Dying to Understand

COMMON PROBLEMS OF ADVANCED ILLNESS

Written by
Dr Colin Dicks

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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.

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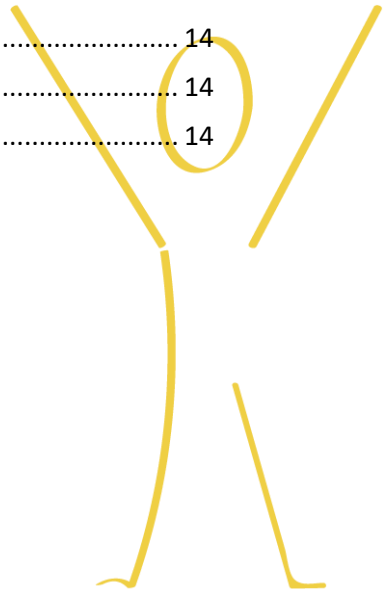

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INTRODUCTION

There are few surprises in the symptoms associated with advanced cancer. Most are predictable and, although not everyone gets all the symptoms, it will be uncommon for a palliative care physician to be caught out by the following set of common symptoms included in this book.

It is totally different for the carers and patients who often have no idea about what's ahead. We were appalled by the lack of information about the symptoms or expected symptoms around palliative care found in recent research, particularly in regard to cancer.

Ignorance may be bliss, but it is not when a little bit of knowledge goes a long way in mitigating and reducing the distress associated with advanced illness. I have written here of a few common problems encountered in advanced cancer. The thoughts are not to replace the doctor/ patient relationship, but to provide a framework for further discussion.

INSOMNIA AND SLEEP DISTURBANCE

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.

Add the burden of illness to poor sleep, and it is easy to understand how a downward spiral is set in motion: you feel poorly, sleep poorly and then feel increasingly worse as time goes on.

Most people with advanced illness are exhausted, not only from the illness but also from the lack of sleep. And they are not the only ones affected, as caregivers and anyone who gets in the way of a sleep deprived 'angry bear' can appreciate. That's right, a sleep-deprived person can be a dangerous animal indeed.

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 side effects.

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. After all, you should spend up to a third of your life sleeping.

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 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, will all over-stimulate you and make it harder for you to fall asleep. 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?

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 worry and anxiety 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.

Manage anxiety and depression

You may be feeling anxious or depressed for completely justifiable reasons. Work to eliminate the causes as far as possible, but you may have to accept that some issues are beyond your control.

Be realistic about your expectations and lower them if that is what is necessary. There is nothing wrong with celebrating a bronze medal if you cannot get the gold.

If anxiety and depression are part of the problem, see a professional, such as a psychologist, sooner rather than later. Resolving emotional issues can be tricky. Don't try to do it all yourself.

Use medication

Although you need to exercise caution when it comes to sleep medication, this can be an effective short-term solution. Your palliative care team will know which drugs are right for you. Sleeping tablets are reasonable to use for a while, but there may be better options, particularly if you are already rattling from all the drugs you need to take.

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.

Insomnia is not easy to deal with. Seek professional help early and regularly. Aim for small wins. Sweet dreams - may they be yours.

NAUSEA & VOMITING

There can be few things as distressing as nausea and vomiting. For some people it can be a nightmare. Vomiting is so unpleasant it remains locked in the memory for a long time - you can probably clearly recall the last time you vomited.

How nausea and vomiting work

At a simplistic level, we vomit to protect ourselves from harm. It is our way of expelling toxins and poisons from our body - we only have to think of binge drinking and the aftermath to understand the poison theory. But vomiting is more complicated than that. Vomiting is regulated by two key areas in the brain, and these areas are affected by signals from many different areas in the body.

Although the mechanisms and pathways are complex, these can be easily understood by thinking of a region of the brain that regulates nausea and another region regulating vomiting.

The region regulating nausea is called the chemo-emetic trigger zone. This zone can be stimulated by nerve impulses from the intestinal system (such as the stomach, intestine or liver) and the ear. Drugs, toxins, chemical metabolites in the body and movement (such as sea sickness) can all stimulate the trigger zone, resulting in nausea.

