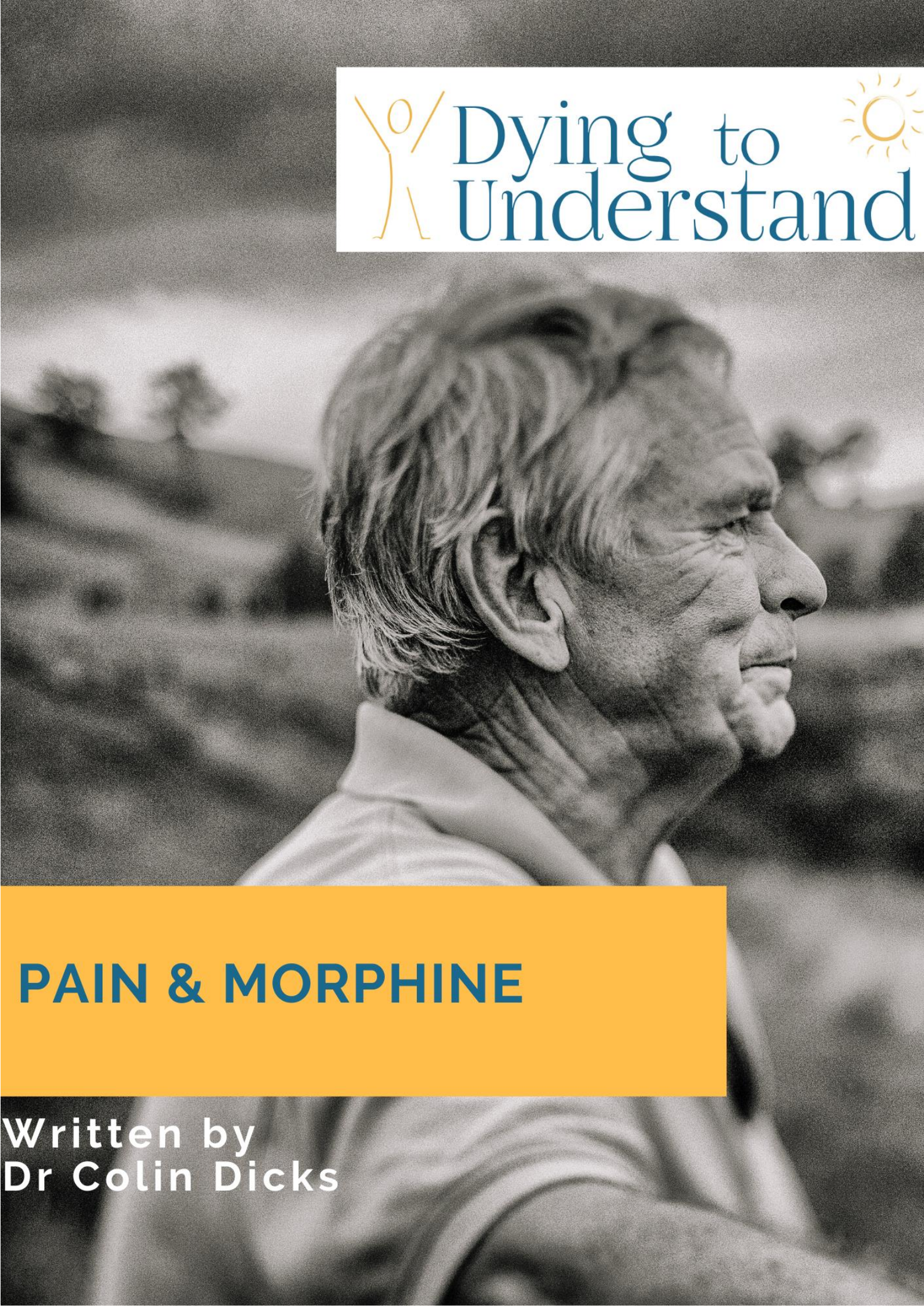

Dying to Understand

PAIN & MORPHINE

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.

Dying to Understand

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INTRODUCTION

One of the most feared things about advanced illness, and cancer in particular, is pain. Pain is a common symptom in advanced disease at the time of dying, so knowing about pain and how to manage it is important. Uncontrolled pain serves no purpose, so there is never a point where putting up with pain is a good option.

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.

I hope the thoughts within this book provide a starting point to conversations and strategies for managing pain. Ideally, I wish for everyone to be pain-free.

THOUGHTS ON PAIN

There are different kinds of pain in life. All pain is unpleasant and best avoided, but you may be surprised to hear that there are 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 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 worsens. 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 of the pain. This means taking into account all of 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.

So, what is pain?

Pain can be defined as an unpleasant sensory and emotional experience. The sensory aspects are well defined: in essence, pain occurs following tissue injury. When this happens, special chemicals are released at the injury site. These activate specialised nerve fibres that relay an almost instant message to the brain.

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. The reaction is to remove the body from the source of pain quickly.

