

Guidelines for managing pain and other distressing symptoms.

Introduction:

Pain is one of the most common symptoms that lead patients to seek medical help. Often the problem is straight forward, easily sorted out and quickly resolved. The patient is relieved and the doctor feels a sense of professional satisfaction.

At times, however, the problem is not so quickly resolved and a vicious cycle of ever changing prescriptions, confusing investigations, unpleasant procedures, mounting medical bills and fruitless referrals lead to increasing frustration and anxiety in both the patient and the doctor.

This guide will not solve all the dilemmas that face you. If it stimulates you to find new ways of dealing with these difficult situations without you or your patient developing a peptic ulcer then it has fulfilled its purpose. There are no "Magic Bullets" for Ms X's persistent headache, Mrs Y's recurrent abdominal pain and Mr Z's painful feet! But you don't need a Ph.D. to manage pain better and more safely than you do at present.

Getting started:

First ask yourself two questions:

1. What is my patient trying to tell me?
2. What am I actually trying to achieve?

Before you brush this aside as simplistic, think a bit further. If you cannot answer those two questions clearly and honestly, you are heading for a lifetime of endless frustration. You are not going to cure any pain that has been there for more than 6 months! Don't be flattered by the new patient who says, "I've heard such a lot about you, doctor, I'm sure you can help me." If, however, you have listened intelligently to your patient's story and have done an appropriate examination, you and your patient will be able to formulate a reasonable assessment of the problem(s) and a workable joint management plan. If you are not jumping up and down by now in disbelief and irritation, you haven't grasped what I'm trying to say! If you want a new lease on life rather than just another way of continuing to pull the wool over your own and your patients' eyes, then read on.

What is pain?

All of us know what pain is yet most of us find it difficult to describe. It is an unpleasant, often frightening sensation, which may indicate actual or potential tissue damage. Pain is always subjective and in that sense it is always 'all in the patient's mind.' That's what can make it so frustrating for the doctor. Do you really believe your patient? Yes, always! Pain is a signal not a destination. It's your job to find out the meaning of the signal and discover where it is pointing. Life without pain can be very dangerous, asks any person with leprosy. Your job is to make a reasonable assessment of the problem, explain this to your patient so that he/she can make a choice that takes into account all options especially with regard to the use of any medication. While your job is not to make your patient happy, part of your patient's problem may be emotional, social or spiritual difficulties. You yourself may not have all the answers but you can still help your patient make a good choice about how to find the right kind of help. That is your job.

Minding your P's and Q's.

A useful way to decipher pain is to use the sequence of letters, P,Q,R,S,T, where P stands for precipitating factors, Q is its quality, R is relieving factors, S is its site and T its relationship to time. But there is a lot more to consider before putting pen to prescription pad. Do you really understand this drug you are going to prescribe or were you just dazzled by the rep's earrings? How does it work, how long does it last and what are its side effects and safety? Does it clash with any of the drugs the patient is already taking? So before you finalise your choice, get out your copy of the South African Medicine Formulary and read the fine print.

Types of Pain.

Most pains can be grouped into one of 3 categories. **Acute pain**, this is the common type of pain we are all familiar with. It comes on after an injury, operation or is associated with an acute illness. Most acute pain should be better by 6-8 weeks. If not, you may need to reassess your diagnosis. The

management is usually straightforward. Treat the underlying condition and use simple analgesics and/or non-steroidal anti-inflammatory drugs (NSAIDs). Initially, analgesics should be given regularly to pre-empt the pain and later on a 'when necessary' basis. There is no evidence that combination tablets containing small doses of codeine and tranquilizers work better than simple analgesics. Avoid such fixed combinations.

Any pain not due to a malignancy and that has been present longer than 6 months should be regarded as a **chronic pain**. This needs an entirely different approach. You are not going to cure it with pills. Here it is essential to understand the effect the pain has had on your patient, the changes that have taken place in his/her life and the potential secondary gain that may be derived from the sick role. Management is usually a combination of explanation, exercise, improved communication skills, infiltration of trigger points and support often in the setting of a multi-professional team. The following table gives a comparison of acute and chronic pain.