These nausea impulses then stimulate the vomiting centre located in a different part of the brain. However, the vomiting centre can also be stimulated directly by impulses from the ear (motion sickness), the gastrointestinal tract and impulses from conscious thought (such as when you see or smell something repulsive, or like seeing someone else vomiting and feeling compelled to vomit in sympathy).

Although this description might be an oversimplification of the complex nature of nausea and vomiting, it serves to illustrate that there are a number of different nerve pathways involved. This means that there are a variety of drugs that can be used to control nausea and vomiting. Knowing the pathway is key to managing these unpleasant symptoms. There are few one-drug-fits-all policies; a number of different drugs are often required.

Although nausea and vomiting are mostly subconscious reflexes, conscious thought plays a significant role. This consciousness can have a positive effect; for example, when you suppress the need to vomit. However, awareness also has its downside, as when your feelings of repulsion set your vomiting off. Many people who have undergone chemotherapy have anticipatory nausea and vomiting. The very sight of red cordial, for example, which resembles one of the chemotherapy drugs, can trigger vomiting in some people.

Causes of nausea in advanced illness

In advanced illness, there are several reasons why you might feel nauseous and vomit. Typically, these might be:

- Treatment, such as chemotherapy or radiotherapy
- Drugs, such as morphine and other opioids
- Metabolic disturbances, such as kidney failure, raised blood calcium or diabetes
- Bowel obstruction, partial obstruction or irritation
- Raised intracranial pressure (swelling of the brain, as in secondary cancer)
- Infections
- Other drugs
- Vertigo (movement and balance disturbance)
- Conscious or psychological triggers, as seen in anticipatory nausea and anxiety

Treatment for nausea and vomiting in advanced illness

A three-pronged attack is needed. The first tactic is to try and remove the cause of the nausea and vomiting if practically possible. The second is to offer the correct drug for the type of nausea. As a general guide:

- Chemotherapy and radiation require a drug such as Ondansetron
- Opioid nausea requires a drug such as haloperidol or metoclopramide.
- Gastric stasis requires a drug such as metoclopramide.
- Motion sickness requires a drug such as cyclizine or hyoscine.
- Corticosteroids are non-specific anti-nausea drugs, and they are particularly useful in cases of raised intracranial pressure.

The third prong of attack is to manage the distressing conscious effects of nausea. This may require the following tactics:

- Removing the triggers as much as possible
- Eating snacks or a few mouthfuls of food in one sitting rather than having a big meal
- Psychotherapy
- Antianxiety therapy such as benzodiazepines
- Acupuncture or hypnotherapy

Sometimes vomiting occurs because of a blockage of the intestine. This is a very different cause of vomiting, which will require an urgent surgical opinion. In all probability, an operation will be needed if conservative management does not resolve the problem.

It is often not necessary for you to suffer. Taking the time to correctly manage your nausea can make a huge difference to your quality of life. Sadly, for some people, nausea and vomiting will remain a feature of their illness. In these circumstances, working with palliative care physicians is an important part of managing symptoms.

SHORTNESS OF BREATH

Being out of breath 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. Optimising breathing when you are short of breath is always going to be a bonus.

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.

We have all experienced breathlessness at some time in life, usually after exertion. But for some people with longstanding lung damage, breathlessness is a way of life. It is often associated with distress due to social withdrawal, an inability to function 'normally' and the fear of an exacerbation of breathlessness. Add to this illness treatment such as radiation, and pain, and the experience of breathlessness can seem quite hopeless.

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. Ensure that anaemia (a low red blood cell count) is treated, heart failure is excluded as a cause of your breathlessness and that, where possible, inhalers and nebulisation are as effective as possible.

Quickly report any change from your baseline breathing and make sure that your medical team treats reversible causes, such as chest infections or fluid on the lungs (pleural effusion), aggressively.

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.

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 about using oxygen

Discuss the use of oxygen with your doctor. It is not the answer to everything, but if your oxygen concentration levels drop, taking in extra oxygen may make the world of difference to the way you feel.

