WARRNAMBOOL & DISTRICT COMMUNITY
HOSPICE

The Manual for Living and Dying *in style*

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Acknowledgements

Much of the material in this manual already existed in previous booklets:

Home Care

The Complete Prescription

Living and Dying in Style

Palliative Care: The 'Doing it in Style' Kit, including the Wellness wheels

End of Life Preparations: The Essentials

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Contents

Introduction

To die well requires thought and planning. This manual presents ideas and ways to make dying, and death easier for yourself and your family. Preparing well in advance for this inevitable time of life is the key.

The manual is divided into three sections:

Section One: Living and dying in style
Section Two: End of life preparations
Section Three: Home care

The first section outlines steps you can take to prepare for your own (inevitable) death. This includes looking at ways of living well, as those who die well have generally lived well. There are attitudes and qualities to develop during life which will arm you to deal with your approaching death, however far away that may be.

Section two covers the essentials of end of life planning. Included is information to help you make plans for your end of life care, your death, and your funeral.

In the third section, the focus changes. This section provides a practical guide to providing care for someone choosing to die at home.

Section One: Living and dying in style

Let’s look at ways of living well. We can develop attitudes and qualities which will help us to deal with possible deteriorating health and our approaching death. We’ll look at questions around dying, and at the problems of dealing with advanced illness.

Some things are easier to talk about than others. Anybody can talk about the weather, the unseasonal rain or lack of it, the wind, the temperature – all safe, easy topics.

Football is also popular in conversation. The highs and lows of one team versus another keep lively discussions going throughout the season and beyond.

Other subjects are more difficult.

Take politics for instance. There is a little hesitancy in some circles to voice particular views in case they offend. Sex is not so easy either – a matter of privacy perhaps.

But how about dying as a topic to stop a conversation in its tracks? In spite of the fact that we all know that the death rate is one per person (and that an exception will not be made in our case), it is the minority who are willing to talk and prepare for this inevitability.

It’s not that people don’t want to. Surveys indicate that those with terminal illnesses are often eager to prepare for the end of life, but for various reasons do not make the most of their opportunities. The topic may be deliberately avoided to protect others from painful emotions such as anxiety and fear. Doctors and nurses may feel that discussing death is to remove hope and make the patient’s management more difficult. Everyone is waiting for someone else to introduce the topic and no-one does.

The issue of death and dying needs to be dealt with so that life can be enjoyed and appreciated to the full. Amanda McBroom in her song *The Rose* says:

> *“… it’s the one who won’t be taken who cannot seem to give,*
>
> *and the soul afraid of dying that never learns to live.”*

People confronting this issue are an inspiration to others as their open communications lead to a celebration of life.

Perhaps death is not so dreadful anyway. Survivors of near death experiences talk of feelings of peace and seem to lose their previous fears of death.

Ian Gawler, a survivor of what was almost terminal cancer, wonders if the moment of death may in fact be a moment of delight -

> *“… better than the best chocolate sundae you ever had,*
>
> *… better than the best orgasm you ever had,*

> *… better than the dearest, happiest moment you hold in your memory”*

He continues -

> *“The only thing that scares me about the moment of death*
> *is that I may come to it unprepared.”*

Preparation for death is well told in the book *Tuesdays with Morrie* by Mitch Albon. It is the author’s account of conversations with his former professor who is now dying of a progressive neurological disease. Every Tuesday becomes a lesson on Morrie’s philosophy of life and death. Morrie says we need to look for a certain peace with the idea of dying – it’s part of life’s deal – and only then comes peace with living, finding perfection in an average day.

Dying is the great equalizer and enables you to see life differently, focus on its essentials, and be drawn to nature and things spiritual.

One of these essentials, says Morrie, is our relationships with each other. Relationships need to be negotiated in loving ways with room for both parties – with concern for the other’s situation as well as your own. He quotes the poet Auden, *‘Love each other or perish*.’ Love is how you stay alive even after you are gone. Death ends a life, not a relationship!

On feeling sorry for yourself and mourning lost abilities, Morrie says set a daily limit – concentrating then on good things. He says we need to learn the ability to detach, particularly from emotions that might dominate our thinking as we die, such as fear, grief and pain. Experience those emotions, know them for what they are, but don’t let them control you.

He encourages us to stand back and look at our lives without needing a prod from some life-threatening illness. Deal with any regrets otherwise pain lingers on. Forgive yourself and others at the earliest opportunity before it becomes too late.

It’s never possible to go back, nor should you want to, says Morrie. You become different in attitudes, see a different perspective and grapple with the ‘big’ questions.

Dying becomes a time of growth and understanding.

Ten steps to prepare

The following ten steps summarise the essentials of preparing for the end of life:

1. Understand as much as you can about your illness, and what to expect later

If you need help, or have any worries, talk to your doctor or another member of your health team.

2. Be organised

This refers to recording your symptoms, their timing and severity, the medication you take, and writing down the questions you want to ask at your next appointment. Make sure that you remain part of the decision-making process.

3. Complete an Advance Care Plan

This involves having conversations that will help you make, and then document, decisions about your future health care, including your choice of place of care. It also involves appointing someone to be your Medical Treatment Decision Maker who will have the authority to speak on your behalf in case you cannot speak for yourself. This person will have to abide by what has been written in your Advance care directive in the way of a legally binding instructional and/or values directive. Your doctor is an essential witness and will help you complete this process correctly.

4. Make opportunities to resolve ‘unfinished business’

This applies particularly to relationships with family and friends, and to other spiritual and/or religious matters. Write that letter, make that phone call, visit that friend. In the long run, this is what really matters.

5. Live as well as you can

There will no doubt be limitations now and a need to consciously pace yourself. Study the *Wellness Wheels* illustration and be inspired to do what you can. This will help you remain realistically hopeful and work towards peace of mind.

6. Learn about meditation and mindfulness

Meditation deals with stress by stilling the mind. Techniques such as concentrating on the breathing and progressive muscle relaxation help achieve this. Mindfulness just means paying attention to the present moment, without judgement. For example, when you walk, concentrate on how it feels to walk; when you eat, concentrate on eating. This is described in Dr Jon Kabat-Zinn’s book, *wherever you go, there you are*. Living in the present removes regrets about the past and anxiety about the future.

7. Record your story in a life review

This is an opportunity to be creative and choose a selection of snapshots from your life to write down, or speak about, and to leave a message for people who are important to you. Read the guidelines (see Section 2) and ask for help if you would like it.

8. Put legal and financial matters in order, particularly a will

To assist with the management of your affairs if you are unable to do so, it is wise to appoint one or more people to fill the role of Enduring power of attorney, and your will needs one or more executors to arrange your funeral, and deal with the estate.

