

 Dying to  
Understand 

**AGEING, DEATH & DYING**

Written by  
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## Foreword

*There is a great deal of knowledge when it comes to illness and the thorny topic of dying. However, this knowledge is often confined to the medical realm, remaining in the hands of the clinicians, palliative care physicians and allied health workers who treat us.*

*Of course, we expect professionals to have this knowledge, but for those of us who need palliative care, or those of us on a personal journey with cancer or serious illness, there can often be huge gaps in the information that is available to us.*

*The purpose of this book is to help you fill these gaps. It gives you a framework of essential basic knowledge that will help you to have meaningful discussions with the people who are providing you or your loved ones with medical and palliative care.*

*This is not a textbook with academic references and scientific jargon. Rather, it provides you with easy-to-read information about common palliative care topics from a cancer perspective.*

*While the focus is on cancer, much of the information crosses over into other fields of palliative care. As such, this book offers you a powerful knowledge base to negotiate better outcomes, not only for your health, but also for other aspects of your wellbeing. Topics have been organised into physical, emotional and spiritual themes. Not all of these may be relevant to you at a particular time, but they are there for you to read when the time is right.*

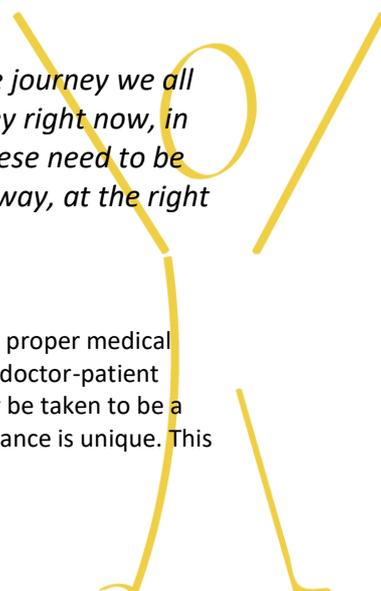
*This booklet is for everyone on the palliative care journey, whether as a direct recipient of palliative care or as a friend or family member of someone who is.*

*Palliative care is a rapidly changing field of medicine. Information that is relevant today may be out-dated by tomorrow. This book does not intend to keep up with scientific literature and is **not** the final say in palliative medicine. It is intended only as a framework for discussion.*

*I hope this book will enrich your knowledge and understanding of the journey we all take at the end of life. Regardless of where you may be on the journey right now, in time we all require palliative care. As humans we have needs, and these need to be communicated. I hope this book helps you communicate in the right way, at the right time, to the right person.*

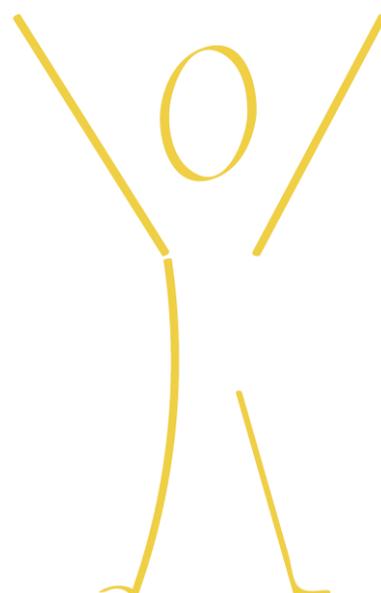
### DISCLAIMER

Any medical advice taken from this booklet needs to be placed in context with the proper medical care that is administered by the attending physician and within the domain of the doctor-patient relationship. As no such relationship can exist through a book, this book can never be taken to be a formal comment on medical advice. Each person's medical condition and circumstance is unique. This book cannot meet the specific needs of every person.