The difference with cancer pain

With cancer, sometimes the cause of pain cannot be eliminated immediately. This is because the cancer releases a soup of chemicals that constantly trigger the pain nerve fibres. The nature of this pain can vary – it can be dull and throbbing, spikes of pain, a burning sensation, or a combination of the three. The pain can come and go, it can be unpredictable, or it can be associated with movement.

While the nature and intensity of cancer pain can vary, the pain will persevere unless the cause is eliminated. Getting from a place of having constant pain to a place of being pain-free should be the main goal.

Dealing with cancer pain

Here are ways you can deal with cancer pain.

See a doctor

Pain is a message that tells you something is wrong. Don't ignore the message, even if it is a soft and intermittent whisper. See a doctor because the cause of the pain needs to be identified.

Diagnose and eliminate the cause

As far as possible, your doctor will try and diagnose what is causing the pain. This may take time.

The next step is to eliminate the cause of pain. If this cannot be done immediately, you should at least have a game-plan for going forward. Your journey to being pain-free may involve surgery, chemotherapy or radiation. Radiation is particularly useful in eliminating cancer pain.

Manage the pain

Manage the pain sensation immediately. Don't be tough and put up with it—the pain you are experiencing with cancer serves no purpose. Get to the doctor and use the pain medication that your doctor prescribes for you.

Typically, the drugs you will be prescribed will depend on the level of pain you are experiencing with medication such as acetaminophen/Panadol being used for mild pain and morphine or other opioids for severe pain.

Monitor the pain

Review and keep track of what is happening with the pain. This helps your doctor to diagnose the cause of the pain. Keeping a pain diary will really help with this. If possible, include comments about:

- The intensity of the pain with 0/10 being no pain and 10/10 being the type of pain that you don't think you could tolerate a moment longer.
- The nature of the pain - is it dull, aching, burning, tingling, associated with numbness, throbbing? It helps to try and think of a way you can explain the pain to your doctor. E.g. the pain is like being stabbed with a knife, hit with a hammer, like toothache or being struck by lightning.
- The timing of the pain. E.g. if it occurs in the morning or at 4.00pm in the afternoon.
- The spread of the pain. E.g. 'it starts in my chest and spreads to my neck and arm'.
- What makes it worse. E.g. coughing or sneezing.
- What makes it better. E.g. holding up an arm, massage or changing position.
- What you have been using to manage the pain in the past 24–48 hours. Include the drug and the dose.
- How long the pain lasted.

Use the right medication

Use the right drugs for your pain. Don't miss a dose or change a dose or use your spouse's drugs because they worked for him or her. Stick to the prescription and regularly review the pain and prescription with your doctor.

Try other management strategies

Use additional measures to control the pain, such as heat packs, TENS machines, massage, psychotherapy, meditation or splinting.

One of the most effective non-pharmacological approaches to cancer pain is radiation. Radiation is very effective in reducing cancer pain, in particular, cancer bone pain. It works by destroying cancer cells and the associated pain chemicals. The radiation dose should never be big, and the benefit should be defined as pain control and not anything else. Always see a radiation oncologist if cancer pain is an issue.

Not everything works. It is best to avoid unproven and/or potentially dangerous therapies in pain control, such as smoking dope, imbibing whiskey or taking sleeping tablets.

See a specialist
See a palliative care or other pain specialist if the pain persists and is not well controlled.

With intervention from your medical team, you can be hopeful that the pain will be short-lived and easily relieved by the right drugs. Usually, the cause of pain can be eliminated, or at least moderated, by the right intervention.

Remember that you should not have to put up with pain. Every effort should be made to understand your pain and what affects it.

It can sometimes take a while to get on top of pain. Don't give up, press on for the outcome that makes you pain-free.

When pain persists

Living with pain is not an easy burden to bear. Make sure your doctor understands your pain so that he or she can help you to relieve it. Never accept pain as your lot in life, as your penance or punishment for a past sin, or attribute to it any other meaning.

In some situations, pain never fully goes away. As with all disappointments in life, this fact can be made less distressing by reviewing the boundaries. In these circumstances, secondary endpoints need to be defined. If it is not possible to have a pain intensity of zero, a pain intensity of 3/10 will be better than one of 5/10. Work with what you have and look for improvements where you can get them. Sometimes a compromise is required. Always review pain and go over it again thinking about what may have been missed or what can we change?

The role of the palliative care team cannot be over-emphasised in the settling of difficult or refractory pain. There is always a way to make things better, even if they cannot be perfect. Work towards small wins if the large wins are not possible.
May you be blessed in being pain-free.

Having a pain control strategy

When it comes to pain, it is important to have a pain management strategy. The worse thing to do is to have a 'slug out of the bottle of morphine' approach to pain control and hope for the best. Here are my recommendations for a more comfortable life.

- Accept pain. By doing this you are already on the way to improvement. Pretending pain is not there serves no purpose.