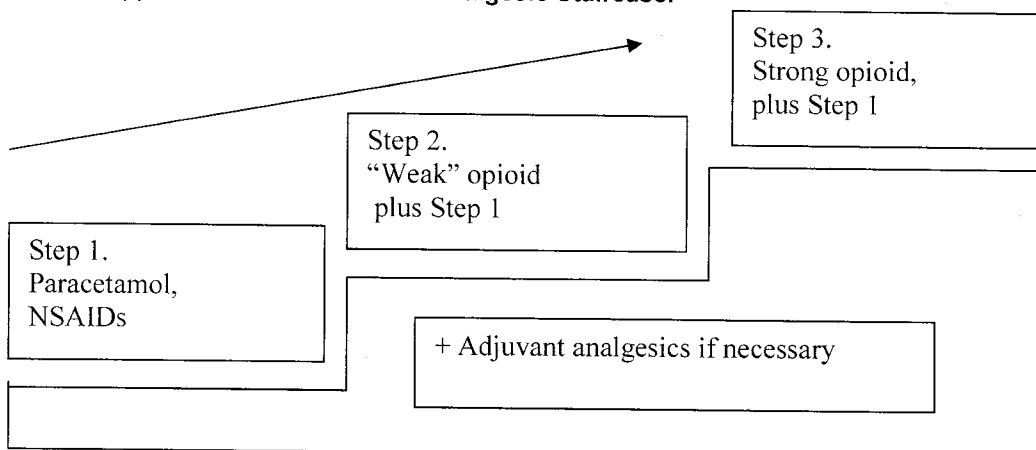
	Acute	Chronic
Onset	Well-defined, specific	Poorly defined, non-specific
Cause	Trauma or acute illness	Multi-factorial, uncertain
Duration	Days or weeks Limited and predictable	Months or years Unlimited, unpredictable
Mood	Initially anxious, more cheerful with time	Depressed or withdrawn
Appearance	Obviously in pain Sign of sympathetic over-activity	Not obviously in pain No sympathetic over-activity
Attitude	Pain has meaning	Pain does not have meaning
Behaviour	Initial inactivity, increasing activity with time. Returns to normal role	Gradually becomes less active May resist suggestion to change Role changes.
Treatment	Treatment of cause Temporary use of analgesics	Multidisciplinary, multi-modal, Group therapy helpful.

Re-look at our first two questions and see where your patient's pain fits. If necessary, get help from a colleague experienced in chronic pain management.

Malignant Pain

The pain associated with cancer needs an entirely different approach. While the situation may appear to be grim, there is much that you can do to help your dying patients to be comfortable and pain free.

1. Assess the cause of the pain. Is it due to the cancer itself, its treatment or the associated disability? Or is it due to some unrelated condition? Explain the reasons for each pain in an appropriate way to your patient.
2. Will further chemotherapy or radiotherapy help? Malignant pain is usually **persistent and progressive**. It requires a logical approach based on a clear understanding of the cause of the pain, the duration and strength of action of the drugs being used as well as their possible interactions and side effects.
3. A useful approach is to use the **WHO Analgesic Staircase**.



Step 1. Start with a simple analgesic such as paracetamol 1 Gm 4 hourly by mouth.
(Maximum 6 Gm/ 24 hrs)
Add or substitute a Non-Steroidal Anti-inflammatory Drug (NSAID) such as ibuprofen if there is pain from bone metastases.

Step 2. Add codeine 30-60 mg 4 hourly (1-2mg/kg/dose). Dihydro-codeine (DF118) and tramadol are also weak opioids (If these are not available, jump to Step 3)
NB: Give senakot 2-4 tablets at night and 30ml lactulose syrup in the morning to prevent constipation.

Step 3. Substitute oral morphine solution for codeine if the pain is not being controlled by Step 2.
Calculate the equivalent dose of morphine by dividing the dose of codeine by 10.
Increase the dose of morphine by 50% (rounded off to nearest 10mg) every third day.
Give an additional dose, equivalent to the 4 hourly dose, if necessary, for any **break-through pain**. By gradually increasing the dose you will be able to give as much morphine as your patient needs without any risk of doing your patient harm.
Respiratory depression, addiction and tolerance are not a problem in such a patient.

NB: Analgesics for malignant pain must be given **by the clock** and not just as required.
A convenient schedule for oral morphine solution is 06h00, 10h00, 14h00, 18h00, 22h00, 02h00.
Once the patient is stabilised on this, one can change to slow release morphine tablets.
To do this, calculate the total dose of the oral morphine, divide by 2 and give 12 hourly.

Parenteral morphine (by injection) is only needed at the very end when the patient is unable to swallow. It is then best administered sub-cutaneously by means of a syringe driver.

Difficult Pain Problems:

By applying these simple measures you should be able to manage >90% of your patients. Every now and then you will encounter a difficult problem. If the pain is described as 'burning' or 'shooting' it may be due to pressure on or damage to a nerve. Such pains are often opioid resistant. Steroids (Prednisone 15-30 mg daily) may give a dramatic though short lasting improvement in this **neuropathic pain** by reducing pressure on the nerve. A tricyclic antidepressant such as amitriptyline 50 mg at night or an anti-convulsant such as carbamazepine 400 – 800 mg 12 hourly are also useful if there is no response to steroids.