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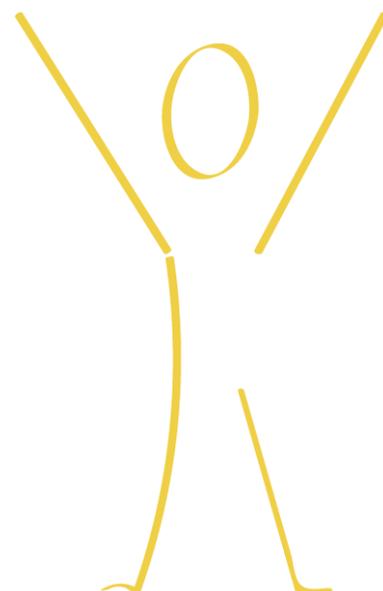
## INTRODUCTION

In recent research, I became aware of the very different topic of death and dying. Usually the two terms are mixed up and used interchangeably when, in fact, they are very different.

'Death' is a noun and it is mostly an abstract; a concept that we can all live with. We are acquainted with death, and it is part of our language: 'the computer died', or 'the villain in the movie died', or we, in fact, may be the instigators of death by killing vermin along the way as a good thing. We do not particularly mind the fact that 150 000 people die every day. As a noun, death is not too nasty, provided it remains a noun.

The term 'dying' however, is a different kettle of fish. It is a verb and by implication is an action. It is a process, and we find that, at some point in our lives, dying is very personal and direct. It may be someone we know who is dying or it may be, as it inevitably will be, that we find ourselves struggling with this action-word at the end of our life.

Our initial thought is that dying is terrible, but it is not. At some point in life, dying is a kindness. While this may seem untrue, let me discuss the alternative and try to prove my point. I am not saying that life should not be embraced and enjoyed, but I am saying there is a cost to living and this cost may become too great.



## DEATH AND AGEING

*Death is caused by swallowing small amounts of saliva over a long period of time.*

*~Attributed to George Carlin*

Death is not a popular topic. For most people with an advanced illness, it is a taboo topic and often it is never discussed. As a doctor, I know how difficult it is to broach the topic of dying when it is relevant to your patient. The topic of dying is much better left unmentioned, and it then becomes the obvious elephant in the room - everyone knows about it, but no one is saying a thing.

This is not acceptable. In recent research into education on dying, it was more than apparent that there was very little education on dying. This left carers and patients exposed to dying without being equipped for what is a 100% certainty for everyone in life. One of the comments made was that education about death should start early, be part of school teaching perhaps, and equip us, as individuals, for death as a normal part of life.

As humans, we are never promised immortality, yet by the way we approach death, many of us have an expectation that death won't occur. We view death as wrong, abnormal or unfair. Feelings of guilt and shame are often common in those facing death. It is as if someone should be to blame when death occurs, as if it may have been preventable.

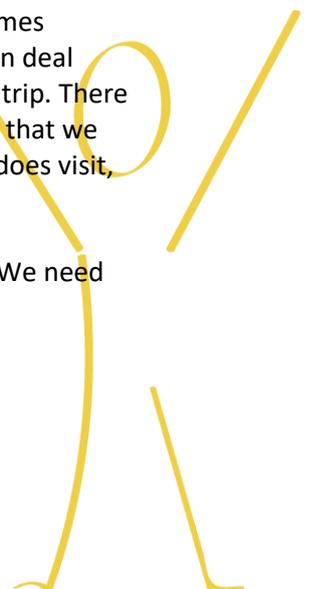
The news flash is this: regardless of your current health, the skill of the health system, the knowledge of your doctor, the size of your bank balance, or the strength of your faith, death is going to happen to you and everyone around you -eventually. These words may seem harsh, but this also illustrates the problem we have with dying and the unrealistic expectation that death should not occur.

Patients sometimes ask me if they are going to die and I am happy to say "Yes, but not yet".

It is in this 'yes to death' that we become liberated from our irrational and abnormal fear of death. The promise of immortality is false, and I think this false promise is the reason there is such a disappointment and loss when someone is faced with the possibility of death. The reality is not *if* you are going to die, it is *when* you are going to die.

Once we can get past this hurdle of mortality, the conversation about death becomes possible. Death is then no longer a distant abstract threat; it is a reality that we can deal with and prepare for in much the same way we prepare for winter or an overseas trip. There are important things to do and consider. Being prepared for death does not mean that we invite death to visit in an untimely fashion, in contrast, it means that when death does visit, we are ready, our bags are packed and there is minimal fuss about it all.