9. Consider a death and a funeral plan (see Section 2)

10. Make use of available resources

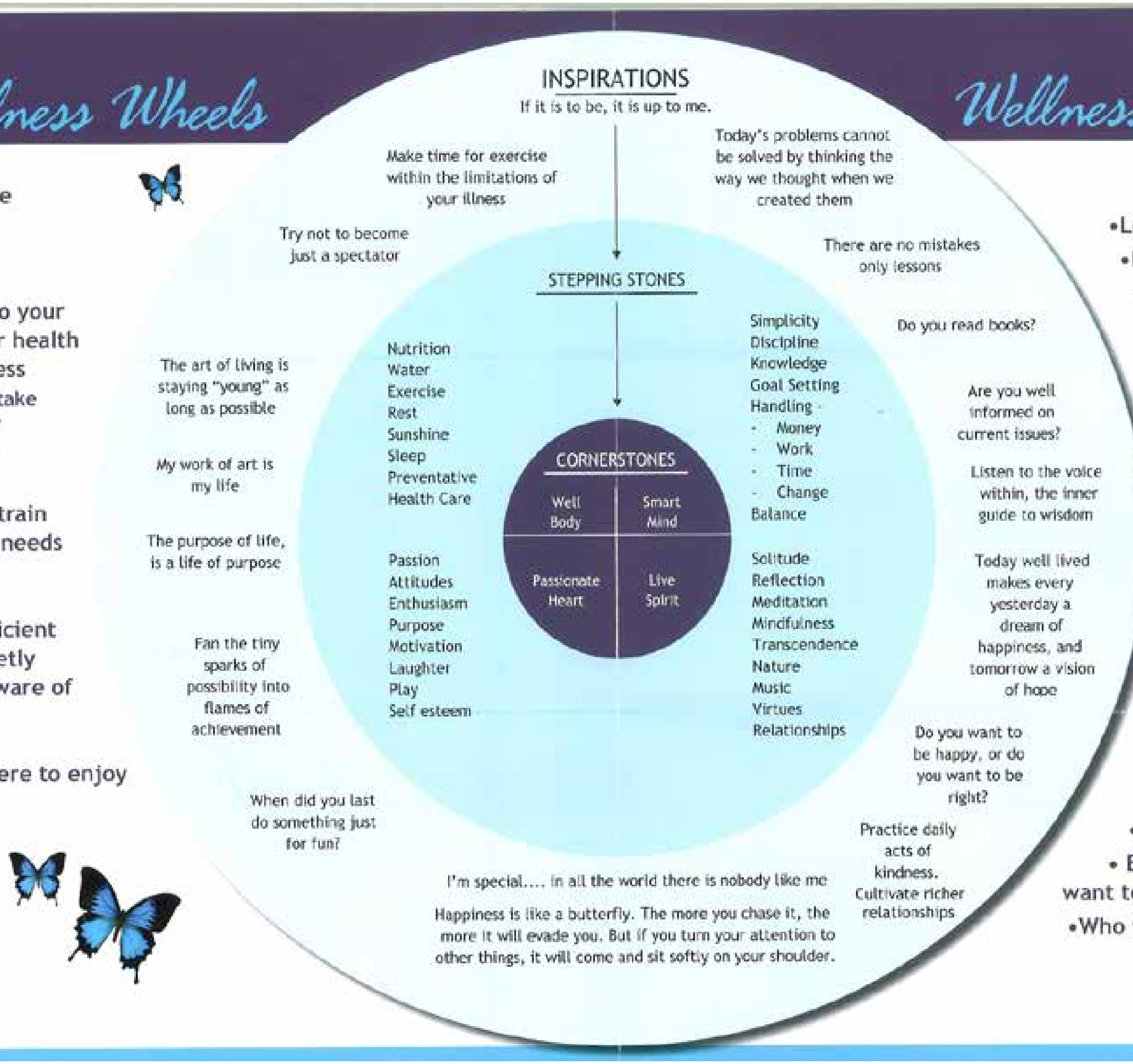
You will find that many people are willing to help. Make the most of your compassionate community and coordinate their efforts for the sake of you and your family. Members of the health team include doctors, nurses, allied health professionals such as occupational therapists, dieticians, counsellors and psychologists, perhaps art and music therapists, pastoral care workers and volunteers. A variety of written materials are available, there are educational and support groups and other services to draw on if needed. Ask your doctor or your Palliative Care team member for more information.

There is always room for hope. Plan for the worst but hope for the best. Hope to be content with what is happening right now. This is the ultimate in doing it in style. Hope for healing, which occurs when there is peace of mind. Healing goes beyond curing and may take place when curing is not an issue or has proved impossible.

Keep death in its place: plan for dying and live in style!

Wellness Wheels

- Be simple
- Be kind
- Attend to your own inner health & happiness (This may take a little self discipline)
- Do not strain after the needs of life
- It is sufficient to be quietly alert & aware of them
- Life is here to enjoy



INSPIRATIONS

If it is to be, it is up to me.

Make time for exercise within the limitations of your illness

Today's problems cannot be solved by thinking the way we thought when we created them

Try not to become just a spectator

There are no mistakes only lessons

The art of living is staying "young" as long as possible

My work of art is my life

The purpose of life, is a life of purpose

Fan the tiny sparks of possibility into flames of achievement

When did you last do something just for fun?

Do you read books?

Are you well informed on current issues?

Listen to the voice within, the inner guide to wisdom

Today well lived makes every yesterday a dream of happiness, and tomorrow a vision of hope

Do you want to be happy, or do you want to be right?

Practice daily acts of kindness. Cultivate richer relationships

I'm special.... in all the world there is nobody like me

Happiness is like a butterfly. The more you chase it, the more it will evade you. But if you turn your attention to other things, it will come and sit softly on your shoulder.

STEPPING STONES

Nutrition
Water
Exercise
Rest
Sunshine
Sleep
Preventative Health Care

Simplicity
Discipline
Knowledge
Goal Setting
Handling -
- Money
- Work
- Time
- Change
Balance

Passion
Attitudes
Enthusiasm
Purpose
Motivation
Laughter
Play
Self esteem

Solitude
Reflection
Meditation
Mindfulness
Transcendence
Nature
Music
Virtues
Relationships

CORNERSTONES

Well Body	Smart Mind
Passionate Heart	Live Spirit

Wellness Wheels

- Live differently
- Love more lavishly
- Laugh more often
- Find goodness & beauty
- Put your loved ones first
- Sleep & rest more
- Value vacation more than overtime
- Forget the trivial
- Forgive the offence
- Be more grateful
- Believe in the value of NOW
- Be more spiritual
- Be the change you want to see in the world
- Who we are matters to everyone else.

A step backwards

Faced with a life-threatening illness, it may seem that life lurches out of control, gathering pace between appointments and treatments, adding to the existing stresses of life. A step backwards may well be the way forward. (I must say that I see a step backwards as being very different from a backwards step!)

It's a bit like calling a 'time-out' in basketball. Coaches make this call when things aren't going so well. It allows time to regroup, to be reminded of the basics of the game, or to change tactics. For a moment, it's taking a step backwards.

A step backwards from an emotionally charged stressful situation makes sure that hasty reactions do not suddenly become part of the problem. It reminds us to take a good old-fashioned count to ten.

Í am sure Albert Ellis would approve of a step backwards. A psychiatrist by training, he proposed the idea that we need time to challenge our irrational thoughts in order to keep our feelings and emotions appropriate to whatever situation. Counting to ten gives us time to remember that this is not a perfect world, that not everybody thinks like we do and that it's not necessarily a disaster if the perfect solution to our problem is not found.

We live our lives forwards but understand them backwards, according to the philosopher Kierkegarrd. He said that if we take time for that step backwards, we can learn from those who have gone before us.

> *"They would live differently –*
>
> *… love more lavishly,*
>
> *… laugh more often,*
>
> *… find goodness and beauty around them,*
>
> *… put their loved ones first,*
>
> *… sleep and rest more,*
>
> *… value vacation more than overtime.*
>
> *… forget the trivial,*
>
> *… forgive the offence,*
>
> *… be more grateful,*
>
> *… believe in the value of NOW,*
>
> *… be more spiritual,*
>
> *and want you to be the same."*

The Marathon Mentality

Fortunately, it's not essential to run marathons to discover the marathon mentality.

I see the marathon mentality in the weaver, progressing one narrow thread at a time towards lengths of material metres long. I see it in the person laying irregular slate pavers up the driveway - checking for size, shape and colour before settling for just the right one, and then the next one, just right. In fact, it can be found all over the place because it has application in many areas of our lives.

Surely it was behind many of the sayings heard years ago extolling the virtues of patience and taking things one step at a time. They hint at some of the admirable features of the marathon mentality such as:

- Patience and persistence - I'll just keep going.
- Discipline - I'm not stopping now.
- Purpose - I have a goal in mind.
- Positive thinking and positive attitudes - I'm feeling stronger and stronger.
- Pacing yourself - I'll save something for later.
- Practising detachment - I'll just take my mind away for a while.
- Self belief - I can handle this.
- Enjoying the present - I'm feeling good, and the company is wonderful, but I'll press on one step at a time until the goal is eventually accomplished.

These are the ingredients of our worthwhile achievements. We should make every effort to cultivate them in our ordinary day-to-day living, in the small and simple things of our living. Then when it comes to the latter stages of whatever 'marathon' we seek to complete, our training will stand us in good stead. We will know that we have the physical, mental, emotional and spiritual resources to finish our journeys in style.

Putting the Garbage Out

According to Leunig, life commentator and cartoonist, some of the garbage we have to deal with is the stuff we think about. He says we retain too much of this and, unless we deal with it, then the following statements can be taken very seriously: “I’m stuffed,” and “The world is stuffed.”

It sounds like we need to be putting out any garbage thoughts we have cluttering up our minds. (Other thoughts might be worth recycling, some worth composting.) Identifying the garbage ones is the first step:

- angry and resentful thoughts
- judging and defensive thoughts
- bitter thoughts
- guilty thoughts.

None of these lead to peace of mind, that’s for sure. Our righteous indignation perpetuates them.

Jerry Jampolsky, an American psychiatrist, says there is one question we can ask ourselves to get rid of garbage thoughts. This is it:

“Do I want to be happy or do I want to be right?”

Thinking about this for a moment makes us realise that the end result of proving our rightness may not be happiness. For our own sake it is better to let go, to forget and to forgive. Forgiveness of ourselves and others, says Jampolsky, enables us to move on from such debilitating emotions as anger, resentment and guilt. It costs nothing and gives plenty in return. It clears the mind for more enjoyable thoughts.

And the good thing about putting out the garbage thoughts is that you don’t have to wait until the next collection!