Management of other symptoms in advanced disease

Introduction:

It is not uncommon to come across a dying patient who has been told by a doctor, "I can do nothing more for you." This is sad as it never needs to be true. While we may not be able to cure, we can do a lot to relieve the distressing symptoms that accompany the process of dying.¹

In this section we will look at some of the more common symptoms that such patients experience and that illustrate the principles of good palliative care. It is, however, important to consult more detailed references for further information especially when dealing with the patients with very complicated problems. In palliative care, the dosage of certain drugs may differ from those recommended in the normal population. Ideally one should have access to a formulary specifically dealing with drugs used in palliative care.²

The management of any symptom in a dying patient must be aimed at improving comfort and not simply at sustaining life at all costs. No doctor has the right or the obligation to prolong dying! Even the process of investigating the patient's problem may be unacceptably burdensome. In such circumstances the doctor may need to act in the patient's best interest and treat the symptoms without discovering the definite cause.

Despite these limitations it is usually possible to come to a reasonable decision regarding the underlying cause of the troublesome symptom, based on a careful history, an appropriate and gentle

examination, a review of the illness and the current medications as well as an enquiry about the patient's own perception, concerns and expectations. The condition and the available options should be carefully explained to the patient and, where appropriate, the family as well. The difficulty of the situation needs to be acknowledged and the patient's preferences must be respected. By a gradual process of explanation and negotiation, it is usually possible for the doctor and the patient to reach a shared understanding of the problem with all its complexities and to jointly make the necessary management decisions. By regular review of the response to treatment and gradual adjustment of the medication, most patients can be made more comfortable.

The following topics will now be discussed:

- Nausea and vomiting
- Breathlessness
- Terminal restlessness.
- Emergency situations
- Dilemmas regarding food and fluids

1. Nausea and vomiting

Nausea and vomiting are common, occurring in about 50% of terminal patients. Although they may be more difficult to relieve than pain, most patients (>90%) can be made more comfortable.

There are 3 basic mechanisms leading to N&V:

1. Mechanical – gastric stasis, intestinal obstruction, excessive coughing
2. "Toxic" – drugs, radiotherapy, infection, renal failure, hypercalcaemia
3. Brain metastases & raised ICP

Management:

1. Try to identify the underlying cause so that the most appropriate solution may be chosen.
2. Correct any reversible factors – pain, anxiety, infection, cough, tense ascites, hypercalcaemia, dehydration, raised intra-cranial pressure, unnecessary drugs, inappropriate feeding and constipation.
3. Consider surgery for obstruction (seldom necessary or successful)
4. Start with an appropriate first line drug³:
 - Mechanical (except for complete intestinal obstruction) – metoclopramide 10 mg 6 hrly by mouth. This dose can be gradually increased up to 100mg/24 h and given by continuous subcutaneous infusion (CSI) using a syringe driver.
 - "Toxic" – haloperidol 1-5 mg daily by mouth in a single dose at night or by CSI over 24h.
 - Raised ICP & intestinal obstruction – cyclizine 50 mg 8 hrly by mouth, 100 mg rectally 8 hrly.
5. Consider second line drugs (choose a drug with a different mode of action):
 - Combine haloperidol with metaclopramide or cyclizine. This may be needed in about a third of cases.
 - NB: Don't combine metaclopramide and cyclizine as the prokinetic effect of the first is cancelled by the anticholinergic effect of the second.
 - Add prednisone 15-30 mg once daily. This is especially in cases of raised ICP but may also be beneficial "toxic" & mechanical causes.
 - 5HT₃-antagonist, such as ondansetron (Zofran) especially after chemo or radiotherapy, bowel distension or renal failure.
 - Add hyoscine butylbromide 60-120 mg/24 h in a syringe driver to reduce cramps and secretions in malignant intestinal obstruction.
6. Continuous nasogastric drainage is seldom necessary. Some colleagues are using intermittent nasogastric drainage under sedation using low doses of midazolam for unresponsive vomiting in terminal bowel obstruction.⁴
7. Consider continuous sedation for intractable and unbearable nausea & vomiting in a moribund patient.
8. Ask for help from a more experienced colleague.

Most patients can be made reasonably comfortable for most of the time using a combination of a continuous infusion of appropriate drugs, careful mouth care and frequent small sips of water. There is little if any place for the usual surgical approach of "Drip and Suck".

