



Broken Body User Manual

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 Dying to Understand

Preface

Over the past 30 years, I have treated many people with advanced cancer and the one thing I have noticed most, is how vulnerable most of us are when it comes to dying. As humans, we are able to achieve the greatest feats, endure the toughest treatments and pay the greatest price to stay alive.

But when that is no longer an option, most people go into hiding. They hide from the reality of their situation, covered in a blanket of denial. After all, it is only other people who ever die, it is not going to happen to me!

Well, yes, it is.

It is not uncommon for patients to ask me, "Am I going to die?" My answer is always the same, "Yes you are, but not today!" May that continue, may you be in good health forever, but we all know that forever runs out of steam at some point and with it, good health. No one lives forever, and eventually we all need to face the reality of our mortality or the mortality of those we love.

In my book *Death, Dying and Donuts* I cover the topic of death, and for those who need a foundation to understand our mortality, it is essential reading. But the book deliberately does not cover all the physical challenges we face when our body stops working.

This book is about what to do when health runs out and the body is broken. It is written from a cancer perspective because that is what I know as an Oncologist. It is not a textbook or an academic book, but rather things I would say to those whose lives are ending and whose bodies are broken. The anecdotes reflect real stories with some poetic licence and fictitious names.

This is not medical advice. The information provided is to add depth to your discussion with your health providers. They, in partnership with you, are responsible for your health decisions. Our goal is to empower you to make better decisions.

I hope that you find it useful.

Chapter 1. Introduction to symptom management

Phillip kept saying the wrong words, much to the frustration of his wife who was easily embarrassed in social settings. Out of the blue he would say “Goodnight!” The startled friends and family would kindly let the misplaced word pass or have a bit of a chuckle and continue the conversation while his wife squirmed at the social blunder.

By looking at him, it was impossible to tell that he had a nasty brain tumour that would eventually end his life. In a few months he went from a fully functional rational man to a man with a broken brain. While it is tempting to think that this will never happen to me, or to think that by willpower and determination I will be able to control the circumstances of my health, the reality of that is simply not true. When the body is malfunctioning, we hate it, we resist it, we complain, and we object, but in the end, we accept it because we don't have any other option.

No one really wants to end their life or be locked in a care facility. We are happy to negotiate functioning at 90% capacity and then 90% of that, and so on until we eventually reach a point of not functioning at all.

Having a brain tumour is a tough ask. Having bone pain from cancer is a tough ask. Having neurological loss due to cancer treatment or cancer is a tough ask. Being nauseas and vomiting is an unbearable thought. Running out of breath – frightening, spending the rest of life confined to a radius of two meters from a toilet – inhumane. Yet these are some of the things people have to endure as their body breaks down.

What I have realised is that we spend an enormous amount of energy, effort, and resources to be fixed, to get back to 100%, and to be as we were before. Doctors believe this myth, and they openly sell it as a product of their wisdom and ability to halt sickness and disease. While they may have amazing success most of the time, they are all destined to fail because this is what inevitably happens to our bodies as we get old. Our bodies break down.

We need a different game plan when our bodies are broken and don't seem to work. Hoping for the best is not the best plan if we must live with illness and the loss associated with illness. I comment from a cancer perspective but many of these concepts are applicable across all failing health scenarios.

It sucks to be unwell! But it will suck more if we do not know how to manage a broken body. When our bodies are not functioning, we need to have a different framework than when we are in good health. You would not wear summer clothes in the frozen heart of winter, nor would you wear a huge fur jacket in the blazing heat of summer. People would assume you are nuts!

The same applies in health and illness. You cannot frame illness in healthy expectations, they will not fit. Equally, as doctors, we sometimes have healthy people who keep trying to frame their life in illness. There is a time and a season for each and there is wisdom to know which season we're in when it

comes to health. Wishing for summer when it is winter is not going to make it get warmer. It is not a good strategy against the cold. In the same way, wishing for good health when good health is no longer an option, is a failed plan.

The first hurdle along this transition between good health and no health is to manage our expectations and face the reality of our situation. Everyone who is unwell must deal with loss and disappointment, so it is worth looking at this first.

Loss and disappointment

I am sure that you are no stranger to loss or disappointment in life. We all experience it at some stage of life. It may have been the time you did not get the promotion you expected, or your favourite team lost the championship final, or you only won a silver medal rather than gold. All disappointments are painful and unpleasant. They can be very bitter and enduring, yet new opportunities are missed if we dwell on our losses, potentially resulting in even more disappointment.

At the heart of loss and disappointment is expectation. We are disappointed when our expectations are not met. It does not matter how small our expectation may be, if we do not achieve it, we will be disappointed. I am not a professional gambler, but I am in a monthly draw to support a charity and perhaps win a magnificent Mercedes Benz. My expectations to win are close to zero and I am happy to support the charity. Yet, despite my zero expectation to win, I am caught out by the tiny flicker of disappointment I experience every time the prize moves on. My mind tricks me, because although I rationally think I am ok, I am not. I am emotionally engaged, I want to win, I have expectations to drive away in a prize car.

While this is a trivial example of loss, it does illustrate that when it comes to loss and disappointment, we are not always truthful with ourselves. We may say that we accept the disappointment or that we don't really care. We may intellectually rationalise it and say, "It is what it is", but our feelings betray us. They tell us what is really going on in our situation. When it comes to illness, there is always a failed expectation and with it will come disappointment. No one is immune!

Typical emotions of loss and disappointment include shock, denial, anger, bargaining, depression and eventually acceptance. Consider the example of a tyre puncture.

Think about the last time you had to change a tyre to know what I am talking about. Perhaps you swore or kicked the tyre. The magnitude of your emotions would depend on your expectations. If you were expecting a puncture because you were driving on a building site littered with nails and screws, your emotional response may be mild compared to if you were going to miss a flight because of the puncture. If you had high expectations to be in Paris the next day and this is never going to happen, your emotional response to the high expectation will be different. Your response will also depend on your personality and lifetime experience.

The same emotions are applicable in illness. If you are in your eighties, it may not be such a shock to have to deal with illness, but this is very different if you are in your forties and have to deal with something like cancer. Life is not always fair.