Soul Searching

Scott Peck, author of *The Road less travelled*, says we have a spiritual dimension, whether we acknowledge it or not. The soul, surrounded by our human traits, given the opportunity, searches for something greater than our everyday problems - seeking to make sense of the mysteries that technology cannot decode, helping us to live with questions that have no answers.

People facing death still ponder these questions about the meaning of life but, according to this Leunig poem, thinking alone is not the solution:

> *"And so the soul in which we sail,*
>
> *Unknown by years of thinking,*
>
> *Is deeply felt and understood*
>
> *The moment that it's sinking."*

Perhaps understanding the soul is like the pursuit of happiness:

> *"Happiness is like a butterfly –*
>
> *The more you chase it, the more it will elude you;*
>
> *but if you turn your attention to other things,*
>
> *it comes and softly sits on your shoulder."*

In *Handbook for the soul*, John Gray says that every day we have opportunities to use the attributes of our soul - to help others, to have compassion for them, to be tolerant of them. Meaning is added to our lives through relationships with others, giving us perhaps a glimpse of the big picture.

Nevertheless, an understanding of our real selves also requires time out from human activity - building on those moments when the mind naturally approaches the meditative state. This may occur both inside and outside of religious frameworks. Religion and prayer are along one of the paths that nourish the soul, but other paths find answers in nature, music and meditation.

The Maharishi Code summarises it all by telling us to

> *"… be simple, be kind. Attend to your inner health and happiness* [this may take a little self-discipline]. *Do not strain after the needs of life - it is sufficient to be quietly alert and aware of them … Life is here to enjoy."*

However, don't delay - there is a deadline!

Don’t Quote Me!

Once a diagnosis of any life threatening illness is made, one of the first questions that springs to a person’s mind is: “How long have I got?” Any answer you receive has to be a ‘guesstimate’. Statistics can only tell you so much, and very little about the individual, or possible complications that may, or may not, occur to qualify the answer, and then there are other variables.

Doctors in general have been shown to be way too optimistic. Patients, at least initially, seem to be too pessimistic, fearing that death is just around the corner. This uncertainty is difficult to live with. It creates anxiety and makes planning difficult. Sound advice is to plan for the worst but hope for the best.

Nevertheless, the question will continue to be asked and doctors are perhaps the best to attempt an answer. Their knowledge of the natural history of the disease, and previous experience of similar patients are a start. An initial guide will take into consideration the overall wellbeing of the person, their energy levels, their day to day functioning, their dependence on help, and how much time they need to spend resting in a bed, or chair.

As a rule of thumb, once more than half the time is spent in bed, survival time is probably measured in months.

The rate of decline, and certain signs/symptoms are also a guide. A poor appetite, loss of weight, swelling of the legs, shortness of breath, and delirium are all indicative of a poor prognosis, especially if they all occur together.

As well as taking all this into consideration, people themselves often have a good ‘gut’ feeling of their own survival times, and perhaps more control over the actual timing of their dying than is realised. But don’t quote me!

Dying Clichés

Although in itself a cliché, perhaps in the context of dying, ‘honesty is the best policy.’

It is often said that ‘life is too short …’ for this, that or the other. Once a life-threatening illness has been diagnosed, life is too short to pretend. There is a sense of urgency which calls for honesty. It is the time to deal with the unfinished business which pretence perpetuates.

Honesty in facing up to the reality of the situation demands courage. It is difficult for families at different stages of acceptance, seeking to protect each other from bad news. It is difficult for families with different ideas on the best course of action.

It is difficult for all families to talk about death. But there is no other way in the long run. There is nowhere to hide and, if not expressed verbally, then our body language speaks volumes. Open and honest discussions between health professionals, patients, families - including children - and friends ‘clears the air,’ leading to opportunities to move on. How to talk with and listen to each other is an essential skill for living and dying in style.

“It’s not what you say but how you say it!” This cliché of communication underlines one of its very basics: there are feelings behind words. This has implications for when we talk and when we listen. To be a good listener, we need to pay attention to non-verbal cues. We need to listen with our eyes and our hearts, as well as our ears! Good listeners are not trying to get a word in edgeways, rather waiting for the whole message, without judgement one way or the other. Silences are not interrupted with “Don’t worry” or “You don’t really mean that” or “I know how you feel” or “You should” or “You shouldn’t” or “Everything will be all right.” Unlike honesty, these cliché expressions are not the best policy!

The Last Lap

In the last lap of this life-threatening illness, like any endurance event, fatigue is a common problem. There are physical and mental adjustments to make, all requiring considerable effort.

Where to be for this last lap is a decision for families and friends to discuss. The best chance of living as normal a life as possible is at home. Routines can be those you choose, rather than the ones imposed by a hospital, palliative care unit or a nursing home. But this is not always possible or practical.

The last lap need not be completed alone. The informal network of family and friends can combine with the health professionals, and community organisations such as Hospice, to help out as required.

New and different attitudes are needed. Accepting help is often the first adjustment, followed by the need to take a veritable cocktail of medications for various symptoms, with reserves of patience being called upon as the ability to be independent wanes.

Hopefully by now, all your legal and financial affairs are sorted, your Advance Care plans are in place, and any other unresolved issues, if not dealt with already, will be soon.

Last lap suffering means coping with a variety of problems – physical, psychological, social and spiritual. There is always the uncertainty of how it will go, and the struggle to strive towards understanding, acceptance and peace of mind.

Progress around this lap might be made easier by finding someone to listen to your thoughts and feelings, to hear how this illness has intruded on your life, and to tell them what no-one seems to understand. Fine tune that ability to detach and rise above the difficulties.

As with all last laps, pre-event preparation and early pacing are the keys.

That’ll Be the Day

What does the day that we die hold in store for us? There are no analogies for this one - we will be in new territory.

The process of dying, for many people, is more of a worry than actually being dead.

It might be reassuring to recall the experience of those who have nearly died but didn’t. They speak of a peaceful, even loving event involving, amongst other features, a life review and a bright light. Whatever we believe about the significance of this, these people are not afraid of dying afterwards.

I also suspect that on many occasions, watching someone die can be more distressing than the dying process itself.

Most people dying after a prolonged illness gradually become weaker and sleepier, so that on the day they die, they will be exhausted and in a coma. The sound of secretions in the back of their throat as they breathe is often disturbing for relatives and friends, but something that the dying person will not be aware of. Nor will they be aware of their breathing starting and stopping, their colour fading or their cold nose as the circulation gradually fails.

Dying of itself does not need any special medical treatment. It is, after all, just the last stage of living. Nevertheless, there may be ongoing treatment required, although it will take on a different emphasis. Previously important medications, for instance for the control of blood pressure, no longer matter. Other medications take their place. Pain control remains important and there may be a need for something to control restlessness or perhaps confusion. Inability to swallow by now means that these treatments will be given by some other route - usually, but not exclusively, by injection into the fat (subcutaneously), sometimes using a syringe driver to trickle the day’s requirements in at a slow, steady rate.

On the day that we die, we will probably not eat or drink. Dehydration may be present but is generally not a problem. In fact it can be an advantage as secretions are decreased and urine output reduced. There is no need for an intravenous drip, but swabs are used to moisten the mouth and lips for comfort.

Occasionally, for whatever reason, the event is more dramatic, but such possibilities can usually be anticipated and arrangements made to have the necessary treatments on hand.

The aim of the exercise is always comfort. The doses of any medications used are measured against the symptoms present as the dying process comes to its natural conclusion.

So what will matter in the long run?

Stephen Jenkinson has a message for everyone in his book *Die wise*. Dying well is something we owe to our family and friends, he says. This is what they will remember; it is not what happens to you, but what you do.

High tech health care has become an undeclared war on dying; and no-one wants to be accused of giving up. But any extra time gained is lived in the shadow of the inevitability of dying, and it can become a nightmare.

In the end you die but are exhausted trying not to die. Coping, hoping, and doping fail.

It would be better if your way of living and dying created meaning and became part of the meaning of life for others. Instead of ‘fighting for life’, try wrestling life for its meaning. Make it a time for living with purpose, without losing sight of the finality, and sorrow, and grief that dying must bring.

Michael Josephson, an ethicist and poet, sums it up this way:

What will matter:

> *“...is not what you got, but what you gave;*
> *is not what you learned, but what you taught;*
> *is not your success, but your compassion;*
> *What will matter is not how many people you knew,*
> *but who will be inspired by your example*
> *and who will feel a lasting loss when you are gone.*
> *What will matter is not your memories,*
> *but the memories that live in those who loved you.*
> *Living a life that leaves such a legacy won’t happen just by accident.*
> *It’s a matter of choice, and courage.*
> *Choose to live a life that will matter.”*

This is the challenge of living and dying in style!