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

Get additional help if anxiety is a huge component of your breathlessness. See a professional team of psychologists when anxiety drives breathlessness into the stratosphere. Make your doctors part of the solution.

Breathlessness can be very distressing and, if combined with panic, things can soon spin out of control. It is important to note that breathlessness in itself is not life threatening. You will not choke or suffocate to death. As terrible as it may seem, shortness of breath gets worse with anxiety. Learning how to manage anxiety and use breath-control techniques go a long way to relieving this distress. Always involve your doctor when breathing deteriorates or head to the emergency department if it cannot wait.

SEXUALITY

Sexuality is at the core of what it means to be human. It enables us to make intimate physical, emotional and, possibly for some, spiritual connections with other people. As an essential part of who we are as humans, sexuality is often a neglected pleasure in advanced illness.

The importance of sexuality

Sexuality is central to our body image. As teenagers we become ever aware of the physical changes in our body as puberty progresses. These changes, combined as they are with the discovery of sexuality in early adulthood, clearly tie sexual experience to bodily function and physical sensation.

Sexuality, however, is more than just physical. It is also closely linked to core values, beliefs and culture. Sexuality really begins in the mind. It is in the mind that one person appears to be more attractive than another. It is in the mind that the chemistry of intimacy begins. Most relationships are established by attraction and this leads to enduring intimacy and sexuality.

While most men consider sexuality to be the *grand finale* of intercourse, most women appreciate that sexuality is a far more intimate process. Sexuality involves the mind, the skin, the mouth, the hands, the breasts, the pelvic organs and the genitalia. Any injury or loss to any of these can affect or reduce sexual feelings.

Sexuality starts with enticing words, gentle behaviour, a seductive touch and then culminates in the pleasure of intercourse. It doesn't take much to realise that sexuality is a problem for many people without illness being part of the equation.

Psychological barriers to sexuality

Because all sexuality begins in the mind, things that occupy the mind affect sexuality. Often, it is injury to the mind that has the most profound effect on sexuality. Feeling unattractive or experiencing emotional conflict are powerful obstacles to expressing intimacy. Depression and anxiety do little to enhance sexuality and attraction. Add illness to the many stressors in life and it is easy to see that sexuality is often abandoned.

Resolving these mind issues is an important step to restoring sexuality, but is often deemed too difficult, too embarrassing or too personal, and the hope of expressing sexuality is lost. Open, honest communication is important, and a professional might need to help address mind issues and sexuality.

Physical barriers to sexuality

Mind issues, however, are not the only issues that affect sexuality in the setting of advanced illness. Physical factors play their part as well. These include feeling unwell and fatigued. Pain and immobility are barriers to sexuality. Drugs and treatment can affect performance. Age is also a factor in many cases.

Overcoming barriers and exploring sexuality in advanced illness

In the face of so many obstacles, the focus should not necessarily be on an end goal of intercourse and orgasm. The physical experience of sexuality begins with touch. The largest sex-organ in the body is the skin. Touching or caressing the skin initiates intimacy and sexuality, and for some, physical touch may be the starting point to rekindling sexuality when it has been lost.

The Masters and Johnson four-stage model of sexual response begins with the excitement phase. This is initial sexual arousal, and this may be a sufficient goal at first. Take time to work towards the other goals of full arousal and orgasm, and make the journey fun and exciting. Intercourse is not performance-based; there are no awards for being a super stud or a hot babe. Take it slow and express your sexuality in your way.

Sometimes medical assistance and intervention are required to overcome obstacles to expressing sexuality and having intercourse. Sadly, medical practitioners are often poorly trained to help patients with sexuality issues. They will not initiate the conversation and might be embarrassed if the topic is raised. It takes courage, so be bold and discuss your needs with your medical practitioner. Ask for a referral to a specialist in the field if the general practitioner is unable to offer real assistance.