Example:

Mrs M is 55-yrs old and has been receiving chemotherapy for the past 8 years for metastatic breast cancer. Her condition has been slowly deteriorating and she has developed metastases in her ribs, liver, scalp and left humerus. She spends most of the day in bed and vomits frequently. She used to be an avid reader but find this difficult to do as she has a persisting headache and blurred vision. She has decided to stop further chemotherapy but would like to be made more comfortable. Consider the possible causes for her vomiting and suggest how you would manage this symptom.

2. Breathlessness

The Afrikaans word "benoud" which means a feeling of distress, anxiety and pending doom captures an important aspect of the symptom of breathlessness. The increasing awareness that one must breathe more is accompanied by the growing realisation that it is becoming more difficult to do so. The ensuing panic aggravates the situation as the distressed person breathes more rapidly and increasingly less effectively. The respiratory centre is bombarded with messages from receptors measuring the levels of oxygen and carbon dioxide as well as others measuring the expansion of the lung. Adding to the panic are the thoughts and fears of the dyspnoeic person.

Helping the distressed person to reinterpret these unpleasant symptoms will go a long way to relieving this distress.

Management⁵

1. Try to identify the underlying cause so that the most appropriate solution can be chosen.
2. Correct any reversible causes: infection, bronchospasm, anaemia, cardiac failure, pulmonary oedema, pleural effusions and anxiety.
3. Calm and reassure the person by explaining the reason for the distressed feeling. Encourage and coach slow breathing.
4. Open the window or put on a fan.
5. Oxygen is only helpful if there is severe hypoxia ($\text{SaO}_2 < 90\%$)
6. Distract by conversation or music.
7. Nebulise with saline/water.
8. If the person is still distressed, give Lorazepam 1 mg sublingually.
9. Give oral morphine, the equivalent of the 4 hrly dose plus 50%. This is usually very effective. It works by reducing the sensitivity of the respiratory centre to the bombardment, relieving anxiety and slowing down the respiratory rate.
10. Prednisone 30-60 mg once daily orally. This is especially useful in cases of superior vena cava syndrome and lymphangitis carcinomatosa.
11. In a situation where an imminently dying patient is severely distressed and where there has been little relief from all these measures, there may be a place for continuous sedation. In such cases one would use just enough sedation to keep the person calm.
12. Ask for help from a more experienced colleague.

How would you respond in the following situation?

Paul has advanced pleural mesothelioma and recurrent anaemia. A pleural effusion was recently drained. This relieved his breathlessness for a while. Today you check his lungs and they sound clear. As you are leaving his wife asks why Paul's feet and hands are puffy. "I get so frightened, doctor, when he is struggling to breathe. Will he drown in his own fluid?"

3. Terminal restlessness⁶

Dealing with terminal restlessness presents us with a number of challenges. The first is to recognise the problem, the second is to discover its cause and the third is to deal with the situation effectively, compassionately and ethically.

Recognising the problem:

While many dying patients slip peacefully into a coma, some may become unexpectedly restless, noisy and aggressive. This often happens at night and it is very disruptive for other patients, alarming for family members and may even be dangerous for the staff.

Look for the following features:

- Inattention
- Muddled thinking and incoherent speech
- Altered level of consciousness – drowsiness or over-vigilance
- Sudden onset and fluctuating course.

The presence of 2 or more of these features should alert you to the possibility that the patient is delirious. Between 60-80% of dying patients will become delirious.

Discovering the cause:

This is not just an academic exercise. In about a third of patients the cause is reversible. A useful mnemonic, DIMTOP may help to remember the causes of delirium.

D – Drugs (morphine, cortisone and many of the anti-emetics can cause delirium)

I - Infection (especially a severe UTI, pneumonia or meningitis)

M - Metabolic – Renal or hepatic failure, hypercalcaemia (especially with multiple myeloma, breast, lung and renal cancers).

T- Temperature/Fever

O – Oxygen (lack of)

P – Psychiatric illnesses, Pain or Poisons,

NB: Don't forget to check for urine retention and faecal impaction.

Management:

1. Stay calm and ensure everyone's safety.
2. Explain the situation, especially to the relatives. The patient is not "mad", the prognosis is poor and options are limited.
3. Use appropriate drugs in **effective doses**⁷.