Section Two: End of life preparations: the essentials

> “*Meditate early and often on the art of dying, so that in the end, you do it properly, just once” (Umberto Eco)*

As it stands, health professionals control dying and after death, the funeral industry takes over. This is not to say that their services are not required as they help us to negotiate what is unfamiliar territory for most people. However, in the process, individuals’ wishes are often not respected, or even known. But with appropriate preparation, people can have more control than they realise.

There are things to know and things to do. If the system and the rules are understood, you can use them to do it your way. Plans need to be made before a crisis occurs, they need to be shared appropriately, and there has to be at least one person chosen to speak up for you if and when the need arises.

Plans

There are three types of plans to be considered:

- The End of life care plan
- The Death plan
- The Funeral plan

Various amounts of detail will be required depending on your wishes, the choices you would like to make yourself, and the ones you are willing to leave for others. While the task is challenging, even daunting, it is important to get started while you are legally competent and before capacity might be lost through either illness or accident. What matters in the long run are the memories you create for those who are left behind. A great gift to those you love is to make sure the memories are as good as they can be, and for the transition to life without you, to be no more difficult than it has to be.

Choosing your support crew

A key decision early on is to name the person, or the people, who will be prepared to speak and act on your behalf in various roles to be discussed later. They need to be able to handle the responsibility, be assertive if needs be, feel comfortable with death and dying, and be able to separate their feelings from yours. Those entrusted with these duties are usually family members, or friends.

Alongside will be your informal caring network made up of family, friends, neighbours and/or work colleagues. The degree of their involvement will depend on circumstances, particularly if home is your preferred place for end of life care.

This is a time when existing relationships are tested, and carers need to be prepared for the impact on their own lives, as well as the rewards of satisfaction and achievement. No prior experience is necessary, and almost without exception, carers say they would do it all again. Strong relationships exist within these networks, which may develop spontaneously or be initiated.

Informal networks will interact with the formal networks made up of health professionals (eg. GPs, palliative care, district nurses, and different home care services). They are on the periphery of the network map, but their advice, reassurance and on-call availability are much appreciated.

In some communities people other than friends and neighbours, and formal service providers, step in to help. The Warrnambool & District Community Hospice Inc, a not for profit volunteer organisation, has set up a free Hospice in the home program to assist people to be cared for at home. Their volunteers have an understanding of the dying person’s and carers’ needs and are very willing to become part of your support crew.

It is time well spent to consider the make-up of your support network. The digital world has stepped up to assist in this regard. The website www.gathermycrew.org is designed to help families in a co-ordinated fashion so that needs are met by appropriate offers from their willing supporters. Similarly, Palliative Care Australia has released a new mobile app, AllowMe! . This also mobilizes communities to help people who are caring for someone with a life-limiting illness with practical tasks.

Important conversations

Having given some thought to your support crew, it is now important to let them know your wishes. This may mean having conversations that are difficult for people to have, the sort you put off until the 'right moment 'comes along. Don't wait. Make use of the framework of the various plans (see later) to get you started.

Firstly though, have you thought about what is important to you in terms of end of life care? What are your values, and what are your priorities? There will be things you want, and things you don't. There may be things you would like, but which are not appropriate. At some point, for most people, quality of life will become more important than length of life. What would you consider to be a reasonable, or worthwhile, quality of life?

Reflecting on who you are, and your connection with all aspects of life, may be guided by a small pamphlet on *Spiritual Wellbeing* produced by the Melbourne City Mission Palliative Care. It asks a series of questions about you, your community, your relationship to the environment, and your beliefs. For example:

- What makes you a unique person?
- What gives meaning and purpose to your life?
- What makes you happy?
- Who are the important people in your life?
- Who are the important groups of people in your life?
- What activities do you enjoy sharing with others?
- Where do you feel most at home and at peace?
- How do you make sense of life?
- What are your beliefs about life and death?

Some background medical information is also important to understand while having conversations, hopefully before any crisis complicates the situation. Firstly, not all treatments will benefit all patients, and doctors are under no obligation to initiate a treatment considered to be futile in a particular situation. Sometimes it is reasonable to trial a treatment for a short time, with the option of continuing if it is beneficial, or stopping, if not. Whatever decisions are made about medical treatment, palliative care will always be offered to relieve pain and other suffering, along with food and water. In fact early palliative care leads to significant improvements in both quality of life, and mood, with less aggressive care at the end of life, but longer survival.

Act now: plan ahead

Plans you make today may differ from the ones you might make later on. So it is important to realise that changes can be made to the people you appoint to various roles, to decisions about medical treatment, and to your will, *as long as you remain mentally competent.* Once decision making capacity is lost, the Medical Treatment Decision Maker and Enduring power of attorney are activated.

The End of life care plan

There are four main parts to the End of life care plan:

The first part of the End of life care plan is Advance care planning, including writing an Advance care directive. The second part involves completing a valid will. The third part of the End of life care plan is appointing Powers of attorney and alerting them to your wishes. Lastly, there's completing a personal life review and legacy.

Under the authority of the *Medical Treatment Planning and Decisions Act 2016*, legally binding choices about present and future health care can be made by a person with decision making capacity. To ensure that your wishes are respected even if you are unable to speak for yourself, it allows for the appointment of a Medical Treatment Decision Maker (MTDM). In fact, more than one may be appointed, but they need to be listed in order of priority, and only one has the legal authority to speak at any one time.

Appointment of the MTDM requires two independent witnesses, one of whom is a medical practitioner, and the role must be accepted in writing on the same document. The Medical Treatment Decision Maker has the right to consent or refuse treatment on your behalf and must be consulted by any health practitioner considering treatment if you are unable to speak for yourself. The MTDM must comply with your Advance care directive.

Writing an Advance Care Directive

Advance Care Directives may be written in two ways:

An **instructional directive** that is used to consent to or refuse a particular medical treatment.

A **values directive** that is used to document preferences and values in regard to health care, without making decisions about individual treatments. Values may be easier to talk about than deciding about specific treatments. To help you through this process there is a useful website www.myvalues.org.au developed by Barwon Health. By answering a questionnaire, this resource ends up creating a report for you that summarises what really matters to you personally when it comes to decisions about your future health care.

The Act also allows for the appointment of an official support person to help you write an advance care directive. This person will need access to your medical information and will generally help you get organised to make your own decisions and may help co-ordinate your care. While the roles of the support person and the MTDM are different, it is possible for your support person and the MTDM to be same person.

One of the essential issues to consider when making an advance care plan is what you would like done in case of an emergency in regard to resuscitation.

About Resuscitation

You will need to give thought to what resuscitation treatments you may or may not want in the case of emergency, and also about your attitude to life prolonging treatments over the longer term. You have the opportunity to say where you would prefer to be cared for, and for any personal, religious or cultural beliefs to be respected.

Resuscitation or CPR (cardio-pulmonary resuscitation) would be considered, for example, if a heart attack caused your heart to stop beating effectively and you collapsed. To answer this question you need to know what resuscitation involves, and how successful it might be.

CPR is an aggressive treatment. It involves attempts to keep your circulation going by repeatedly compressing the heart between the breast bone (sternum) and the back bones (vertebrae)...so-called 'external cardiac massage'... requiring force that may well break some ribs. To provide oxygen to the lungs a tube is passed into the wind pipe (trachea), and assisted breathing is commenced. Depending on the rhythm of the heart, an electric current may be applied to the chest wall using the paddles of a defibrillator in an effort to re-establish normal heart muscle contractions. An intravenous line will be inserted into a vein to inject various medications to try and make your heart beat effectively again.

CPR is not nearly as successful as many people think. Overall it works in around 15% of cases, and is more likely to be successful in younger people without other health problems. It needs to be commenced within 2-3 minutes to minimise the risk of brain damage from lack of oxygen. In older people with a number of health issues the success rate drops quickly. In those with advanced illness, the success rate is virtually zero.

It might be helpful to think of different options under the heading of resuscitation as follows:

Option A. CPR - full treatment (as above). Younger people without other obvious health problems may choose this option.

Option B. 1. No CPR, but for ventilation. This might be appropriate for someone with severe pneumonia requiring temporary breathing support by a ventilator.

2. No CPR, no ventilation, but for life prolonging treatments such as intravenous injections and/or antibiotics and/or blood transfusions. This might be for people with severe infections or blood loss causing the emergency.

Option C. Not for resuscitation (NFR). No CPR, no ventilation, and no life prolonging treatments. Older people with advanced disease might choose this option where the focus of any treatment will be comfort and symptom control i.e. good palliative care. People may choose to be in hospital, or at home, for this option.

Your choice needs to be crystal clear if you want to be designated as NFR. If there is any doubt, resuscitation will most likely be commenced.

It is important for your statements to be clear, unambiguous and convincing. eg. “I would rather be dead than to be relying on a breathing machine to keep me alive”. Legal documents may be complemented by letters from your family and your doctor, to add weight to your decisions.