For most people, death comes at the end of a long life and the process of ageing. We need to understand this to put death into perspective.



## Ageing

Ageing is universal. Everything ages. Clothes become threadbare, shoes wear out, equipment malfunctions, and even seemingly permanent features of the landscape changes. Nothing remains new forever and this is particularly so in our fragile biological system. The changes over time are a fact of life, we cannot avoid them, and we dare not deny them.

We reach our peak of health at the age of twenty. After that, it is downhill. If all goes well, we can expect to get old. Some people do not get this privilege, and this is neither kind nor fair. For those who do get old however, there is the ever-increasing cost of ageing.

Here are the obvious losses associated with ageing:

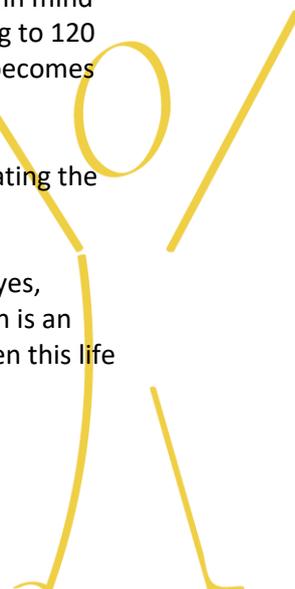
- Loss of senses - smell, taste, hearing, sight all deteriorate over time and the loss becomes debilitating
- Loss of strength and vitality – as we age, it is impossible to do what was once an easy task. Walking, kneeling and getting out of bed are all challenges as age progresses
- Loss of sexuality - "It ain't working no more," and it probably hasn't been for a while
- Loss of memory and cognitive function - the dread of dementia is ever-present with increasing age
- Loss of friends - as you get older, it's inevitable that friends will pass and perhaps even your life partner so life becomes lonely
- Loss of independence - with increasing age comes an increasing need for assistance. This may be after losing a driver's licence, for example, or losing normal function
- Loss of confidence - Things that were once easy and required no thought, now become a challenge. Even going to buy groceries or the newspaper becomes difficult, and with this comes an increasing lack of confidence

The loss associated with ageing is cumulative - it never gets to a point where it ends, or when we can say this is as bad as it's going to get. As we get older the losses become greater. If it is difficult at 80, it's worse at 90 and much worse at 100. Even the fittest and fastest person stumbles in their 90's. While there are some amazing people in their 90's or even 100's, this is the exception. A gentle stroll through the dining hall of a retirement home is a grim reminder of what waits for those who live long enough.

If you could live as long as you like, what age would you choose to live to, bearing in mind that there is a cost to ageing that we all have to endure? Would you consider living to 120 years or perhaps outrageously to 150 years? There is a point where living simply becomes too difficult.

One of my professors used to refer to pneumonia as the 'old man's friend', illustrating the kindness of death when it calls.

Can it even be possible to consider death as a good thing? I believe the answer is yes, particularly when life becomes a painful existence associated with suffering. Death is an even greater kindness for those with a faith and an expectation of an afterlife when this life becomes worn out and old.



## *Measuring death*

While it may be possible to accept death as a good thing for those who are old and worn out, the discussion about death is much more poignant for those whose lives are ending early. In this circumstance, there can be no explanation or bearing of this loss. Why do some not live long and fulfilled lives? We may never know the reason for this. As much as it may seem unreasonable, it is not death that is at fault, it is our common destiny.

May we all live long enough to experience the loss of very old age. Or perhaps not. We are fickle in our choices about how long we wish to live. And this, I think, is the key - living.

We cannot really measure death if we don't contrast it to life. We are all offered life: 24 hours a day to be the best we can, to do the best we can and to make the most of our talents and gifts. Anything less than this is a waste of life. For those whose lives end early, how much would they not want to have the time we so easily squander?