Don't give up on sexuality. It is a core part of what makes us human. Intimacy is a starting point in terms of sexuality. Being with someone that you love and care for is an important first step. Although the intimacy of intercourse might not be possible, it might be possible to rediscover your partner by way of touch, caressing, gentle words and, most importantly, acceptance. It is also vital to accept oneself, warts and all.

If you have abandoned sexuality, why not consider the following.

- Accept that sexuality is a good thing.
- Be open and honest with yourself and your partner about your shared sexuality and needs.
- Start with the mind - see a professional if there are unresolved conflicts, anxieties or depression.
- Set a small goal, and have fun discovering or rediscovering sexuality along the way.
- Seek medical advice early, if required. For example, to address issues such as pain control, hormone replacement therapy, drugs for erectile dysfunction and a review of drugs impairing sexuality.
- Remember that medical practitioners might be reluctant to discuss your sexuality, so ask for a referral to a specialist.
- There is no age limit to sexuality.
- Find time and a private place to explore your sexuality.

Often, sexuality is abandoned in times of illness or in advancing age. However, it is never too late to rediscover that which is lost. Look at what remains and build up from there. It may start with a caress, a touch or a kiss. Perhaps it is rediscovering what those teenagers are trying to discover in the very first place.

BLEEDING

From our first fall as a child and experience of the pain associated with red liquid oozing from the wound, we understand that bleeding is a dangerous consequence of ill health or injury. We all know blood by its vibrant red colour. The sight of blood can create a powerful emotional and physical response, and there are many stories of brawny men fainting at the sight of a drop of blood. We intuitively know that something is dramatically wrong when we bleed.

Surprisingly though, some people ignore mild bleeding when it occurs for the first time, hoping that it is a one-off abnormality and won't happen again. Unexpected bleeding can have many causes. In some cases, it may point to an undiagnosed cancer. Regardless of whether the bleeding is a little or a lot, it should always get your full attention.

However, if you do see blood, don't panic! You are not going to immediately die from bleeding, but you do need to take action.

Blood and the process of bleeding

To understand bleeding, we need to understand the nature of blood and how our circulatory system works.

Blood is a complex and essential element of life. It is made up of the obvious red blood cells that we immediately notice when we bleed. They transport oxygen to the tissues. The white blood cells (actually little blue critters) are the hostile police-force arresting, killing and starting outright war if they detect any unwanted guest (germs) in the body. The third cellular component of blood are the platelets. These cells are the maintenance crew plugging up holes in the circulation. Add to this a liquid called plasma, and voila, we have blood. Plasma contains dissolved gasses, nutrients and, importantly, clotting factors that prevent blood from flowing freely when it escapes the circulation system in which it is contained.

The circulation system is a vast network of plumbing, starting at the heart and the aorta as the arterial blood supply, and ending back at the heart as the vena cava, the venous blood supply. The arterial blood is pumped at a high pressure and the venous blood flows back at a low pressure. The large blood vessels get smaller and smaller as they move away from the heart, until the arterial and venous system meet in microscopic plumbing called capillaries.

Every day, at an average of 72 beats per minute, the heart pumps this blood around our body. The blood remains where it is, and we are happy.

We bleed when we disrupt the plumbing. We already know about the possibility of trauma in which the plumbing is damaged by an external force, releasing the bright red liquid. The amount of bleeding is directly proportional to the size of the blood vessels, the pressure of blood in the vessels and the number of blood vessels affected.

Bleeding in cancer

In cancer, bleeding occurs by two possible mechanisms.

The first is where the abnormal cancer invades into normal healthy tissue. With cancer, the blood vessels are small and poorly, and haphazardly formed as a result of the abnormal growth of the tumour. As a consequence, these blood vessels leak, and bleeding occurs. This bleeding is usually not dramatic or life threatening. It can present as bleeding from:

- The skin and surrounding tissues, as seen in head and neck cancers
- The bladder, with dark to red coloured urine or even clots in the urine
- The lower bowel, with dark blood mixed with bowel material
- The anus as bright red blood
- The stomach with resultant foul-smelling sticky tar-like bowel motions (melena) or as vomit, with small particles resembling coffee grounds
- The oesophagus, with dark to bright red blood brought up
- The lungs, seen by coughing up blood or blood-stained sputum
- The vagina, in gynaecological cancers resembling a period
- The nose with bright red blood