When you get a puncture, or suffer a disappointment of any kind, there comes a time to stop kicking the tyre. There comes a time to move on. The one way to move on is to accept the reality of the situation. Emotionally it helps to talk to someone, anyone – even if they are deaf. Get the feelings off your chest. Express your feelings and resentment and frustration. If they are mild and you move on, that is great. But if your emotions are wild outbursts like the corona of the sun, harming all in the way, including yourself, please get professional help. Speak to a counsellor or psychologist. Seeking help does not mean you are weak, but rather that you are wise. There is a world of difference.

The second way to be wise is to understand fitness and illness.

Understanding fitness and illness

Brian would come into my office with his laconic personality and declare that everything was “Good as gold!” He told me about his exercise routine and stretches, how he hitched the caravan and headed 600 km down the road. I was impressed that a 90-year-old could still do all these demanding activities. On one occasion I asked him to show me his stretches and he obliged by reaching up and then bending over put both hands flat on the floor. Imagine my amazement! My days of touching my toes are long gone unless I am sitting in a chair with my hips and knees bent.

Contrasted to this was Bill who at 65 looked 90. He was immobile, stiff, grey, and needed a wheelie-walker to shuffle into my room.

Why the difference?

It is easy to argue lifestyle and all the things we do to our bodies like smoking and drinking or working with noxious chemicals, but they are nothing in comparison to the role played by our genes. Our genetic makeup is the blueprint of how our bodies function and ultimately cease to function. Using a motor vehicle illustration, genes determine whether we are Fords, Fiats, or Ferraris. It does not matter so much where we have been on our journey, it matters what’s under the bonnet.

With time, our genes, like everything else in nature, become weathered. They develop small mutations and errors in coding resulting in malfunction and these accumulate to cause a range of degenerative illnesses including cancer.

Cancer, for example, is not some mysterious disease caused by cigarette smoking or exposure to human papilloma viruses or sunlight. It is the expression of our genetic weakness which may have been multiplied by external factors such as smoking etc. There are dedicated smokers, professionals in the way they churn through cigarettes, who never get cancer. There are people who have been exposed to enough sunlight to be crispy, but they do not get skin cancer. One person like Brian, survives a cancer and Bill struggles with so many other health issues that his cancer is a secondary concern.

This genetic predisposition does not mean that we can abandon ship when it comes to fitness and health. By being fit and healthy we give our aging genes every chance to function better, to last longer and to keep us ahead of our peers. Brian’s stretching and exercise allow him to be amazing at 90, what would he have been like if he blobbed around in front of Netflix and drank beer?



Whether you are Brain or Bill or Bob or Mary, you can only do your best with what you have been given. Despite good health choices, we all ultimately end up with something broken, something wrong. For some this means a cancer diagnosis, for others a stroke, for others a cardiac event.

Knowing what can happen in advanced illness, does not mean that it *will* happen. It is not an invitation to live in anxiety or fear. Being aware of what can go wrong is an invitation to be aware of your body and to be empowered and proactive about staying in the best health possible.

Chapter 2. The breakdown

The body can break in many ways.

Sometimes the breakdown can be abrupt and require a visit to the emergency department with no warning. Like a bolt out of the blue, something unexpected, unwanted, and possibly unrelated occurs resulting in malfunction. Strokes, heart attacks, falls, fractures, and a handful of other conditions can precipitate the unwanted journey to hospital. Not much can be done about the events as they happen and unfold. May they rapidly resolve.

Sometimes the breakdown comes with plenty of warning. If it were one of the Fiat, Fords, or Ferrari's, it might be a slight decrease in performance, perhaps an unusual sound like a groan, or perhaps difficulty starting in the morning. After a visit to the dealer's service department, the problem should be apparent and easily fixed unless it is too expensive to fix. In this setting, the plan is to keep the car on the road for as long as possible at minimum cost.

The warning signs in the body and indications that it's time to pull over are symptoms like pain, weight loss, decreased appetite, weakness, nausea and vomiting, anxiety and poor sleep, and shortness of breath. Add to this poor performance specific problems like bleeding and it soon becomes apparent that, like an old car with rust, the body is less desirable. No one ever speaks about sexuality in illness, yet it is an important part of the cost of illness.

Why not just abandon the 'car'? This is the greatest temptation. Give up! Give up on yourself. End our life – that's why they have created voluntary assisted dying and like everything else in life, we too are then disposable. But what if we have a purpose? What if our purpose is to cross the finishing line, to continue making a contribution in life despite illness and to receive a reward? I think everyone is worth it, even if they finish life limping across the line.

If we are going to finish the journey in life, we need to make sure that with brokenness, we have the best chance to keep going. Here are the obstacles and how to overcome them. These need to be discussed with your doctor, they are not solutions but suggestions.

There is a lot of misinformation and misunderstanding when it comes to managing advanced disease. The examples used are relevant to cancer, but they are applicable across the range of end stage symptoms. There are three key questions to ask your doctor to keep things honest and in perspective.

- If this was you or your mother, what would you advise?
- What are the alternatives?
- What is the benefit?

Many people fear physical symptoms because they associate them with progressive illness. This brings up an important point. With incurable illness, like being on the Titanic*, it does not matter which part of the ship sinks first or sinks next. The key is to move to 'high ground' and to make the most of the time, rather than to run around from room to room in panic.

*See *Death Dying and Donuts*

When it comes to advanced symptoms there is no place for heroes. No one wins a prize for putting up with pain, suffering, loss, and distress. Being stoic and refusing medication for pain does not make you stronger, it makes you weaker. Understanding the body's dysfunction and how to manage this is better than trying to return to health when this is no longer an option.

Although the health professionals are skilled at taking care of our broken bodies, they do not own our bodies. Their experience is always second hand, they depend on information about the symptoms not the experience of the symptoms. They are trying their best to put together a puzzle based on the latest update of their user manual. Their judgment is sometimes clouded by being too focussed on one specific thing. For an oncologist, everything is cancer, for a neurologist it is always about the nervous system and if you see a surgeon it will have to come out. If something does not seem right, don't accept it, do another loop, and go back for a second look or a second opinion.

Make sure this is not the opinion of 'Dr Google', because there is no training or context in Dr Google's opinion. Don't ask the plumber or your hairdresser or the non-medically trained guru for their opinion because it will be worthless.

The information presented here is to provide background of the common things that are implied but not said, the things that are often neglected and missed because there is not enough time in a consultation or because the focus is on the symptoms and not the bigger picture.

When it comes to brokenness the following are common symptoms and treatments. By knowing about them you can negotiate a better deal when you see your doctor.