The Will

Dying without a will makes life very complicated for your family. Far better to choose the person(s) who will act as executor and give them the authority to make sure your wishes are carried out in regard to the disposal of your body and the distribution of your estate.

To write your own will, you can buy legally valid kits prepared by State Trustees from your local Post Office. These are suitable for those whose affairs are simple and straightforward. However, if you have a family trust or a self-managed super fund, or if there are any special circumstances making matters more complicated, it is best to seek professional assistance.

The State Trustees also provide a storage service for wills which is free to all Victorians. Wherever it is kept, it is important that the will is safe and secure, and that your executor(s) knows where to find it.

Enduring Powers of Attorney

Powers of attorney laws changed in Victoria on 1 September 2015. Enduring powers of attorney (financial) and enduring powers of guardianship made before this date are still valid.

An Enduring power of attorney is a legal document that allows you to appoint a person(s) you trust to make decisions for you, including if you ever lack the capacity to make decisions for yourself sometime in the future.

The attorney can make financial decisions, personal decisions or both, but these are completely different from the health decisions to be made by the Medical Treatment Decision Maker. If the same person is to fill both roles, the appointments must still be documented separately on the appropriate forms.

It is also possible to appoint more than one attorney, and to specify how they act. The attorneys must sign to accept the appointment. As long as the forms are completed, and witnessed correctly, it is not necessary to go to a solicitor, but many will appreciate that sort of guidance, especially if their affairs are complex.

Other powers of attorney include the supportive attorney (promoting the autonomy of a person who can make decisions but needs some help) and a general Non-enduring power of attorney, mostly used for a set purpose for a set time (for example, managing someone's finances for them while they are away somewhere). The legal documents needed to appoint the different powers of attorney are found in a booklet called *Take Control* published by the Office of the Public Advocate, and available from the Legal Aid website.

Life Review and Legacy

This is included as part of an End of life plan because it is your way of telling others who you are, and what you would see as your legacy.

You can do what you like when you record special memories, recipes, jokes, or leave drawings, notebooks or photos. This is not a legal document; it is an opportunity to leave a message for people who are important to you, to say what you have learned about life that you want to pass on, to express your hopes and dreams for your family and/or friends. It will become something of yours, beyond goods and chattels. Your family will treasure this into the future.

A template to help construct your story, and express your thoughts, follows. How it is presented is entirely up to you.

This is my life

- Name, date of birth, and place of birth.
- Childhood and school day memories.
- Developing interests and talents.
- After school - work, university, travel.
- Important relationships - family and friends.
- Passions, hobbies, interests, activities.
- Decisions and turning points, ups and downs, good times and bad.
- Life lessons.
- Hopes and dreams for family and friends.
- Anything else?

The Death plan

When someone dies, and the death is expected, there is no hurry to do anything. If the death has occurred at home in the middle of the night, there is time for people to come and say their goodbyes before anyone is notified. However, before any funeral arrangements can be made, a doctor must sign a certificate that confirms the death.

The Death plan deals with how you would like your body treated after death. As with the end of life plan, there are opportunities for individuals to have more control, but without planning ahead, these opportunities may be lost.

Many people will not be used to looking after a body after death, so it may be quite daunting. Choosing a funeral director to completely take over this responsibility is a common solution. However, for family and/or friends who want to be more involved, there is help available.

The Natural death care centre (see bibliography) has developed Fact sheets to assist your thoughts about these matters.

- Home (or DIY) funerals led by the family are possible. This can be a natural extension of caring for someone who dies at home, but it can still be arranged for people who die in hospital, or a nursing home.
- Even in the case of unexpected death requiring an autopsy by the Coroner, it is still possible to have a home funeral.
- As long as a method of cooling is employed, a body may be kept at home for several days (in NSW the legislation states five days; Victorian law does not specify a time).
- Where available, cool mats (rather like the reverse of an electric heating blanket, but driven by their own motor), are the most effective way of keeping a body cool.
- It is not necessary to be buried in a coffin, but a coffin is necessary for transportation. The body may then be buried in a specially made shroud.
- You can make your own coffin (specifications apply)
- Cardboard coffins are available.

There are several questions to think about with these facts in mind:

- How ‘hands-on’ (eg. caring for you before death, washing and dressing you after death) would you like your family to be?
- How ‘hands-on’ would your family like to be?
- Would your family like to keep you at home for a certain period after death?
- What resources are available to help you do this?
- Have you thought whether you want to be buried or cremated, or do you want your body disposed of in some other way? (Possible, but more difficult, and perhaps more expensive.)
- If cremation is preferred, what will happen with your ashes?

- Have you made any decisions already? eg. organised a prepaid funeral, purchased a particular burial site?
- Do you have any special requests?

The Funeral plan

A funeral or a memorial service is the traditional ritual for family and friends to gather to express their grief, celebrate life and say goodbye. It is also traditional that a funeral director will take charge of the arrangements, make sure the death certificate is collected, register the death at the relevant government office, notify newspapers and even help with the flowers.

However, there is no requirement to have a ceremony and if you do, the form it takes will depend on your own personal, religious and cultural beliefs. Funeral directors may be involved to a greater or lesser extent. Once again, there are choices on offer and decisions to be made. Some people like to plan their own ceremony in detail, while others will leave it up to family and friends.

Here are some things to consider:

- Will this be a DIY funeral, or assisted by a funeral director?
- Will there be a ceremony?
- Will it be a religious or secular one?
- Will everyone be invited, or will it be private for family and close friends?
- Where will the ceremony be held? For example, a church, funeral parlour, other building, home, public space, graveside, crematorium.
- Who will lead the ceremony? For example, a Minister or Priest, funeral celebrant, family member, friend.
- Who will speak?
- Are there any special requests, including preferred music, readings?
- Will there be an audio-visual presentation?
- Will the coffin be present at the ceremony, and if so, how will it be transported?
- If needed, who will be the pallbearers?
- Any other requests eg. flowers, charity donations?
- Who will provide refreshments afterwards, and where will they be served?

After someone dies, a lot of decisions must be made in a short space of time. How much better to think things through in advance, making life easier for everyone concerned! What matters in the long run are the memories you create for those who are left behind. A great gift to those you love is to make sure the memories are as good as they can be, and for the transition to life without you to be no more difficult than necessary.

My Death and funeral plan

Now it’s time to get organised! Use these headings to collate your own personal information in one easy-to-access place.

The first group of headings concerns your wishes for the care of your body, including burial details.	
Preferences for care after death. This includes site of care, family/friends’ involvement, dress preferences:	
Death notices, for example which social media sites, newspapers:	
Prior arrangements, for example details of a prepaid policy, burial site at a particular cemetery:	
Funeral Director’s contact details:	
Funeral or Memorial Ceremony?	
Place:	
Who will lead the ceremony?	
Contact details:	
Who else will be involved, and in what capacity?	
Readings:	
Music:	
Flowers?	
Charity donation details:	
Burial or cremation location details:	
Ashes to be scattered:	
Memorial stone or plaque	
Any other requests?	

The next set of headings is about making life easier for your family. Your own personal details come first.	
Full Name:	
Maiden name, or other previous names (if applicable):	
Usual address:	
Marital status:	
Date of birth:	
Place of birth:	
Date of arrival in Australia (if applicable):	
Occupation, (ABN if applicable):	
E-mail addresses:	
Phone number(s):	
Religion:	
Place of marriage (1):	
Age when married:	
Spouse/partner:	
Wife's maiden name:	
Place of marriage (2):	
Age when married:	
Spouse/partner:	
Wife's maiden name:	
Father's name:	
Occupation:	
Mother's name:	

Mother's maiden name:	
Occupation:	
Now for information about important people in your life. Complete names and contact details as appropriate.	
Next of Kin:	
Relationship to you:	
Children (full names and dates of birth)	
Other family members: (eg. siblings, grandchildren, great grandchildren)	
Friends:	
Medical Treatment Decision Maker(s) 1. 2.	
Support person (if appointed)	
Powers of attorney: Enduring power(s) of attorney	
Supportive attorney (if appointed):	
General non-enduring power of attorney (if appointed):	
Executor(s) of the will:	
Other important people:	
Employer	
General Practitioner:	
Specialist(s):	
Dentist:	

Solicitor:	
Accountant:	
Clergy:	
Representatives of Community organisations/clubs:	
Funeral director:	
Funeral celebrant:	
Others:	
Next is your important medical information.	
Major diagnoses:	
Allergies:	
Medications:	
Pacemaker (yes/no):	
Implanted defibrillator (yes/no):	
Private health insurance details:	

Now for the details and locations of those important cards and documents.	
Driver’s licence:	
Passport:	
Medicare card:	
Bank cards:	
Credit cards:	
Myki/travel card:	
Seniors card:	
Other cards:	
Passwords location(s)	
Birth certificate:	
Marriage certificate:	
Property titles:	
Advance care plan:	
Medical Treatment Decision Maker:	
Powers of attorney:	
Life review:	
End of life plan:	
Death and funeral plan:	
Will:	

The following items relate to your financial life.