The second mechanism of bleeding occurs less commonly but is equally important. This is due to an abnormality in the platelets, the components of the blood that block up holes in the vessels. If the platelets are dysfunctional, they cannot plug microscopic holes in the normal or abnormal blood vessels. As a result, tiny areas of bleeding can occur over a large area. This bleeding is not readily visible, but when noticed, it is seen as pinprick bleeding in the gums or under the skin as tiny purple spots.

Treating bleeding

Because bleeding can occur before it is clinically obvious, the first test to reveal an abnormality is a low haemoglobin score on a blood test. Low haemoglobin is known as anaemia and a finding of this should prompt your doctor to search for a cause of bleeding when bleeding is suspected.

Obvious signs of bleeding will always be distressing. However, it should not be seen as your body failing, but as an opportunity to fix something that was previously hidden and potentially lethal. Bleeding does not cause the illness, but it is the perfect tattletale if illness is lurking away in the background. In this setting, bleeding is a friend and not a foe.

In advanced cancer, bleeding often indicates that the cancer is progressing. Apart from sometimes having to replace blood with a transfusion, it is also important to try and stop the cause of bleeding. In these circumstances, bleeding is usually well managed with a short course of radiation. Sometimes invasive radiological embolization techniques or surgery may be necessary to stop bleeding.

What you can do if you are bleeding

Don’t panic

If you are bleeding and it is not caused by trauma, take a deep breath and try not to panic. Yes, the sight of blood can be very distressing, particularly if it is your own blood. However, keep in the forefront of your mind the knowledge that your bleeding can be managed.

Seek medical advice urgently

If the bleeding is from a wound, compression and a dressing will help. Call for an ambulance if you are unsure about the seriousness of the bleed, or if the bleeding is ongoing and heavy or associated with dizziness, shortness of breath or feeling unwell.

Recall details

Try to recall when the bleeding started, its duration and how frequently it occurs (e.g. does it happen every time you cough or every second day or so).

If bleeding seems severe, try and estimate the volume of blood-loss by stating how many towels were needed to clean up the blood for example.

Take all your medication with you when you see your medical professional or visit the hospital.

Bleeding may be associated with other causes, such as an infection or inflammation. Try to recall overseas visits, episodes of feeling unwell and feeling feverish.

Severe bleeding

Bleeding is rarely fatal. In most cases, with good management, even moderate bleeding can be well managed.

Bleeding is always distressing. Don't ignore bleeding. It is the red light to stop and seek medical attention. Always mention bleeding to your doctor, even if it was only once and seems to have got better on its own.

CONSTIPATION

Constipation is unpleasant and it can lead to unnecessary hospitalisation and unwanted distress if it is not managed. The good news is that it is easy to manage. If you are suffering, don't let constipation make your life unbearable. When it comes to a healthy bowel, a poop a day keeps unhappiness away!

The digestive process

In the process of normal digestion, food is ground by the teeth and enters the stomach where acid starts the digestive process. In the small intestine, enzymes from the pancreas and gall bladder aid in digesting proteins and fats. The small intestine is filled with an 'intestinal soup' of nutrients, undigested food, enzymes, fluids and waste material. When the 'intestinal soup' reaches the large intestine, fluid is resorbed. The large intestine (or colon) is responsible for the recycling of fluid.

If the intestinal soup is too runny or if it moves through the colon too quickly, the result is diarrhoea. If the same soup lingers in the colon for too long, too much fluid is resorbed (sucked out of the intestine), turning the soup into an ever-hardening stool until it becomes impacted like little chunks of charcoal. Faecal impaction is the dreaded end result of unmanaged constipation and often the impacted hardened lumps of stool have to be removed physically.

Constipation occurs when this normal digestive process is disrupted in any way that slows down the transition of the intestinal soup through the colon. It can be defined as difficulty in passing a bowel movement and, more specifically, passing a bowel motion less than three times per week.