- Pain
- Drug therapy
- Fatigue
- Sleeplessness
- Breathlessness
- Weight loss
- Nutrition
- Mouth care
- Constipation
- Nausea and vomiting
- Bleeding
- Brain failure
- Sexuality
- Radiation

Chapter 3. Pain

There are different kinds of pain in life. All pain is unpleasant and best avoided, so you may be surprised to hear that there are some positives to feeling pain. Pain is a protective survival mechanism that alerts you to injury and helps you to avoid things that cause you pain and may possibly kill you. Being stung by a bee, for example, is painful and unpleasant yet it serves as a warning not to go near a beehive without caution. Stepping on a thorn is a strong reminder to wear shoes.

We all remember the immediate pain that happens when we step on something sharp or fall and hurt ourselves. It is transient and usually sufficient to motivate us to avoid repeating the same painful behaviour (although not always, as demonstrated by people who play rugby union, gridiron, or ice-hockey).

Another type of pain is that which occurs in illness or with injury. Initially, this pain serves as a protective function, alerting us to a serious physical problem and motivating us to seek medical help. Again, this pain is usually temporary and eventually eliminated with treatment. Consider, for example, the contrast between having acute appendicitis and the way you feel after surgery – pain-free at last!

Sometimes, however, pain is relentless and persistent. This sort of pain is common with cancer. It can present in many different and complex ways. This pain is not protective and serves *no useful purpose* in terms of a survival mechanism. If left unattended, it can result in depression and a sense of hopelessness. Pain can sensitise leading to further pain, and uncontrolled pain may initiate a nervous system feedback loop where it continually gets worse. A spiral of pain, hopelessness, and depression can then begin and lead to complex pain that becomes difficult to treat and manage.

When pain becomes entwined with our emotions and past experiences, we need to take a holistic view. This means considering all the factors that are influencing the sensation of pain, physically and psychologically. Such treatment often requires specialised medical care and even then, pain management can be tricky.

It is sometimes impossible to get rid of all pain and, if that is the case, smaller steps and smaller wins may be necessary. Less pain may be acceptable if *no pain* is unachievable. Understanding the drug therapies and non-pharmacological therapies in pain management, should be part of everyone's knowledge base.

So, *what is pain?*

Pain can be defined as an unpleasant sensation and emotional experience. The sensory aspects are well defined: in essence, pain occurs following tissue injury. When there is an injury, pain related chemicals are released by the body at the injury site. These chemicals in turn activate specialised pain

nerve fibres that run to the spinal cord, connect to other fibres up the spinal cord and are perceived in the brain almost instantly as pain. Ouch that hurts!

Our physical response to pain can be even quicker than our consciousness; it is a reflex that protects us even before we have time to recognise what has happened. Consider how quickly you snatch your hand away from a burning flame, for example. It happens before you have time to even think about it.

But sometimes pain is not from an external source like a thorn or a burn, but from an internal source as part of illness, such as cancer. It cannot be eliminated by moving away from the cause, so we require a different strategy to manage pain. Here are some suggestions:

Acknowledge the pain

Pain is telling you something about your body no matter how trivial it may seem. It is tempting to ignore pain, particularly if there is background pain every day. Ignoring pain won't make it go away. Acknowledging the pain also won't make it go away, but it may be the beginning of a journey to have less pain.

Understand the pain

Pain can be complex and the more that is known about each pain, the greater the chance of success in managing pain. There can be different pain for different reasons and mapping out each pain provides the doctor with a golden opportunity to provide the best pain management strategy. Keeping a pain diary may be a very useful tool when pain is multifocal and complex.

Things to document are:

- Where each pain is located
- Is it well defined or vague?
- What is the nature of the pain: is it burning, throbbing, aching?
- How long does it last?
- What makes it better?
- What makes it worse?
- Does it spread or radiate to other areas?
- How severe is the pain at its worst and best – use a score out of 10*
*Where 10/10 is "I am going to die" and 1/10 is I am not convinced there is pain. Perhaps a 3/10 is the need to take pain medication and an 8/10 one that makes you go to the hospital.
- When does it occur, how often does it occur?
- Does any medication provided help the pain and if so, by how much?

The response to these questions will help define the nature of each pain and allow for a basic individual understanding and how to improve the situation.

Be responsible and get help

Never feel the need to put up with pain. Get help when something hurts. Chronic unresolved pain serves no purpose. It weakens the immune system, causes hopelessness and depression, and can accelerate the pain experience making it worse.

Start with the general practitioner but don't leave it there if the strategy is not working. There are specialists who may be able to help, including palliative care specialists or alternatively, pain specialists. Don't settle for second best if there is a better option. Don't take no for an answer.

Remember, it's your body, your pain and ultimately your pain control is your responsibility. Don't abdicate care, be part of the solution and the strategy going forward. Don't be negligent in sticking with the plan. Pain drugs do not work if they are left untouched in the box next to the bed!

Avoid the triggers for pain

It seems so logical but avoiding the trigger for pain is a strategy that is not used often enough. In considering the pain, think about what triggers the pain. It may be something trivial like a specific movement, or something uncomfortable like a pair of ill-fitting shoes. If you know what makes it worse, avoid that. Get slippers if shoes are uncomfortable. Get a walking stick if the hip hurts and the stick helps. Get a wheelie walker if it limits pain on mobility.

A colleague saw a patient who said, "My leg hurts if I hold it in this position" and his response was, "Well then, don't hold it in that position!" While this may seem such a ridiculous situation, there is an element of truth here. Stop doing what hurts.

Take medication

It is impossible to build up resistance to pain. Unlike a muscle that gets stronger with exercise, nerves don't care. They don't become thicker and more robust when we stimulate them. Their function is to send a signal, and when the signal is pain, it arrives in the brain on time with a message – "Ouch!"

Nothing changes in the pain if we resist it. It is true that we can override pain by mental effort but that is different to being able to diminish the nerve impulse. The first goal in pain control is to put the fire out, and we do this by taking medication.

Medication does not get rid of the cause of pain, but it is great to be pain free! Medication works quickly by changing the intensity of the chemical signals that cause pain, diminishing the way the nerves signal pain, or reducing the way the brain perceives pain. Once the pain is under control and manageable, it may be possible to reduce the amount of medication required to control the pain. I cannot emphasise enough – when it comes to pain, put the fire out!