Bank accounts:	
Direct debits (eg. accounts, charity donations):	
Mortgage:	
Loans:	
Other debts:	
Money owed to me:	
Superannuation:	
Binding beneficiary?	
Superannuation pension:	
Binding beneficiary?	
Centrelink benefits (Yes/No)	
Type:	
Customer reference number:	
Returned serviceperson: (Yes/No)	
Unit:	
Number:	
Department of Veteran Affairs benefit:	
Property:	
Shares:	
Chess reference number:	
Stockbroker:	

Other sources of income: Tax file number:	
Location of current accounts/receipts:	
Transport and insurance items next.	
Motor vehicles: (year, make, model, registration number, registration due, keys)	
Caravan:	
Boat:	
Insurance policies: Life/Accident/Income	
House and contents:	
Vehicle(s):	
Other (eg. caravan, boat):	
Council rates:	
Utility providers:	
Water:	
Gas:	
Electricity:	
Phone(s):	
My digital world: (Computer, iPad, other devices, Facebook, Twitter, LinkedIn etc)	
User names, passwords:	
Miscellaneous notes: (other information not covered above, valuable possessions, requests)	

Changes

As time passes, there may be changes made to the information provided previously. Simply put one straight line through whatever no longer applies and make note of the new correct information below. Sometimes new documents are required, if old ones become void.

If you want to change a Power of attorney, a revocation document may be completed. Another appointment on a new document, with a later date, takes over as the current attorney.

If you wish to change your will, it is best to do a whole new one.

For the executors: Further information and resources

When someone dies there are a lot of people and organisations who need to know. A checklist and some phone numbers collated by the Department of Human Services is listed below.

The Department also lists the types of assistance, and the claiming process for payments from CentreLink, and services such as:

- Bereavement allowance
- Widow allowance
- Double orphan pension
- Pension bonus bereavement payment

Counselling services, and a free financial information service are available. More information may be obtained at the website www.humanservices.gov.au or call 136150.

In cases of specified compassionate grounds and severe financial hardship, the law does allow for the early access of superannuation before your preservation age is reached. Contact your superannuation fund for the details.

The MoneySmart website www.moneysmart.gov.au helps you to make the most of your money if you lose a partner.

Debts of the person who has died will be paid for by the estate, and do not have to be paid for by relatives, unless the debts are in joint names.

A name may be removed from mailing lists by registering details on the Association for data-driven marketing and advertising website www.adma.com.au or write to them at:

ADMA GPO Box 3895 Sydney NSW 2001

Social media accounts may also need to be considered. The best thing to do is contact each network separately through the ‘help’ section if you want to close an account.

Useful phone numbers (Department of Human services):

Australian Taxation Office	132 865
Centrelink Payments	132 300
Child Support Services	132 272
Department of Veteran Affairs	133 254
Australian Electoral Commission	132 326
Medicare Services	132 011

Section Three: Home Care

This section is a practical guide for those who are considering caring for a dying family member at home.

The best chance of living as normally as possible in spite of the illness is at home. Routines can be those you choose rather than the imposed ones of hospital. There is privacy to behave and react however you wish in your own home.

One of the main benefits of helping someone to die at home is that it encourages family and friends to be involved in maintaining the best quality of life as possible. Families often feel much closer as a result.

At the same time, you will find that your normal routines change dramatically. Home care can be an emotional strain with moments of despair, fear, embarrassment and exhaustion.

Your previous relationship with that person should therefore be considered, along with the time you have available and what must be done to meet their needs.

The task will never be easy, and circumstances do not permit everyone to do it. Do not feel guilty if you start and have to change your mind or if it is just not possible in the first place.

However, it can be one of life’s experiences that is rewarding for all concerned in terms of the opportunity for personal growth and the sense of fulfilment achieved.

Preparing for home care

1. Can I care for a dying relative at home?

Caring for a dying person means 24 hours a day care. It is therefore a difficult task on your own. You will need help – even if you are a relative with some nursing training. On the other hand, lack of nursing experience does not disqualify you.

Estimates of how long this care is likely to be needed are not always accurate, so it is important to pace yourself, giving yourself the best chance to go the full distance.

You will need support. Make the most of it, share the load – allow yourself time to relax a little before returning to the demands of nursing care.

Recognise your limitations and think about your resources – people and services – who will give you support. It is sensible to do this early on so that, when the need arises, those helping are familiar to you, not strangers. It may be helpful to work through a check list of the pluses and minuses of home care with your relative, and with others who might help.

2. What professional help is likely to be available?

You can seek assistance from several different health professionals through a palliative care service, local hospital, community health centre or general practice clinic.

Doctors – particularly your general practitioner, will provide ongoing management for your relative's illness and will help co-ordinate other medical and paramedical services as required.

District Nurses or Palliative Care Nurses – will visit regularly according to need and provide assistance with medication, hygiene, pressure care, bowel and bladder management, dressings, injections and so on. Sometimes they will visit just to talk about the care. On other occasions, advice or reassurance over the phone might be all that's necessary.

Occupational Therapists – are able to advise on changes in the home to make caring easier, such as rails, ramps, items of equipment, eg. commode, wheelchair.

Social Workers – can assist in counselling and inform you about other services which might be helpful and what financial assistance is available.

Chaplains or your own minister of religion – can provide pastoral care, seeking to integrate spiritual concerns with those physical, social and emotional ones.

Hospice in the home- in Warrnambool there is a free Hospice in the Home service to assist families caring for a dying person at home. Their volunteers have an understanding of the dying person's and the carer's needs.

It is important that you know who to contact in case of emergency. Sometimes problems seem to occur just after the doctor or nurse has been for that day! Make a list of the names, addresses and phone numbers of everybody involved.

3. Are there any other kinds of help?

Some cancer care services have volunteers trained to provide practical and emotional support. It is often beneficial to have someone who is not emotionally involved supporting you and your family. They might shop for you or stay with your relative while you go out.

Your local Government Council often provides assistance in the form of meals-on-wheels, home help, home handyworkers and sometimes respite care.

Church communities are very supportive – from spiritual counselling to more down to earth practicalities such as a roster for preparing meals.

Friends and neighbours are a great support but occasionally need encouragement to keep in touch for fear they might be intruding.

All things considered, successful home care can end up being a real community effort.

4. How should I prepare the home?

To make life easier for all concerned, a few changes are sometimes necessary in the home.

- Ensure the bed is accessible from both sides. A small bedside table is useful.
- Rearrange or remove unnecessary furniture to allow space for wheelchair access, nursing procedures and for visitors to come in.
- Provide a view to the outside if possible eg. a garden outlook is desirable.
- Alter bathroom and toilet area if feasible. Bathrooms and toilets can suddenly become very small as you try to get more than one person (the patient, district nurse and maybe you), a wheelchair and a shower chair all in at once. Changing a door to swing outwards can make a lot of difference to access. Rails and raised toilet seats are helpful in this area of the house.
- Provide a removable ramp made to help negotiate a couple of steps. This can make movement around the house easier, especially for a wheelchair.

- Allow access to a place set aside for the patient in the living area if possible. This enables them to be a part of daily activities and the to and fro of conversation.

- Provide a simple bell for the patient to ring, or a remote call system. This will give you more freedom to move around the house and garden.

5. What equipment might be needed?

The equipment needed will vary according to a number of factors, including your relative's particular illness and its likely progress and their mobility or degree of dependence.

The features of your home, such as the proximity of the bathroom and toilet to other rooms and the presence of steps, also influence items required. Some or all of the following items could be of assistance:

- A special mattress to reduce risk of pressure areas such as an air mattress.
- Sheep skins to lie and/or sit on, or booties to protect heels.
- A 'boomerang' pillow, extra pillows.
- A plastic sheet or mackintosh to cover the mattress.
- 'Blueys' – disposable and plastic backed 18"x 14" are handy to place on a chair or under the patient's buttocks in bed. They can save a lot of washing.
- Special absorbent sheets.
- A bed table or bed tray.
- Flexible straws, feeding cup with spout, mouth swabs.
- A commode, raised toilet seat, bedpan or bottle.
- A wash basin, shower chair.
- A wheel chair and/or walking aid.
- Sometimes a hospital bed makes life easier.

These items are usually available from your community palliative care team.

Skills for home care

6. Are there any special medical or nursing problems I should know about?

These will vary according to the type of illness; you may require specific advice from your doctor or nurse.

Pain: This is almost a universal fear but not all people dying suffer pain. Of those who do, the vast majority can expect relief. Pain may be aggravated by emotional or social problems.