Causes of constipation

Common causes of constipation are:

- Inactivity often caused by illness. This results in a 'lazy' bowel and a delayed transition time through the colon
- Insufficient fluid intake, making the intestinal soup less runny to start off with
- A poor diet with insufficient fibre. Fibre keeps the liquid in the intestine for longer

- An inability to get to a toilet in time when it is required. In these circumstances the brain overrides the signal to go to the toilet. In waiting, even more fluid is resorbed in the colon
- Opioids - morphine and similar pain medication can slow down bowel movement and delay the transition time through the colon
- Drugs to treat diarrhoea - they slow down the time through the colon resulting in fluid being resorbed
- Other drugs - a wide range of medication may promote constipation

Symptoms of constipation

Constipation can present in many ways including feeling bloated or nauseous, lacking appetite, back pain, abdominal pain, abdominal cramping, feeling just generally unwell and, for the unsuspecting, diarrhoea. In the elderly and frail, constipation may contribute to delirium, a confused state of mind. These symptoms may be associated with less frequent bowel motions, straining to pass bowel motions and passing hard or firm stool nuggets.

Severe constipation can result in the unwelcome event of faecal impaction and overflow diarrhoea. This occurs when the bowel content becomes so hard and packed together that the only substance that can pass through the colon is liquid. This liquid trickles past the impacted stool and resembles diarrhoea. It presents with cramping, frequent motions and watery diarrhoea without formed motions. For many people who experience this, the logical thing they think to do is to take anti-diarrhoea medication. However, this can make things much worse. A vicious cycle of suffering can occur if impaction and overflow diarrhoea are not diagnosed and managed appropriately.

Managing constipation

The best way of managing constipation is to prevent it happening in the first place. The best way to do this is to have a bowel motion every day or every other day.

Here are some suggestions for managing constipation.

- Always anticipate that constipation may become an issue.
- Don't become dehydrated; make sure you drink enough fluid.
- Try and get regular exercise.
- Ensure that a toilet and privacy is available so that if it is time to 'go' you have no holdups or obstacles. Often the urge can pass, resulting in a delayed evacuation and consequent hardening of the stool.
- Ensure there is enough fibre in your diet.
- Take medication to ensure a regular bowel motion. Laxatives are essential if opioids are being used.

There are many drug combinations available if constipation troubles you. You should choose a drug that is well tolerated, with minimal side effects and one that promotes a regular bowel motion. For resistant stubborn constipation, enemas may be required. These vary in strength and mode of action. Take as much medication as required to achieve a bowel motion in consultation with your doctor. It is better to go twice a day than to miss two days without a bowel motion.

Constipation and morphine use

Constipation is very common if you are using morphine or another opioid. If you are using morphine, you will need to take regular medication for constipation. For constipation that is resistant to usual medication, you may find a new range of drugs, including Relistor (methylnaltrexone), useful. Ask your doctor about this option if constipation is an ongoing or severe problem.

If you are constipated, don't ignore the problem. Take action and prevent or treat your constipation before it prevents you from living your everyday life.

FATUGUE

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'.

Fatigue is very common in advanced illness. Often it goes unrecognised, leaving you feeling guilty or depressed when you can no longer keep up. These negative emotions can make things even worse. Fatigue is not laziness. Rather it can be defined as a subjective sensation of tiredness, weakness or lack of energy. This makes it clear that fatigue is a feeling. It is also unique to the individual.

The effects of fatigue can be devastating. It can make you feel simply too physically and emotionally exhausted to perform routine daily activities or spend time with friends and family. When time is precious and limited, not being able to do things is a cruel burden to carry.