- Try and characterise each pain and write it down - have a pain journal.
- Have only ONE pain doctor. Managing pain is impossible if there are too many doctors involved. A single doctor should be on point for the pain management and this doctor should then co-ordinate and write all the pain scripts. Ideally this will be a palliative care specialist/oncologist/pain specialist/GP.
- Remember there is no one plan that fits all. Consider pharmacological and non-pharmacological approaches to pain management.
- Review the pain strategy regularly.
- Have realistic expectations - any improvement in pain may be good enough.
- Remember radiation for cancer pain relief.
- Always remember there is a plan B. If one thing does not work, there is another option.
- Do not be afraid of using morphine for severe pain, as well as to improve pain control.
- Remember, pain has an emotional component as well and getting psychological support is sometimes more important than having bucket loads of medication.

THOUGHTS ON MORPHINE and OPIOIDS

Although morphine is one of the most commonly used drugs in advanced illness, it is also one of the most misunderstood. People are often reluctant to use it. Common misconceptions include that it is the beginning of the end, that addiction is certain or that the drug is too dangerous. Clinicians often under-prescribe opioids for fear of inducing respiratory failure. Confusion about opioids seems more common than confusion from opioids. Here is some clear thinking about these essential drugs.

All drugs have therapeutic effects and side effects, morphine and the opioids are no exception. It is important to understand the positive effects and side-effects of morphine and to dispel myths about the drug. The truth is, that when it comes to treating pain, there can be no better drug than morphine. Understanding morphine and the opioids allows for better drug use, better therapeutic outcomes and fewer side effects.

What is morphine?

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.

For patients with advanced illness, the main purpose of morphine is to reduce pain while & drug side effects. The trick is, not only in getting the dosage right, but also in choosing the right drug combination. Each individual metabolises drugs in a unique way, so an opioid that works well for one person, may not work well for the next person. Often, getting the drug and dosage right is a trial and error process.

Confusion about opioids begins because of the large number of different drugs available. Consider some of the common opioids:

- Codeine - the weakest opioid
- Morphine - the gold standard & ten times as potent as codeine
- Diamorphine (Heroin) - used in the United Kingdom only
- Fentanyl (Durogesic) - best known as a patch
- Hydromorphone - five times as potent as morphine
- Oxycodone - twice as potent as morphine
- Methadone - very tricky metabolism requiring specialised care

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.

Issues doctors consider when prescribing morphine and opioids

The issues your doctor needs to consider when prescribing these drugs are:

- How they are metabolised and excreted from the body. Different choices will be made depending on whether liver or kidney failure is involved in your illness.
- How long they work: most people require a combination of a long-acting and a short-acting drug.
- The physical property of the drug: liquid, tablet, capsule, lollipop, injection or skin patch, and which choice is best for you.
- The doctor's assessment of your reliability in taking or administering the drug.
- The expected side effects and how these may affect you.
- The possibility of drug interactions and combinations to manage your pain in the most effective way.

What you need to know about morphine and opioids

From a practical viewpoint, there are only a few things to know about morphine and pain control, such as:

- Long-acting opioids - ones that work for at least twelve hours & 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 & 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.
- 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.
- 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.

The use and role of these drugs is constantly being reviewed. What may be good today may not work tomorrow. Discuss the best options **for you** with your palliative care doctor.

When it comes to pain, morphine is a good friend. There is no need to put up or bear with pain. There is no award for being tough. Get help when pain is the problem.

MYTHS AND MISUNDERSTANDINGS ABOUT MORPHINE

Many people, including doctors, misunderstand opioids and their use in advanced illness. This misunderstanding can be harmful when opioids are misused or abused. But this misunderstanding may prevent opioids from being used effectively to control pain.

Some typical myths and misunderstandings

There are many concerns about opioids. Below we have listed some of the more common ones.

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. Starting at 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.

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?

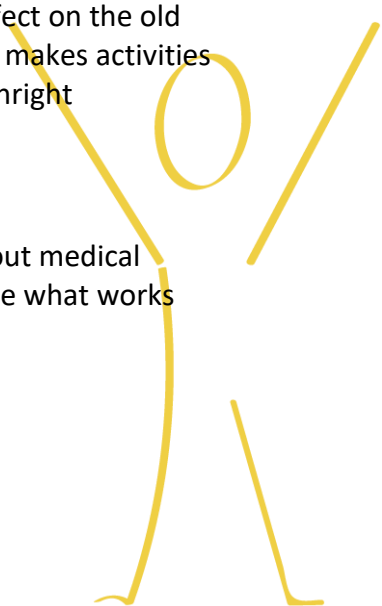
Sometimes being driven around by someone else is not a possibility and patients feel compelled to drive. Depending on the country you live in, driving *may* be possible if your drug dose is low; the drug dose has been stable for more than two weeks; short-acting morphine has not been used; driving occurs 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.



CLOSING

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.

Warning: *This e-book contains general advice & information only and has been prepared as a guide only. This guide is not medical advice and you must consult your health care providers for specific medical advice relevant to your needs.*