Medication prescribed should be taken strictly around the clock. Don’t wait for pain to return before giving the next dose.

Morphine is not a last resort and addiction is not a problem. Other medications may be used with morphine.

Nausea and vomiting: This may be due to a variety of causes requiring specific medications which can be given in a number of different ways. Nausea can in fact be more of a problem than vomiting if it lingers on.

Not eating, losing weight: If there are no obvious causes, simple measures sometimes help this problem which many carers find frustrating. Rather than worrying about balanced meals at regular intervals, encourage patients to eat a little of what they like, when they like, concentrating on foods that are easily digested. A small amount on a small plate may not look so daunting. High calorie drinks are often useful.

Constipation: Inactivity, poor nutrition and fluid intake, dehydration, weakness and drugs make this a common problem. But even with a poor diet, the intestine makes enough faeces for a bowel action about every three days. Encourage mobility, more fluids and a prompt response to the desire to use bowels. With morphine, constipation is controllable by treating it in anticipation with laxatives. District nurses may need to help with suppositories or enemas. Proper bowel care is essential. It is not a shame to disturb a patient to ensure this.

Skin care: The prevention of pressure sores, skin rashes and cracks is most important. Where the body is in constant contact with the bed – heels, hip bones, buttocks and elbows – are the areas most at risk. If the patient is confined to bed, frequent changes in every position (every 2-4 hours), use of special mattresses, pillows and sheep skins, crinkle free sheets, bed cradles, thorough drying after washing, and the appropriate use of powder and moisture creams help in this regard. Further advice is best sought from the district nurses.

Confusion: Disorientation in time and, to a lesser extent in place, is normal in the very ill and dying. Anxiety may aggravate this with nightmares or vivid daydreams. Just talking about them may decrease their fear. Sometimes medication or other medical problems are responsible, requiring attention by your doctor.

Continue to treat the patient as a sane, sensible adult. Avoid restraints and calm fears by explanation and reassurance. Medication is sometimes necessary but as far as possible should be used sparingly.

Weakness: Increasing weakness is often one of the most frustrating symptoms for you and your relative to cope with. There may seem to be less interest in activities as their strength to be up and about decreases. Inevitably more time is spent either sitting in a chair or in bed as time progresses. Rest periods between outings and visitors become important.

Dehydration: In the final stages of advanced illness, patients often lose interest in fluids as well as food. This is no reflection on your care. It is important to remember that dehydration is not distressing for patients – in fact there are a number of advantages. There are fewer secretions to swallow or rattle in the back of the throat, coughing is reduced, vomiting is less likely and there is less urine to get up and pass. This is nature's way of shutting down body processes.

The only disadvantage is dryness in the mouth, but this can be controlled using small ice blocks to suck or moistening the mouth with swabs – perhaps soaked in pineapple juice. Vaseline prevents lips from cracking. 'Thrush' in the mouth requires a prescription from your doctor. Intravenous fluids using a drip are not necessary.

7. Do I need to learn any special nursing skills?

There are a number of skills that you can learn 'on the job' as an apprentice to the district nurse.

How to transfer patients from bed to chair or from chair to toilet and how to position patients in bed for pressure care while preserving your own back are techniques to be learnt early on.

There are ways of changing wet or soiled sheets, sponging patients in bed and positioning pillows that add to the comfort of the patient. Using a draw sheet across the bed on top of the plastic or absorbent sheet means you only change the draw sheet and not the bottom sheet if the patient wets.

Sometimes specific skills such as emptying a catheter bag might need to be learnt.

Being sensitive and aware of what it might be like to have these things done to you is one of the keys to good nursing care.

Finally, learning to listen, encouraging open and honest communication with the expression of thoughts and feelings is a skill worth developing. People with advanced illnesses are often frightened, sad or angry. Talking about these things and talking about dying often helps patients overcome despair and have some realistic hopes for living in the time that is left.

8. What is the best way to handle medication?

Instead of relying on memory it is best to have a written record of the medication and when it was given.

A useful aid for tablets is a dosette, available from chemists. This is a box divided into compartments for days of the week and intervals through the day. Medication can be set out a week in advance making the dosette both a visual reminder and a record of the treatment schedule.

Similarly, a pharmacist can prepare a Webster pack for medication every week.

The treating doctor will review medication needs as the illness progresses towards its terminal stage. However, medication for relief of pain should generally be continued, even if patients are having difficulty swallowing or are sleeping a lot. The doctor or nurse may arrange for that medication to be given by a different route e.g. rectally or by injection, sometimes using a special infusion pump.

Problems in home care

9. What problems can I expect as the illness progresses?

Eventually there may be physical deterioration to the extent that you will probably need to help your relative with their personal hygiene, including assistance with them passing urine and emptying their bowels. Commodes are generally easier to use than bed pans.

Pay attention to preventing falls by removing floor rugs and using some sort of walking aid such as a frame. With increasing weakness a wheelchair may become necessary until finally your relative is confined to bed.

Mental changes can also occur. Sometimes a little or no response may make normal interaction impossible. This can fluctuate from hour to hour, day to day.

Confusion and inability to communicate properly makes it difficult to share memories, and missing the kind of relationship established over many years is one of the most stressful aspects of caring for a dying relative. This is the beginning of your loss.

Mental and physical deterioration calls for a lot of patience.

The course of an illness is sometimes unpredictable, but lack of experience does not mean that you cannot help. Take each day one at a time. You will be surprised at how much you learn in a short space of time. You probably know more about your relative than anybody else, so you can guide others in their care (including the doctor and the nurse) by reminding them of the patient’s likes and dislikes.

10. What personal problems are common to carers in this situation?

Many people find that they have to put their lives ‘on hold’ once they commit themselves to care for a dying relative.

Plans – personal, family and professional – are either not made, altered, postponed or are dropped altogether.

You may be torn between your own family and your dying relative. There may be feelings of isolation from family and friends. If care goes on for a long time you may need to regain a balance between caring and resuming some outside activities.

Personal health may suffer. Tiredness is a common complaint and there often seems to be little time for yourself. Other people may not recognise the extent of care you are providing when your dying relative rallies while visitors are there. Sometimes carers become the target for a patient’s feelings.

Another difficulty may be dealing with advice from others unable or unwilling to be directly involved in care, particularly if they are at a different stage of accepting your relative’s illness. Handling visitors who stay too long and are insensitive to the patient’s needs might be another issue.

Keeping a journal – a record of events, your care and your feelings – is one way of dealing with these problems yourself.

11. What if I'm not coping?

It is okay not to cope.

There may be times when you feel that your relative would be better off with professional care in hospital.

However, check that you have been looking after yourself by eating regularly and getting enough sleep. Ask yourself when did you last do something just for fun or have the opportunity to tell someone close to you how you feel?

Mixed feelings are not unusual. You may be feeling grief in anticipation, yet secretly wish it was all over.

You may be almost afraid to leave the bedside for fear of your relative suffering unnecessary discomfort yet be left feeling impatient and frustrated. You may also have a fear that your relative might die while you are away. It is important to talk about these feelings.

Try not to be too critical of yourself. It may be very appropriate to organise either someone else to care for your relative for a while or for respite care in hospital for a week or two.

Sometimes problems are so great that admission to hospital or a hospice is best for everybody concerned.

12. Should children be involved in the care of a dying relative?

A child's contribution to the care of a dying relative may later be remembered as one of the most important aspects of that care – so it is good to allow children to be part of the caring team.

At the same time, do not burden the child with adult responsibilities. Try to maintain the child's routine.

If possible, try not to separate family members.

Children who are involved are more likely to be able to discuss their feelings about illness and death and understand your own commitment.

Other issues in home care

13. Are there any legal, financial or other matters to discuss?

Before physical and mental deterioration occurs, it makes life much easier for surviving relatives if plans for end of life care have been made in advance. Section 2 of this manual covers this in detail.

14. Is there any financial assistance to care for a patient at home?

If your relative would otherwise be an inpatient in a nursing home and is at least sixteen years of age, you may apply for the Carer Allowance. This is not means tested, does not affect entitlements to pensions or other benefits and is not currently regarded as taxable income. Payment cannot be made for any period prior to your application being received.

A more substantial form of financial assistance comes in the form of a Carer pension, but certain conditions apply. The Carer pension enables you to stay at home and look after someone who needs constant care and attention.

The person needing care must be getting a pension or benefit from Centrelink or the Department of Veteran’s Affairs.

The carer must not be getting another pension and must be living in the same home or an adjacent home. You and your partner’s income and assets must be below certain limits.

Application is made through your nearest Centrelink office.

The Cancer Council of Victoria has a Welfare grant fund. To be eligible you need to have a diagnosis of cancer, be a resident of Victoria and in need of financial assistance but unable to get it from Government relief schemes. It may assist with such things as emergency living allowance, rent, rates and telephone installation. It will not pay for medical treatment or funeral expenses.