We discuss the drugs later so hold your horses for now.

Consider radiation for cancer pain

As a Radiation Oncologist I am always astonished about how little health practitioners know about the benefits of radiation in managing cancer pain. I see people limping into my office with terrible pain and I cannot help but ask, “Why were you not sent sooner?” Why wait until there is unbearable pain when radiation may have left you pain free ages ago. To me it does not make sense.

The amount of radiation required to manage pain is small in comparison to curative radiation treatments. It does not have to be given every day, but 2-3 times a week are enough to control pain and the side effects of radiation at this slower pace, and lower doses are very mild – particularly in comparison to severe pain.

Radiation works by destroying the cancer causing the pain. If the pain can be defined and the cause can be explained, a short course of radiation over a few days can work miracles when it comes to pain control. Half of the people treated with radiation will have complete resolution of their pain in the treated site. It is something worth considering and pushing for if there is cancer pain.

Do more than expected

In addition to medication, consider doing more to relieve pain.

Physiotherapy and massage can help for muscle spasm. Exercise and physiotherapy may strengthen muscles that may help in mobility and reduce pain.

TENS machines can override nerve signals and some people find them very useful in reducing pain. Consider other options such as splints, braces, and hot packs. If you find something that works, stay with the plan.

Also consider the emotional and behavioural aspects of pain. We respond to pain based on previous experiences and these can sometimes make our experience much worse. If there is a behavioural component to pain, please see a psychologist who specialises in this area.

Don't expect miracles, expect results

Miracles do happen but until they do, it is important to have a pain strategy. This does not have to be anything more than steps of how to get from where you are now, to a better place in terms of pain.

A simple strategy is to measure each pain and record it. After that, start on therapy. Evaluate the response to therapy and if it is not working, change the therapy. In this way the best solution will become apparent. When it comes to pain control, there is no 'one size fits all' program and sometimes it is only by trial and error that the best option is discovered and there are measurable results.

Pain gets better, and some people experience amazing results leaving them totally pain free.

But not everyone becomes totally pain free instantly. Sometimes this takes time. Sometimes the improvements are slow, and they require small steps to better pain control. Sometimes the pain won't completely resolve, and we have to settle for a 4/10 rather than a 6/10 pain.

Only have one cook in the kitchen

When it comes to pain control it is important to decide who is in charge. There can only be one cook in the kitchen and a sure way to completely mess things up is to have multiple doctors prescribing pain medication. When everyone is an expert, no one is an expert.

Pick the one you trust and stay with their strategy. If that doesn't work, then there is a clear reason to change either the strategy or clinician, but don't mix things up, it only gets worse.

Be cautiously optimistic

There is always something that can be done. Never accept the "There is nothing we can do" statement without a fight. Even a small win is a win. Don't give up hope.

The recipe is easy. Find a doctor, take the drugs they prescribe. See if they work, if not, change the drugs under the doctor's supervision. Get a second opinion from a specialist if you need one. Use radiation if there is cancer pain. You should be feeling better already.

Chapter 4. Drug therapy

In my experience as an oncologist, I have observed that many people resist the use of opioids as a pain relief method because they either fear that 'it is the beginning of the end' once they start using it, or they are afraid of addiction.

Let's put it into perspective. A drug like morphine is bad for you and should not be used if you DO NOT have pain. But if you have severe pain, morphine is an essential drug for bringing pain under control. As with all drugs there are important effects and side effects that need to be considered, and many of the arguments against morphine are due to ignorance regarding these effects.

When it comes to a broken body and pain-relief drugs, there are four distinct tools in the toolbox. Each one has a unique mechanism of action and sometimes all the classes of drugs are required to get on top of pain. Sometimes specialised drugs such as Ketamine are required. This is in the realm of specialised pain management.

For everyday pain and for most types of pain, the World Health Organisation (WHO) developed a stepwise approach to pain control. It is tempting to skip to the top step and leave the lesser drugs untouched, but each one has a distinct function. The four classes of drugs are: Paracetamol, NSAIDs, Opioids and Anticonvulsants or antidepressants.

Paracetamol

This is the WHO base level drug. It forms the foundation of pain control.

This is the safest drug available if you do not take too much of it. The maximum dose is 4000mg per day and it is usually taken at 2x 500 mg tablets every 6 hours. The exact mechanism of action is still unknown. It should be a standard baseline everyday drug for pain, and it should be continued even if stronger drugs are added.

A common statement I hear is, "These drugs are useless, they do nothing." This is true in that they may not be effective enough for the specific pain, but they are not useless, and they should be continued. They may diminish the number of other drugs that may be required, and they are super cheap. They have minimal side effects. Why would you not take them?

Non-steroidal anti-inflammatory drugs (NSAIDs)

If you have ever been stung by a bee, you will understand the process of inflammation. Inflammation is associated with redness, heat, pain, swelling and a loss of function. The drugs that work best here are the anti-inflammatory drugs. They work by inhibiting the pathway of inflammation and they work quickly and effectively.

Inflammation is often a component of pain, so it makes sense to disrupt this pathway. Common drugs here are Diclofenac, Naproxen and Meloxicam. They are, however, not harmless. They can cause gastric irritation and ulcer formation if used long term. They can also affect kidney function and interact with anticoagulation drugs, so they need to be used with caution and under the supervision of a doctor if used long term.

In the short term, they are wonderful in getting on top of inflammatory pain. They are the WHO level 2 drug that should be added to Paracetamol if it can be done safely.

The opioids

These are heavy duty pain drugs. There is a lot of misunderstanding about these drugs, but they are not complicated if you know their limitations, side effects and use. The most known drug in this class is Morphine. They work by inhibiting pain nerve impulses in the spinal cord and the pain centres in the brain. They are the most effective pain drugs we know.

Morphine is named after Morpheus, the Greek god of dreams. It belongs to a class of drugs called opioids. These drugs have been used for centuries for their euphoric, dreamlike, and pain-relieving qualities. The pleasant psychological effects of opioids make them highly addictive with a high potential for abuse. Intravenous (IV) morphine acts almost immediately to reduce pain, sometimes with an element of euphoria.

