find this too confronting and decide to leave it up to their loved ones.

If you don't want to be involved in planning your funeral, you may like to share your preferences with someone close to you. Family and friends usually feel it's important the funeral is an authentic reflection of your life – they want to honour your wishes. Even if you have no strong preferences for your funeral service, making this clear can be helpful to your loved ones.

> *I've prepared things not only for myself but also for my family. I wrote a letter to my daughter, explaining what needs to be done, in case it's too difficult to explain it directly to her.* – Louise

If you choose to go through a funeral director, they will be able to help you to plan a funeral. Before engaging a funeral director it can be helpful for you and your family to explore what services are available in your area and the options available to you. You may also be able to prepay if this is what you want to do. It is ultimately up to you how involved – or uninvolved – you are with your funeral arrangements.

Funeral expenses can be substantial. If you are prepaying, make sure that you understand the full range of costs and do not be afraid to ask for estimates from several funeral providers.

Grief and bereavement support

Grief is a natural response when facing a life-limiting illness and for those who experience the death of a loved one. Having metastatic cancer can bring struggles or grief to the surface and take you by surprise. Getting emotional support is important because it helps you feel more in control and able to live your life more fully. Sometimes it can be helpful to talk with someone outside your family about your needs and emotional concerns. This could be your GP, a social worker, psychologist or psychiatrist.

It can also be reassuring to know ongoing support for family members is available after the death of a loved one. Bereavement support is available for family members registered with a palliative care service. Bereavement support can include individual or family support and counselling, access to information, memorial services or referral to other support services. To learn more about how palliative care services can provide support to family and significant others in their bereavement visit palliativecare.org.au.

The Australian Centre for Grief and Bereavement also has information about services available. Visit grief.org.au.

Spirituality

For many people, facing their mortality reinforces their existing beliefs about life and its meaning. For others, it is a time to rethink current beliefs or even to engage deeply for the first time about some of these matters.

Spirituality can provide a means of support for many people as they live with the realities that a life-limiting cancer diagnosis brings. Spirituality is not necessarily about being religious, although some people may associate their religion or their faith with spirituality. Sometimes it can be hard to talk to family members. There are many other people that you can speak to. If you are interested in exploring spirituality further, ask to talk to a pastoral care worker at your local health service or palliative care service, or ask a member of your treatment team for a referral.

Organisations, resources and information

Breast Cancer Network Australia

bcna.org.au 1800 500 258

In addition to *Hope & Hurdles*, BCNA provides a range of information and support programs for people diagnosed with metastatic breast cancer, including an online network and a range of booklets and fact sheets.

BCNA's Helpline provides support and information about breast cancer for people with breast cancer and their family and friends. You can contact our Helpline team on 1800 500 258 on Monday, Wednesday and Friday between 9.00 am and 5.00pm (AEST) and Tuesday and Thursday between 9.00 am and 9.00 pm (AEST). You can also contact us by email on contact@bcna.org.au.

Advance Care Planning Australia

advancecareplanning.org.au (03) 9496 5660

Advance Care Planning Australia provides information about advance care planning, why it matters, and documents to assist in the development of an advance care plan. The organisation provides state and territory-specific information, information for Aboriginal and Torres Strait Islander people, and information in languages other than English.

Palliative Care Australia

palliativecare.org.au (02) 6232 4433

The national peak body for palliative care aims to improve access to, and promote the need for, palliative care. It provides access to resources, advance care planning, information for carers, and a directory of services (searchable by category or postcode).

Cancer Australia
canceraustralia.gov.au 1800 624 973

Cancer Australia was established by the Australian Government in 2006 to benefit all Australians affected by cancer, and their families and carers.

Cancer Australia aims to reduce the impact of cancer, address disparities and improve outcomes for people affected by cancer by leading and coordinating national, evidence-based interventions across the continuum of care.

Cancer Australia works with government and the cancer control community around a shared agenda, to deliver informed and effective cancer control and ultimately better outcomes for all people affected by cancer in Australia.

Cancer Council
cancer.org.au 13 11 20

Australia's peak national non-government cancer control organisation. Cancer Council Australia advises the Australian Government and other bodies on practices and policies to help prevent, detect and treat cancer, as well as advocating for the rights of cancer patients.

Carers Australia
carersaustralia.com.au 1800 242 636

Carers Australia represents Australia's carers to improve the health, wellbeing, resilience and financial security of carers. The Carers Australia website also provides links to the different state and territory carers associations.

PalAssist

palassist.org.au 1800 772 273

PalAssist is a free 24-hour telephone and online service for Queensland palliative care patients, carers, family and friends seeking practical information and emotional support. Includes an online chat facility.