We have assumed life is a right when, in fact, it is a gift. Some people are able to merely exist to the end of their lives without ever living. Others live short but meaningful lives. What are you doing with your life today?

## *The problem of dying*

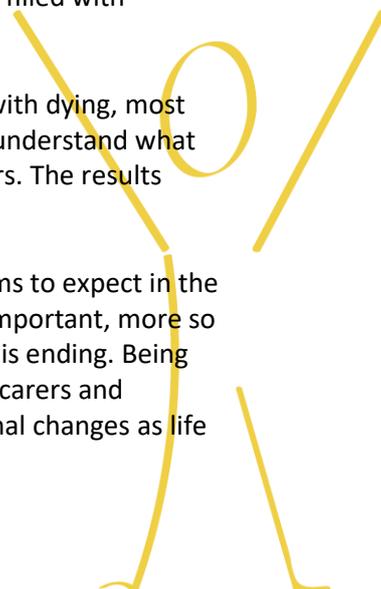
One day, each of us will wake up to what will be our last day. The circumstances will be very varied.

For some, life will end unexpectedly and leave a huge hole in the lives of those left behind. These are the deaths that occur after a sudden cardiac event, or stroke; a motor vehicle accident, or being struck by lightning. There is no time to say goodbye or a final farewell. These deaths are over before they even begin. There is a minimal period of dying or suffering and some people may prefer this exit to life.

Others will suffer illness that lingers for days, to weeks, or months. These deaths are associated with more suffering and loss, but they do allow us to say goodbye, set our affairs in order and be fully prepared for death when it arrives. The challenge with these deaths is the reality of dying. This is the process or action of becoming dead and it is filled with challenges.

While medical teams are well suited to minimise the suffering associated with dying, most people have no idea about what this means. Research was undertaken to understand what education about dying from cancer was being provided to patients or carers. The results were astonishing in that there was so little education provided.

When it comes to dying there is a lot to know. There are common symptoms to expect in the course of illness, the symptoms in the last days of life are similar and it is important, more so in the role as a carer, to know the changes the body experiences when life is ending. Being ignorant of these normal changes can be very alarming and distressing for carers and families, bearing in mind that the person dying is mostly unaware of the final changes as life ends.



Once death has occurred, there is an enormous amount of work that still needs to be done. We don't just die and that's it. For those who have died it is easy enough, but for those left behind, the sorrow and loss are compounded if nothing has been left in place in preparation for death.

## DYING

We will all die differently. For each of us, the circumstances of our death - the surroundings, the timing and the people with us when we die, will be unique.

However, the process of dying is often quite predictable. Understanding this process is important because it may help to reduce our natural fear and anxiety about dying.

Many of us have similar fears about dying. Common questions include:

- Will it hurt?
- Will I suffocate?
- Will I lose my dignity?

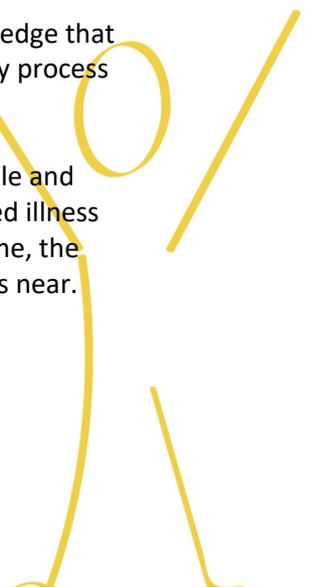
Those who die instantly in an accident or following a sudden critical event, don't get time to ask these questions. Similarly, those who suffer a catastrophic major illness or injury, are possibly so caught up in the fierce battle for life that they don't have the opportunity to ponder these issues. For these people, death arrives abruptly and unannounced.

For many of us, however, dying is something that happens over time. We will know we are dying, and will have time to reflect on uncertainties, as well as on what will happen to us when we die.

One way to understand dying as a process, is to consider the example of pregnancy. With pregnancy, no one can be sure when conception occurs. For the first few weeks there is no indication that a life has started. The first signs may be the morning sickness and a missed period. With time, the signs of pregnancy become all too obvious; the body is physiologically ready to give birth and sustain a new life.