All opioids have a similar function. Commonly used opioid drugs in Australia are:

- Codeine – the weakest opioid.
- Buprenorphine (Norspan) – a weaker opioid available as a patch.
- Morphine – the gold standard, and ten times as potent as codeine.
- Oxycodone – This forms the largest range of opioids used in Australia (Endone, Oxynorm, Oxycontin, Targin). They are twice as potent as Morphine, and Targin has an additional benefit of having a molecule of Naloxone attached to it to limit the constipation caused by opioids.
- Fentanyl (Durogesic) – best known for being available as a patch that can be applied to the skin. It is also available as Abstral, an ultra-fast acting drug for almost immediate pain relief.
- Hydromorphone (Jurnista, Dilaudid) – this is five times as potent as morphine.
- Tapentadol (Palexia) – This is the newest class of drug and is more effective with potentially fewer side effects and less tolerance than Morphine.

- Methadone – this has a very tricky metabolism requiring specialised care, but it has little chance of one developing a tolerance to the drug and has a role to play when other opioids are no longer useful.

Anyone with moderate to severe pain should be on one of these drugs.

Although these are all members of the same family, they don't all behave in the same way. They differ in their potency, duration of action, route of metabolism and elimination, and in the way they are administered; be this via skin patches, tablets, syrups, or injections. Because of these very real differences, changing from one opioid to another can be difficult, and if unsupervised, downright dangerous. Because these drugs have unique properties, they can be used to meet individual preferences.

From a practical viewpoint, there are nine things to know about opioids and how to use them effectively.

- Long-acting opioids – ones that work for at least twelve hours and should be used every day to control the base level of pain over a twelve to twenty-four hour period.
- Short-acting opioids – ones that work for four to six hours and should be used regularly, or as needed, for sharp spikes in pain.
- Pain and opioid use should be reviewed regularly – at least every few days initially because pain changes.
- All opioids cause constipation – treatment for constipation should always be part of the management plan. Take a laxative.
- All opioids may cause nausea and sometimes vomiting – drugs to control nausea should always be part of the prescription.
- In the first few days, opioids may cause some drowsiness, impaired concentration, and may limit a person's ability to drive until the opioid dose has been stable for a few weeks.
- Treatment should start with low doses of opioids – dosage can be increased as required to achieve pain control.
- The physical property of the drug: liquid, tablet, capsule, lollipop, injection or skin patch, and which choice is best for you.
- Opioids are not always a miracle pain cure – they should be part of a range of drugs and management options if the pain is complicated or multifactorial.

There are some myths and misunderstandings about the opioids that limit their usefulness. These need to be put into perspective, taking the pain and the stage of illness into consideration. Common concerns are:

Opioids are always addictive

It is true that opioids can be addictive. However, addiction is uncommon when opioids are used to control pain. Risk factors for addiction include previous addictions such as alcoholism, smoking or the use of illicit drugs.

The fear of addiction should not be a reason to avoid opioids and suffer intolerable pain as a consequence.

If addictive behaviour is a concern, tighter control of the drug and a more rational approach to its use may be required. It is never acceptable to suffer pain for something that may or may not be a problem. Treat the pain.

Opioids cause allergic reactions

Most people think that the nausea associated with morphine use is caused by an allergy to the drug. In fact, this nausea is caused by a direct chemical effect in the brain and is not an allergic reaction. Anyone who feels nauseous using an opioid can solve the problem by taking a simple drug that blocks the pathway of nausea.

Allergies to opioids is relatively uncommon. If an allergy is suspected, for example, you have a rash, itch or swelling, changing from one opioid to another type of opioid could be a solution.

Opioids should not be used with patients who have lung disease

A common belief is that opioids should not be used in advanced lung disease when the risk of suppressing respiration is dangerous. While this wisdom is sound in an ideal world, when a patient is in a world of pain, a choice needs to be made about balancing the relative risks of opioids against the need to relieve pain.

The risk of respiratory failure is low if the opioids are well chosen, well managed, and prescribed for pain. Beginning with lower drug doses and careful increasing of the dose of the drug, allows for opioids to be used safely, even in the setting of advanced lung disease.

Opioids suppress the immune system

Some people fear that opioids suppress the immune system. While this may be true, the effects of uncontrolled pain are probably equally detrimental to the immune system. Why suffer pain unnecessarily?

Opioids cause confusion and hallucinations

Opioids may cause confusion and hallucinations in some people. This does not mean that they cannot be used for pain control. Changing from one product to another may be all that is needed to control these distressing and uncommon side effects.

Morphine – you can never have too much

Sometimes too much morphine is used. Doctors respond to a patient's ever-increasing pain with increased doses of morphine and eventually a point is reached where opioids are no longer as effective.

Morphine toxicity manifests itself as tremors, shakiness, agitation, and an increased sensitivity to stimulus such as touch.

While more morphine means better pain control in low level doses and for early pain symptoms, this is not true when large doses of morphine are used for longstanding pain. Looking for alternatives is important when morphine seems less effective, or the side effects become apparent.

Alternatives such as methadone may reset the body's 'switches' and allow for a rational approach to manage pain. It is essential to involve a palliative care specialist when massive doses of morphine are involved. Don't suffer with your pain, getting a pain specialist could be your answer.

You should put up with pain

Being tough and resolving to suffer pain does not build up the body's resistance to pain or benefit your body in any way. Uncontrolled pain simply causes more pain. However strong you are, this will eventually lead to a sense of hopelessness. Pain potentially weakens the immune system. Ongoing pain is meaningless and significantly decreases your quality of life if it is not addressed.

Morphine is an 'end of the line' drug

While morphine and other opioids are the drugs of choice at the end of life, using them does not mean that life is going to end soon. Life is to be enjoyed and lived to the full and this cannot happen if you are in unbearable pain.

At the end of life, morphine is usually administered by a syringe-driver, a device that injects sufficient drug to minimise suffering. People fear this hastens death but in reality, this device should only be used when death is already in the room and the suffering associated with dying is being diminished by the drugs.

Essential points to consider

So, while there are myths and misunderstandings about opioids, they are, like all drugs, still a powerful and potentially dangerous medication. Being reckless with them can lead to real problems. Find a medical professional who knows their stuff when it comes to morphine and opioids so that you can reduce the risks, while also reducing your pain. Below are a few points to keep in mind.

Opioid control

There is a high risk of misuse and dependence associated with the use of opioids. Because of this, both the dispensation and prescription of opioids are very tightly controlled. Opioids must be safely stored. They should not be left lying around for any Tom, Dick, or Harry to get hold of them. Because of the risk of abuse, prescriptions for opioids are usually short and require regular repeats, so be prepared to accept this reality.