At the time of death

15. What happens just before someone dies?

You should know the physical changes that occur at this time and realise that mostly they do not require treatment, professional assistance or hospitalisation. It is simply the final act of living.

As death approaches people tend to become sleepier, sometimes confused, sometimes restless, difficult to rouse, not taking much food or drink. Vision may decrease.

Secretions may collect at the back of the throat causing a ‘rattle’ which sounds more distressing than it really is.

Urine output decreases and sometimes, close to death, there may be loss of control of bladder or bowels.

As the circulation slows down colour fades; the arms, legs and finally the nose become cool to touch.

Breathing is often more rapid initially, then irregular with seemingly long periods where no breathing occurs until it finally ceases altogether.

16. How should I care for someone who is about to die?

Talk calmly and be reassuring. Hearing is the last sense to be lost and your loved one may well be aware of your presence, even if it is not acknowledged.

Moist swabs will relieve feelings of thirst – don’t attempt to make them swallow food or drink.

Avoid excessive attempts to warm them up. Too many bedclothes or an electric blanket may make them restless.

Incontinence pads and sheets will protect the patient and the bedding.

Elevation of head of the bed with pillows and turning the patient from side to side may relieve breathing problems.

If the patient does seem to be distressed for any reason, the doctor or nurse will be able to help.

Most times, however, just being there – sitting with the patient or holding their hand – is the most important thing to do.

17. How do I know when death has occurred?

There will be no breathing, no pulse, the eyes will be fixed in one spot with the pupils bigger than usual and the mouth might be slightly open with the jaw relaxed.

18. What do I have to do now?

There is no hurry to do anything. Say your goodbyes in your own time. If your relative dies through the night, it is alright to wait until the next day to notify the doctor, the nurse and the funeral director, if you so desire. On the other hand it can be done straight away - the choice is yours. If there is going to be a delay, it is a good idea to straighten the body after death, and for periods longer than a few hours, the body will need to be cooled.

The doctor must write a death certificate within 48 hours, and only after that is complete can the funeral arrangements be confirmed.

For further information, refer to notes made under the section dealing with The Death plan.

19. How can I help myself through the bereavement period?

Even though the death of your relative means the end of their physical suffering, it is still a sad event. Everybody involved will need time and support to deal with the feelings that may arise.

Allow people to help you – particularly someone who is willing to listen as you express your thoughts and emotions without judging or necessarily giving you advice.

Keeping a diary or even writing unsent letters to your relative can help in this essential expression.

Look after yourself in terms of eating and sleeping, not placing big demands on your reserves. Avoid taking inappropriate medications and excess alcohol. If possible delay any big decisions.

Be aware that one of the ways to peace of mind is through forgiveness (of yourself and others) – letting go of angry, judging or guilty thoughts – perhaps deciding that it is more important to be happy than to be justified as being right.

Grief counselling, support groups, books and articles on the grief process can provide support and reassurance, helping you survive the pain of your loss.

Resources

20. What other sources of information and support are available?

Firstly, a reminder that your general practitioner is an important person who will provide medical care and support you in the co-ordination of other services.

The district nursing service can provide vital information and assistance, and it is suggested that contact is made with them early on.

The local hospital, or a community health centre can offer a variety of support – from specialists to paramedical services.

Some places are fortunate to have a palliative care team, or an in-home hospice program for the care of patients with terminal illnesses. The co-ordinator or manager of such services will be able to help you.

Conclusion

In the long run this manual is designed to improve peoples' knowledge of dying and death. The idea is to use that knowledge, well in advance, to prepare ourselves for the end of our lives. Then finally, in difficult times, we will all know what to do to help each other out. We will see that ordinary people are the makings of a compassionate community.

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Organisations and websites

Advance Care Planning

www.advancecareplanning.org.au

Cancer Council Victoria

www.cancervic.org.au

Helpline 13 11 20

Death education

www.ndan.com.au

The natural death advocacy network for death education, funeral planning

Legal Aid

www.legalaid.vic.gov.au

For copies of ***Take Control***

Natural Death Care Centre

www.naturaldeathcarecentre.org

Fact sheets about death and dying matters

Natural Grace (Libby Moloney)

www.naturalgrace.com.au

Green funerals

Palliative Care Australia

www.palliativecare.org.au

Your digital after life

Palliative Care Knowledge Network

www.caresearch.com.au

Helping carers and families

Palliative Care Victoria

www.pallcarevic.asn.au

The ‘About...’ series

State Trustees

www.statetrustees.com.au

Will kits, writing and storage of wills

The GroundSwell project

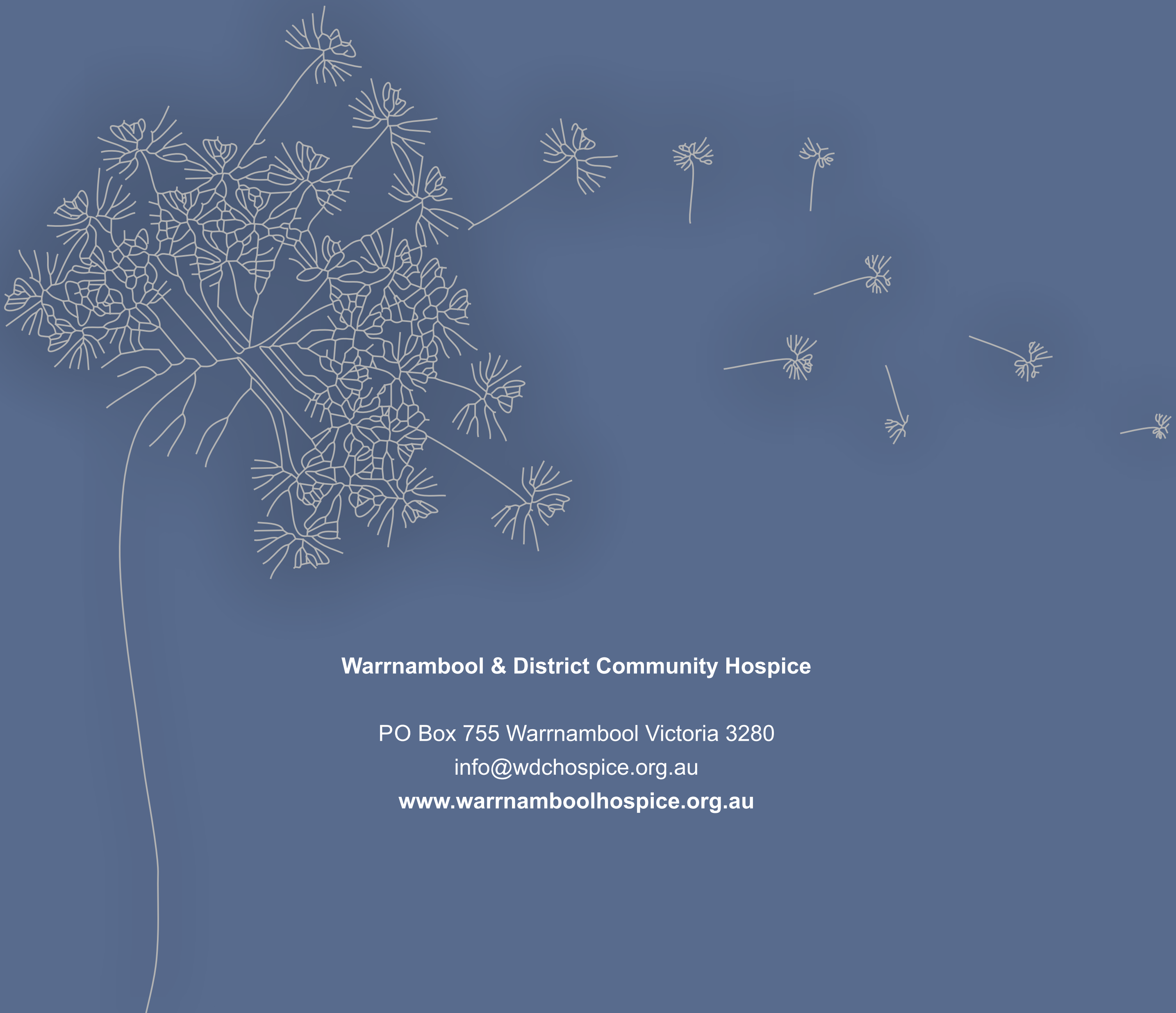
www.thegroundswellproject.com

Improving death literacy

The Office of the Public Advocate

www.publicadvocate.vic.gov.au

Promotes and safeguards the rights and interests of people with a disability. Take control is their publication, with information on appointing a Medical Treatment Decision Maker, making an Advance care directive and making an Enduring power of attorney.



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