CanTeen

canteen.org.au 1800 835 932

CanTeen provides support for people aged between 12 and 25 who have been affected by cancer, including anyone who has a parent diagnosed with cancer. CanTeen provides information, support and connections with others in a similar situation.

Australian Centre for Grief and Bereavement

grief.org.au 1800 642 066

Australian Centre for Grief and Bereavement provides a range of services including bereavement counselling services, bereavement support programs and information for bereaved adults, adolescents, children and families.

Bereavement Care Centre

bereavementcare.com.au

Provides bereavement counselling, information and resources for bereaved adults and children.

GriefLink

grieflink.org.au

The GriefLink website provides information resources on death-related grief for those who are bereaved and grieving, their carers, friends and colleagues, and for health and welfare workers.

beyondblue

beyondblue.org.au 1300 224 636

Support and information services for Australians experiencing anxiety or depression.

Lifeline

lifeline.org.au 13 11 14

A 24-hour crisis support and suicide prevention service.

Kids Helpline

kidshelpline.com.au 1800 551 800

A free, private and confidential telephone and online counselling service specifically for young people aged between 5 and 25.

Books and other resources

What is palliative care?

This brochure provides an overview of palliative care and services provided. It is available in 18 languages. To download a copy visit palliativecare.org.au.

The Bright Hour

Nina Riggs 2017

This book is written by Nina Riggs, a 38-year-old woman with two young children who was diagnosed with early breast cancer and then metastatic breast cancer shortly afterwards. It is her poignant and warm account of how she and her young family lived with metastatic disease.

Dying to know: bringing death to life

Andrew Anastasios 2010

This book seeks to stimulate discussion around death and dying to enable people to talk about their dreams, hopes, fears and concerns.

The intimacy of death and dying: simple guidance to help you through

Clare Leimback, Tyypheyna McShane and Zenith Virago 2009

This book provides practical strategies and advice – from how to talk to children about death and dying to preparing your funeral and dealing with personal grief. It also includes personal stories.

A journey lived – a collection of personal stories from carers
Palliative Care Australia

These booklets are written for people caring for someone with a terminal illness. The first suggests strategies for helping someone living with a terminal illness and the second is a collection of personal stories from people who have cared for someone with a terminal illness.

Supporting a person who needs palliative care
Peter Hudson and Rosalie Hudson
Palliative Care Victoria

This booklet covers the common issues facing carers during a journey with someone facing an incurable progressive illness.

This Present Moment: an art therapy journal
Meg Welchman and Grace Cuell 2015

Art therapy is a form of expressive, mental, and emotional wellbeing. This journal is designed to help readers attain mindfulness through reading, colouring and meditation. Mandalas are included in the book to help the reader focus on colouring to help release one’s creativity and to slow down and be in the moment. The mandalas are not ‘perfect’ and were done intentionally, to remind the reader that life is not perfect. This book is a reminder for us all, that all we have is this moment in time, right now.

Books and resources for children

When your parent's cancer can't be cured. Now what?
and
Living with the death of your parent or brother or sister from cancer. Now what?
CanTeen

The books are for people aged between 12 and 25 and can be read online or ordered free of charge from the CanTeen website.

Talking to kids about cancer: when cancer won't go away
Cancer Council NSW

This booklet offers information on how children of various ages generally react to facing the possibility of death, and advice on talking to children about death.

Winston's Wish
winstonswish.org.uk

Winston's Wish is the leading childhood bereavement charity and the largest provider of services to bereaved children, young people and their families in the UK. It offers practical support and guidance to families, including information on talking to children about dying, compiling memory boxes, tips for writing letters to children and video excerpts that followed families whose mothers were in the final stages of their cancer journeys.

Through Zoe's eyes
Monica Lawson 2007

This book was written for primary school-aged children by Zoe's mother, who had breast cancer.

Sometimes life sucks – when someone you love dies
Molly Carlile 2010

This book provides helpful tips, stories and gentle advice to help teens navigate the loss of someone they love.

Acknowledgment
We are grateful to Cancer Council NSW for permission to use some of their patient information resources as source material for this booklet.

After living with advanced disease for nine years I know of many women who have lived a full and rewarding life with this diagnosis. I get up each morning and embrace life as if today was the last day on this earth. My family and friends are everything to me and I have accomplished things that I never thought I would. I saved to go to Europe thinking that I would never see it if I didn't go a few years ago. I am now looking forward to a second trip. – Julie

hope
&hurdles

Feb 2018

About Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. We work to ensure that people diagnosed with breast cancer and their families receive the very best support, information, treatment and care possible.

bcna.org.au
contact@bcna.org.au
1800 500 258

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