Opioids and driving

Warning! Do not drive when using this drug. Opioids dull the function of the brain, reduce reaction time, and increase the risk of injury when quick thinking is required. Why would you want to drive if using opioids?

Sometimes being driven around by someone else is not a possibility and patients feel compelled to drive. Depending on the country you live in, driving may be possible if: your drug dose is low; the drug dose has been stable for more than two weeks; short-acting morphine has not been used; driving occurs in the daylight; the distances are small and only involve low speed; and the driving has been authorised by your doctor. If not, don't do it, particularly if insurances won't cover accidents. If you are prescribed an opioid, the safest bet is really to arrange for alternative transportation and not drive yourself. Also remember to put away the chain saws and other heavy machinery!

Alcohol

Mixing alcohol and opioids results in an accumulative suppressive effect on the old brain. Mixing drugs and alcohol makes you less able to do things and makes activities riskier and probably less fun as a consequence. In fact, it can be downright dangerous.

Dosage and usage

Never self-medicate with opioids. Increasing the dose you take without medical supervision is never recommended. Never try a friend's drug because what works for them may not work for you.

Opioids are not without risk but, when managed correctly, they offer excellent pain control. If you need morphine, take morphine, and get on with living. Don't let pain control your quality of life.

Anticonvulsants and antidepressants

These drugs work by diminishing nerve signals. They are particularly useful when there is nerve pain: typically a burning sensation that may be associated with tingling. If you have ever bumped your 'funny bone' or had shingles, you will know about nerve pain. Anticonvulsants add to the benefits of opioids here and the drug typically used is Pregabalin (Lyrica). The first drugs used to manage nerve pain were anti-depressants such as Amitriptyline and they should still be considered if nerve pain is an issue.

Other drugs

Sometimes more is needed to get on top of pain. Other options include:

Corticosteroids – These powerful anti-inflammatory drugs are essential for pain control when there is a tumour mass causing the pain, such as in spinal cord compression or brain lesions.

Cannabis – there is new evidence for the role of cannabis in the management of moderate chronic pain. This requires specialist care at a dedicated clinic. My bias is that this may be a fad and that Cannabis is never going to be as effective in pain control as an opioid. The reality is that there is a benefit in using a Cannabis related products, but don't expect a miracle.

Ketamine – This is an anaesthetic drug that is sometimes used to manage refractory pain. It has become a bit of a celebrity drug in California based on its hallucinogenic abilities. It is sometimes required to get on top of pain and can reset the opioid switches so that they work more effectively. It is not the first drug you should use but it may be an important drug if there is no release from pain.

Pain management with all the drug combinations is sometimes very challenging. Remember to go back to the basics of pain management. Don't give up if there is not a perfect drug the first time. Don't expect miracles, all drugs have side effects.

If the body is broken, these drugs may be required in increasing doses. It is not a failure; it may merely be the reality of the situation. It takes wisdom to know that pain is your worst enemy and that there can be good quality of life with good pain control.

Chapter 5. Fatigue

Fatigue is often a difficult and overwhelming symptom of advanced disease. All of us feel tired from time to time, but fatigue is much more than this. Fatigue is when “I am feeling tired” becomes “I have zero energy to do the things I need or want to do today.”

Defining fatigue is particularly challenging. Perhaps the easiest definition is the European Association of Palliative Care’s (EAPC) definition of fatigue being a subjective sensation of tiredness, weakness, or lack of energy. The key to this definition is that fatigue is a personal experience. It is a source of great frustration because, regardless of the opinions of others, there is no fuel in the tank, the battery is out of power, and the broken body can simply not function as before.

The immediate response to fatigue is to either try harder and push through the impossible barriers, or to give up and stop trying. With fatigue comes guilt about not doing the things that matter or misunderstanding about not being able to do the things that matter. Fatigue can be viewed as laziness by others and, because it is subjective, it can be a source of real conflict.

We need a better management plan than to floor it when the rusty old car is broken down. It is not about getting there faster, it is about getting there, period!

Fatigue is common in chronic disease. At the extreme, it is a reflection of the decrease in cellular function, but there are many contributing factors and they can be, and should be, addressed. Even small wins are wins. If you are running on 20%, then 30 % is a huge improvement. If the body is broken, don’t expect to get back to 100%, that is unrealistic and unhelpful.

As with all ill-health, a strategy helps. These are useful tips in managing fatigue.

Acknowledge and accept fatigue if it is a problem

Many people try harder when they are unable to manage due to fatigue. This leads to frustration, and it does not solve the problem. Just as it is impossible to pick up a 200kg weight, so it is also impossible to do everyday tasks when fatigue is a problem.

Once you can accept there is a problem with fatigue, it is possible to do something constructive about it.

Plan for the fatigue

If you are only running on limited power, do those things that matter most first, and allow for rest periods to recharge the battery. Negotiate doing the things that are possible. It may not be possible to mow the lawn, but perhaps you can make a cup of tea for everyone or unpack the dishwasher while everyone is out doing other things.

Negotiate time and make sure that you have time to rest and recover. An afternoon nap may be all that is needed. Spend time with the grandkids but send them home after 10 minutes if that is what is required. Give as much as you have in the tank.

Trade quantity for quality when it comes to time.

Create boundaries

Don't feel compelled to do things outside of your ability regardless of the reason. If Aunt Agatha is coming to visit from Timbuktu, that's great, but don't let it be an all-day affair if you can only manage 20 minutes. Perhaps you don't even like Aunt Agatha, so make it 10 minutes.

Don't feel pressurised to do things outside of your ability. Make sure that you protect your energy and use it for what matters to you and not what matters to others. This may sound selfish but if it is all you have to give, then that is enough.

Accept help when it is offered

When people offer help, accept it without abusing it. Be gracious, say thank you, and try to give back in some way that you're able. This is how friendships and relationships work. I am a very independent person and I do not like accepting help, but I have learnt that those who offer help do so because they want to.

Allow them to help you, but also allow them to help those who are helping you. Accept their offer for a meal or a respite. Their kindness will be rewarded, even if you are unable to offer them anything in return.

Seek help from professional agencies such as social workers, occupational therapists, physiotherapists, or exercise physiologists if they are going to be useful. Which brings me to the next point.