We can only guess when the time is right for labour to begin. Even with the knowledge that it may be soon or may be overdue, labour happens when it happens. In the stormy process of labour and birth, a new life begins with the anguish of labour soon forgotten.

The same process occurs with dying. At first, there is no indication that an incurable and irreversible medical event has occurred. With time, however, the signs of advanced illness become apparent. These signs may be weight loss, fatigue and weakness. Over time, the illness declares itself so that there can be no uncertainty when the time of death is near.



## *Signs that death is approaching*

### Increasing fatigue and weariness

Illness uses up energy, and as this energy is depleted, everyday activities become impossible. Even getting up out of bed is exhausting and no longer possible. Assistance is required with all activities and even the simple act of swallowing may become difficult.

### Lack of interest in surroundings

The excitement of life is lost, and hobbies or activities once enjoyed are no longer appealing. Watching football on television or reading a favourite novel is not worth the effort. Assets worth millions of dollars are no longer important. Everyday things that used to be important no longer have value. Visitors are a burden. Most of the time is spent asleep or resting. Sleep is a friend.

### Loss of appetite

Eating is too much effort, and even the thought of food is distressing. That 'favourite apple pie' loses its appeal. Cigarettes are not needed, and alcohol is unwanted.

### Increased confusion, restlessness

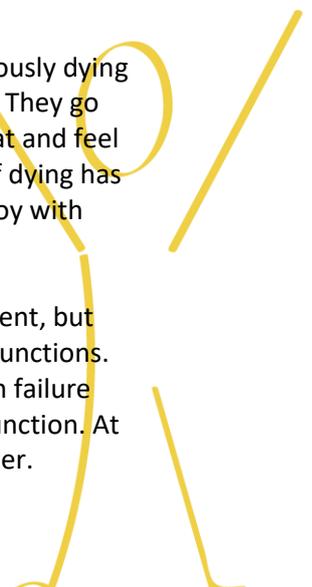
Like wearing a pair of ill-fitting shoes or a scratchy woollen garment, it is as if the body no longer fits. The result is restlessness and fidgeting as the discomfort of illness increases. In addition, the brain, subject to the chemical changes associated with dying, becomes increasingly confused. Increased drowsiness, confusion and impaired consciousness are common as death approaches.

## *The last days and hours*

The signs of approaching death are not absolute or definitive, but should rather be viewed as a signal that death is near. As with labour, dying cannot be rushed or avoided. Some people may take days to die, others only hours.

There may also be false alarms. For unknown reasons, some people who are obviously dying paradoxically, dramatically improve in health a few days or hours before they die. They go from a state of impending death, to being the life of the party. They sit up and chat and feel well enough to eat. Their energy levels increase, and it seems as if the prospect of dying has been a missed call. This unexplained episode of revitalisation is bonus time to enjoy with family and friends.

At the time of dying, the body no longer works. This may seem an obvious statement, but when dying occurs, the spectators are often surprised by the change in the body functions. The normal physiological processes we take for granted stop working. Multi-organ failure begins, resulting in chemical imbalances. In turn, these imbalances affect organ function. At the time of dying, two final failures occur at the same time, each affecting the other.



## The failure of the brain

In dying, like a computer shutting down, the brain can no longer run the programs required for life. The first thing to become affected is our consciousness (our higher thinking function). This results in confusion and sometimes agitation. The dying person may try to get out of bed or sit up. Actions are poorly planned and futile. Words become mumbled as the brain can no longer figure out speech. Groaning is common as language is lost. Brain dysfunction may be associated with hallucinations as signals are no longer properly interpreted. Seizures are uncommon but may occur in the failing brain. As consciousness is lost, so is the ability to swallow.

Sub-conscious functions also deteriorate. As the coma of death progresses, the regulation of what we know as normal breathing is lost. Secretions in the back of the throat can no longer be cleared, resulting in a rattling, noisy breathing process. Mouth breathing occurs with a dry tongue and mucous membranes, which may be mistaken for dehydration.