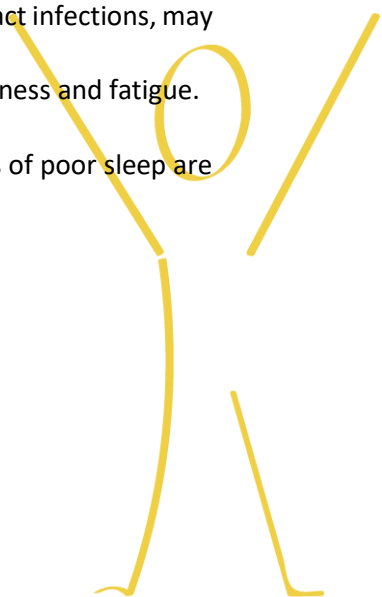
Rather than trying to deny fatigue or giving in to it altogether, find ways of managing it. Before you do, try to understand what may be causing your tiredness in the first place.

Causes of fatigue

Chronic illness such as cancer causes fatigue. This direct cause of fatigue is often progressive and irreversible unless the primary cause of the illness can be eliminated. There are, however, also often many reversible causes of fatigue that compound the problem, and if these are remedied, the impact of fatigue can be lessened.

Reversible causes of fatigue include:

- Drug treatments. Opioids are the most common cause of feeling fatigue but almost all drugs can contribute to feeling 'doped out'
- Anaemia is a common cause of fatigue in advanced illness and occurs when there are not enough red blood cells to adequately transport oxygen in the blood
- 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.
- Underactive thyroid gland
- Poor sleep due to any cause results in fatigue. The common causes of poor sleep are anxiety, pain or a poor sleeping environment
- Depression is a common and often undiagnosed cause of fatigue



Managing fatigue

Identifying reversible causes of fatigue is important. Blood tests will readily identify anaemia, underactive thyroid function, electrolyte disturbances or organ failure. Once identified, these can be corrected. A regular medical check may alert to drug causes of fatigue and it is important to regularly have medication reviewed. Getting it right can be a process of trial and error; often a corrected imbalance can recur and needs to be corrected quite regularly.

When fatigue is irreversible a different approach is needed. It starts with a reality check. This means taking stock of the situation and accepting you will feel fatigued as your body struggles against your illness. Once you have accepted fatigue as being the new normal for you, you'll waste less time and energy in trying to combat it.

Accepting that you will feel fatigued at times allows you to develop a different strategy. It allows you to shift your thinking: quality time becomes more important than quantity time. It is accepting that all things are not going to be possible. The question to now ask yourself is 'what is a priority and how much time can I dedicate to this priority?'

Consider these examples and suggestions:

- Rather than spend the whole day with visitors and friends, allow for defined five-minute visits and make these five minutes count. Trade quantity for quality time
- Schedule times of the day to do routine chores such as bathing, showering and eating. As far as possible, get someone to help you; this will make chores as short-lived as possible
- Accept that resting is good, and rest without guilt or condemnation
- Communicate honestly and openly; tell your loved ones how you feel and work out a plan of action that has everyone's agreement
- Don't feel pressured to change the plan even if Aunt Agatha has arrived from Timbuktu for a visit. Don't do more than is practically possible
- Review the plan because it will need to change as the illness progresses
- Where possible, try to get some exercise and set a realistic goal for each day. Try to stay with the plan, refining it as required. A two-minute walk is better than nothing!
- Sometimes short-acting medication such as dexamethasone or steroids may relieve the fatigue. Drugs such as methylphenidate may benefit some patients
- Discuss fatigue with your doctor, explaining how it affects your life

Remember that fatigue is a common symptom in advanced illness. Many things can cause it and how it makes you feel is unique to you. Accept what you cannot change and change what you can to make this symptom less distressing. You have to be cruel to be kind and a seemingly selfish act may be just what is required to spend quality time with yourself and with others.

CLOSING REMARKS

With increasing age or frailty or advancing illness, it should be no surprise that things can go wrong. Sometimes each thing that goes wrong may feel like the next failure, but it is not, it is simply a part of normal life. It would be unrealistic to expect to stay well forever and a new symptom should not be a battlefield.

I hope that offering some understanding about the changes in the body and the symptoms that can occur, may be empowering to patients and carers. This booklet in not intended to be an academic reference or medical textbook but a 'spare wheel' to get you to the next medical appointment.

We always appreciate feedback so please feel free to contact us at dyingtounderstand.com.