Use it or lose it

Exercise is the one thing that helps. This may seem a contradiction. When there is no energy, it may seem impossible to physically do anything, but do it. The benefits of exercise arrive afterwards, and they improve matters. It does not mean that you must run a marathon, it may be that a short walk is all that is required. Engage an exercise physiologist if this is available, and work to an achievable program and goal.

Identify and eliminate reversible causes of fatigue

In consultation with your doctor, eliminate and work on reversible causes of fatigue. These are commonly:

- Drug effects – Drugs for pain or insomnia are common causes of fatigue and feeling 'doped'. They cannot always be eliminated but it is reassuring to know when they, and not you, are the cause of fatigue.
- Anaemia is common in chronic illness. This is where there are not enough red blood cells in the body. Whenever possible, try and correct this because it will make a difference.
- Infections contribute to fatigue. Often infections, such as urinary tract infections, may be clinically undetected in advanced illness.
- Dehydration and electrolyte imbalances may cause profound weakness and fatigue. Calcium levels can easily become deranged in advanced cancer, and correcting all chemical imbalances will allow the body to work better.
- Underactive thyroid gland – This is uncommon but when it is the culprit, it is so easy to fix with the right medication.
- Poor sleep – A poor night's sleep is a disaster if you want to be an 'energy bunny' the next day. The body requires sleep, and fatigue is a natural consequence if you are not getting enough.
- Depression can cause fatigue and as a treatable condition, it makes sense to eliminate this as a contributing factor to fatigue.

Drug therapy

These require a doctor's prescription and treatment must be directed by your doctor. There is evidence that some drugs may offer a short-term benefit. It may be that a power surge is required for that important event: a wedding or a planned holiday.

Corticosteroid drugs like Prednisone or Dexamethasone may offer short term benefits and they are worth asking about. They do have their own set of side effects but, as a class, they can make a world of difference in a short time.

Modafinil – This is a stimulant which has been used in the management of fatigue in neurological conditions and HIV and may have a role to play in the management of fatigue in the palliative setting.

The reality check

The hardest thing to do when things are not going well is to accept this as a part of life. We inherently want to go back to being fit and healthy. It has always happened in the past, so why not have this expectation.

The expectation is fine if it is realistic but, at the end of life when the body is breaking, this is not a realistic expectation. Limping along at 30 kms per hour may be all that you can achieve and here is the wisdom – You will get further limping along at 30 kms per hour than you will by a 100km surge and then it's all over for the day.

At the end of life, when the cells and the organs in the body no longer function properly, profound fatigue is normal. It is a sign that the journey is coming to an end. This can be a very distressing time made worse by fighting against it. There is a time to stop fighting and to accept that we all eventually run out of gas.

Chapter 6. Sleeplessness

Most of us have been sleep deprived at some point in our lives. Anyone who has had children or worked shifts understands the consequences of waking up tired: red eyes, blurred thinking, a grumpy disposition, and a below average day at the office. When this continues for days, the world is not a happy place.

Sleep is a wonderful gift. When it all goes well, we close our eyes and dream of amazing things while our body recovers and recuperates. The drama of the day gets miraculously washed away, and we awake refreshed and ready to face a new day and new challenges. Without enough sleep, our waking day can become like a nightmare.

Often people with advanced illness are exhausted, not only from the illness, but also from the lack of sleep. More than 50 per cent of people with cancer have poor sleep hygiene. This doesn't mean they are dirty, just that they don't sleep well. Common causes include anxiety, uncontrolled pain, medication effects, over-stimulation, and a background history of poor sleep.

While the easy answer is to take a sleeping tablet, this is not a good solution in the long term. Most sleeping tablets don't work forever and can eventually increase insomnia. In addition, common sleeping tablets (such as benzodiazepines) can be highly addictive and have other serious behavioural side effects. I am often asked to prescribe 'sleeping tablets' when they are no longer effective in aiding sleep but rather have become a part of life for those who are now dependent on these drugs.

Sleeplessness is a real challenge, but as with all things, small steps may go a long way towards getting to a destination.

If you are suffering because of tiredness, consider the following steps to aid your sleep.

Have a safe and comfortable place to sleep

Set aside a place for sleep. Make sure the environment is peaceful and comfortable and free from distractions. Your bedroom should be a place where you sleep or rest, not an office or a television room. The room needs to be dark. Noise needs to be limited. Your bed should be comfortable. If it's time to replace your bed or mattress, then do it.

Have a set time to sleep

Set aside a specific time to sleep. If sleep doesn't seem possible, at least use that time to rest. Train your body to recognise sleep time by keeping to the same hours each day. 'Mat-time' works for children in preschool, so why not give it a go too?

Avoid mental stimulation before sleep

Watching adrenaline pumping television, using electronic devices (your iPad, iPhone, or computer), or doing that last essential bit of office work in the evening hours, makes it harder for you to fall asleep. Rather than wind up the brain, find ways to slow it down. Switch off your electronic devices and create a quiet environment before heading to bed. Instead of watching television, why not listen to some gentle classical music instead?

Also, watch out for those chemical stimulants such as coffee; other caffeinated drinks and alcohol are also stimulants. Avoid drinking these before bedtime. Steroids are particularly bad for a good night's sleep. If you do need to take a steroid, avoid doing so after midday.

Eliminate sleep gremlins as much as possible

Many things can interrupt sleep, but one of the most obvious causes is pain. Ensure that your pain is well managed and that any medication you are taking to manage the night's pain is adequate.

Sleep apnoea and snoring are common causes of poor sleep. Poor oxygenation at night will greatly increase your 'bad bear' feeling in the morning. If you are overweight, a champion snorer (your partner will know!) or you have a habit of tossing and turning all night, ask your doctor about sleep apnoea and how to diagnose it.

The need for frequent toilet runs and the fear of incontinence can make sleep quality worse. See your doctor to optimise bladder function. This may require medication to stabilise bladder function, or it may require a trial of mechanical aids such as incontinence pads or catheters to ensure a dry night and therefore a good night's sleep.

Resist imagination

In life's turmoil, with the burden of illness stacked on top of previous experiences, anxiety remains a common cause of poor sleep. Our worst imaginings often come to us at night, in the early hours of the morning. We anguish about imagined threats – how bad it will be when we die, how much financial ruin will occur, and whether our spouse will end up with someone else. If left unchallenged, our imaginations can become our tormentors.