Breathing patterns change and the intervals between breathing become longer and longer. These may be followed by periods of fast, shallow breaths, which then returns to long breaks in-between breathing (Cheyne-Stokes breathing).

As the breathing shuts down, long intervals occur between breaths with an occasional deep gasp as if the person is not getting enough air. This is not an indication that the person is suffocating, but that they are dying. There is no consciousness at this time.

Muscle tone is lost, and incontinence occurs as consciousness slips away.

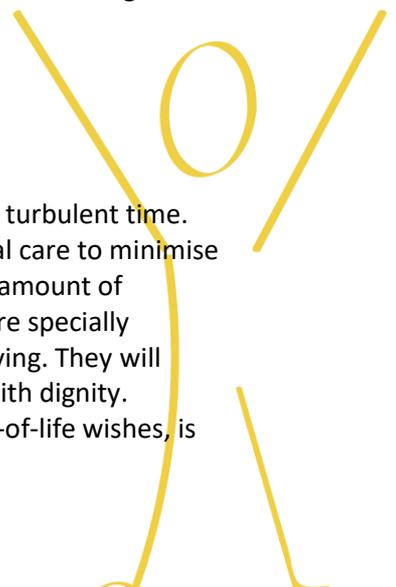
## The failure of the heart

At the end of life, it is not only the brain that fails but also the heart. The feet are usually puffy and swollen due to both low proteins associated with illness and failure of the heart to adequately pump fluid around the body. This circulatory failure results in a spiral of organ failure with an inability to produce urine (or, if it is produced, urine is often very strong and concentrated). As before, this is not a sign of dehydration.

As the pump fails, the hands and feet become cold and blue. The skin becomes mottled. Blood pressure drops and the heart rate decreases. Eventually the heart rests, no longer required to perform its task.

## *The palliative care team*

The role of the palliative care team cannot be over-emphasised during this turbulent time. These people are the 'saints of medicine', providing compassionate medical care to minimise the pain or other symptoms associated with dying. There is no limit to the amount of morphine that can be provided to control pain. The palliative care teams are specially trained to care for patients and deal with the symptoms associated with dying. They will provide the end-of-life care to ensure dying occurs in the right place and with dignity. Involving the palliative care team early on, and clearly communicating end-of-life wishes, is essential to ensure that dying is as peaceful as possible.



As with the travails of birth, dying is also like a storm, raging for a while and then passing by. Somewhere in the battle between life and death, it becomes quiet and peaceful. The body is at rest. What was our greatest fear is to be feared no more. Death brings an end to a life, but not necessarily a 'life' to an end.

### *The end?*

Like a butterfly bursting forth from a dried-out chrysalis, dying is not necessarily the bitter end to life. There is compelling evidence to suggest that at the time of dying, the soul is released from the failing body. The exact timing of this event is unknown.

I like to think that the moment of death occurs sometime before the body finally shuts down. Without the soul the body fails, but without the body the soul is liberated from illness and suffering. This possibility is discussed further in spirituality.

## FINAL THOUGHTS

Death is the ultimate loss and failure. There is no comeback from death *if* it is indeed the final full-stop to all we have lived, been, dreamt and enjoyed in a lifetime. As much as this may seem true from a biological point of view, it is far from true in a spiritual sense. Spirituality cannot be denied.

There are fascinating testimonies to suggest that death is not the end, but rather the doorway to the next adventure. Our past, our memories and our dreams, as well as emotions and friendships have the potential of continuing after death, which for me, is a pretty powerful thing.

The good news is one of redemption - where that which was broken, dysfunctional or lost is restored to being better than new. It is the story of the ultimate upgrade. Death does not have to have a sting. We need hope in death.

One day, I will join the majority: with all those who have already died and experienced the bitterness of death. My hope is that at the time I may be able to do so in peace, with the confidence of a life well lived and an expectation of homecoming with God. This is my hope and my prayer. Maybe it is your hope as well.

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