The easiest thing to do is to wait for morning. Often, in the bright daylight, the things we imagined to be so terrible are put into perspective. They disappear like the mist in the morning sun. Wait for the sun. Make a deal: if your worries and anxieties threaten to deprive you of sleep, take a raincheck. Use a notepad and pen to jot down your concerns. Then agree to deal with the issues in the morning and turn over and go to sleep.

If anxiety or depression are contributing factors, seek professional help.

Use medication intelligently

Although you need to exercise caution when it comes to sleep medication, this can be an effective short-term solution. There may be a need to get one good night's sleep, and then it may be reasonable to take a sleeping tablet. Always do this in consultation with your doctor. Have a strategy to go to sleep, and not to have an anaesthetic.

Find a drug that works for a short period, one that won't leave you drowsy all day and unable to sleep the following evening. Consider a range of drugs rather than resorting directly to sedatives.

Just rest

When all else fails and you are simply unable to sleep, use the time to rest. Close your eyes and relax. Try relaxation techniques. One such technique is to tense and relax each muscle in turn. Start at your foot and work up, muscle by muscle. Tense each muscle and then slowly relax it.

Even if you are unable to sleep, your body will recover if you rest. Think quietly about something positive. Meditate and say a prayer in faith, not in fear.

These strategies may not always work. Psychotherapy may be needed to reset the mind if it is running out of control. Medication may be needed if the body is hurting. Don't disregard spiritual care because sometimes this is the thing that prevents us being at peace. Sometimes the small faith of a child doing a bedtime prayer may be the thing that is most needed before we sleep. Sometimes we need to be reminded about the biggest picture and I can always recommend Psalm 23.

Chapter 7. Breathlessness

Being out of puff can be a terrifying experience. While it is normal to feel breathless when you exert yourself, being out of breath becomes abnormal when it limits normal activities or is combined with disabling anxiety. Breathlessness is a common symptom in advanced illness and affects up to 70 per cent of people with advanced cancer. Breathlessness has many causes and many factors that can make it worse. Having a strategy to manage breathlessness is an essential skill when the body is not playing ball.

The process of breathing

We take breathing for granted but it is a complicated process. When we breathe, air enters through the mouth and nose, travels down the larger airways through to the smaller air tubes, and eventually reaches millions of minute air sacs in the lungs. At this point, the oxygen in the air is exchanged for carbon dioxide through a very thin membrane. The oxygen is then transported via red blood cells found in the blood to the cells and organs that need it to sustain life. The air doesn't get there without the ongoing effort of the respiratory muscles. The diaphragm automatically contracts and relaxes like huge billows, sucking air into the lungs. When more air is needed, the rib muscles become involved, and as a team, these muscles pump air into and out of the chest. Airflow is key.

Breathing is also affected by the way oxygen is transported from the lungs to the brain. Because of this, breathlessness may also have many non-respiratory causes. This is all regulated subconsciously, where levels of oxygen, carbon dioxide and pH, influence breathing. Conscious factors, such as emotion, also affect breathing. Although this is an oversimplification, it serves to illustrate that breathing is a complex process.

Shortness of breath is difficult to define. In essence, it is an individual's own feeling of discomfort in breathing. Breathlessness belongs to its owner. While we have all experienced breathlessness at some time in life, for some people, due to illness, breathlessness becomes a way of life. This can lead to social withdrawal, an inability to function 'normally' and the fear of making things worse.

Because of this, every opportunity to improve breathing should be embraced. Here are a few things that may help.

Accept that you experience breathlessness

Look at small gains (for example, “I didn’t feel quite so breathless today”) as big wins and congratulate yourself on each win. If there is no possibility of things getting better, aim for preventing things from getting worse. Change your focus from how good it was to how best it can be.

Avoid making breathlessness worse

Identify the things that make your breathlessness worse and avoid them as much as possible. This may be anything from a trigger event, such as cold air, pets, or smoking, to doing unnecessary physical activity that results in punishing breathlessness. Don’t be a hero if you don’t need to be one.

Optimise your medical care

Involve a team, including your general practitioner, palliative care doctor, respiratory physician, and physiotherapist. Make use of their knowledge to optimise your breathing and have their emergency number on speed dial. Treat reversible causes of breathlessness such as anaemia (a low red blood cell count), heart failure or chest infections. Use inhalers and nebulisation as prescribed, and take it easy with steroids – self-medicating with these may come back to bite you if they precipitate a lung infection.

Know your body and be quick to react to unexpected changes.

Exercise

Exercise may seem a crazy thing to do and in contradiction to avoiding a trigger for your breathlessness. However, deliberate, supervised exercise may improve your breathlessness in time.

A lung physiotherapist may be just what the doctor ordered.

Practice breathing strategies

Discuss practical breathing strategies with your respiratory doctor and team of therapists. For example, when you feel breathless, taking deep breaths through pursed lips may help.

Have a strategy for managing your breathlessness

When you feel an episode of breathlessness coming on, take action to manage and recover from it. This may be resting in a favourite chair or place or sitting forward and having a cool fan blowing air in your face. Listen to music that brings your breathing into a nice easy-paced rhythm – your 'breathlessness-beating-music'. Don't panic. Remember that you will have been here before and dealt with the situation, and you can do this again. Take control of your breathing.

Think twice about using oxygen

The automatic response to breathlessness is to use oxygen, but this may be counterproductive and, depending on your lung health, decrease the respiratory effort. Things can only get worse!

Oxygen is a very specific solution to breathlessness, and it should always be prescribed by a palliative care doctor or a respiratory physician. Sucking on Oxygen should only be done at a doctor's recommendation unless of course there is an emergency.

Review your medical treatment

Ask your medical team about drug treatment that is additional, or an alternative treatment to inhalers. Possible treatment could include:

- Opioids – they alleviate the distress caused by breathlessness.
- Steroids – worth trying for the short term.
- Short-acting anxiolytics – drugs such as Lorazepam may reduce feelings of panic.

Sometimes nothing will help, and the shortness of breath may seem overwhelming. If things are bad or deteriorating, get to hospital. That is what they are there for. Don't be a hero because a medical professional shooed you away last time. It's your body and if it is not working, call the ambulance, get some help.

Thanks all for now folks! We are working on completing this manuscript for publication.

As a charity we are limited by resources. You can help us out by providing feedback or by sponsoring the "Broken body user's manual" project. Regardless we would like to hear from you with any suggestions, recommendations, or comments.

Thank you!

Colin Dicks