Mild delirium without agitation			
Drug	Dose	Frequency	Comment
Haloperidol (Serenace)	0.5 - 2mg PO	Every hr p.r.n. x3 (Notify Dr if 3 doses not effective. This allows a review of the situation so that the dose can be adjusted if needed)	Usual effective dose is 0.5 -2mg/day Maintenance: Previous day's total used given as a single daily dose & the same p.r.n. dose for break though symptoms NB: Medication is not always needed but as agitation may occur unexpectedly in a new environment consider its use for a short period.
Delirium with mild agitation but no aggression:			
Drug	Dose	Frequency	Comment
Haloperidol (Serenace)	1-2 mg SC	Every 30 min p.r.n. x3 (Notify Dr if 3 doses not effective.)	Usual effective dose is 6-12mg/day Maximum 100mg/day Maintenance: Previous day's total used given as a single or divided dose plus the same p.r.n. dose for break though symptoms
Delirium with agitation, restlessness and aggression			
Drug	Dose	Frequency	Comment
Haloperidol (Serenace)	3-5mg SC, IM or IV	Every 30 min p.r.n. x3 (Notify Dr if 3 doses not effective.)	Up to 1200mg IV per day has been safely used. Occasionally prolongation of the Q-T interval may occur. An aggressive delirious patient may be dangerous and calming the patient must be an urgent priority for all staff. (See second line drugs)

NB: Benzodiazepines such as lorazepam (Ativan) or diazepam (Valium) should not be used alone as first line treatment for delirium as they may result in increasing confusion,

disinhibition and falls. They are however, useful when sedation is needed in patients with delirium due to alcohol withdrawal.

Alternative first line drug:

Drug	Dose	Frequency	Comment
Chlorpromazine (Largactil)	12.5 – 50 mg PO, IM or IV	Every 2-4 hours p.r.n. x3 (Notify Dr if 3 doses not effective.)	More sedating than haloperidol. May cause hypotension

Consider additional second-line treatment where sedation is needed

Drug	Dose	Frequency	Comment
Lorazepam (Ativan)	1-2 mg PO, SL, IV	Every hr p.r.n.x3 (Notify Dr if 3 doses not effective.)	
Midazolam (Dormicum)	3-5mg SC or IV		For rapid sedation
	1mg Continuous SC infusion	Per hour	Titrate the dose according to effect. Max 10mg/hour
Promethazine (Phenergan)	50 mg PO,IM, IV	8 hourly	Very sedating but helpful as an adjunct to other drugs.

5. Maintain sedation at an appropriate level.
6. Discuss the use of parenteral fluids with the staff & family. Artificial hydration is seldom necessary and may even aggravate the situation. In exceptional cases 1-1½ litre of fluids can be given by continuous subcutaneous infusion (hypodermoclysis).
7. Document your assessment and management.
8. Ask for help from a more experienced colleague if you are uncertain.

4. Emergencies

It is fortunate that in most cases the deterioration in terminal patients is predictable and devoid of "drama". Occasionally situations arise that require clear thinking and decisive action. The following 4 situations will illustrate some of the principles of managing such situations.

4a. Spinal cord compression⁸

This complication is important for the following reasons:-

- The early signs may be subtle – a feeling of heaviness, mild sphincter dysfunction or ataxia. Later the pain may suddenly become very severe and be aggravated by flexion of the neck, by coughing or by performing the valsalva manoeuvre.
- It may occur long before the terminal phase.
- If not treated early, the damage is irreversible.
- It occurs in 5% of advanced cancer patients, especially in multiple myeloma, lymphoma, ca breast, lung, prostate & when there is an unknown primary.

It should be suspected in any cancer patient who complains of backache or pain radiating down the leg or urinary incontinence.

Management:

- Immediate treatment consists of high dose steroids (Prednisone 45-60 mg daily) followed by radiotherapy and in some cases, spinal surgery.
- Contact your nearest oncology/radiotherapy department and arrange an emergency transfer.
- If available, an urgent MRI of the whole spine should be done as there may be multiple lesions in approximately 20% of cases.
- If the patient is already bedridden, in very poor condition (prognosis <1 month), there has been complete paralysis for >48 hours or the tumour is not

radiosensitive, conservative treatment may be a better option. This should be discussed with the patient and the relatives.

4b. Haemorrhage

A major haemorrhage is very alarming for all involved. It is fortunately very rare (we have only had 3 cases in the past 20 years at our hospice.) In the context of advanced disease, the appropriate response is not to panic but to make the patient comfortable and allow nature to take its course. Dim the lights if possible, camouflage the blood with dark towels and give IV midazolam to lessen the patient's sense of panic. Scrambling about trying to resuscitate a dying patient is futile and meddlesome.

Consider the following event recounted by Dr Des Swanevelder of Waikato Hospital, New Zealand on bulletinboard@palliativedrugs.com (14/04/2004):

Years ago I was asked to see a man with laryngeal cancer. While interviewing him in hospital, he started bleeding from his carotid. It was initially just an ooze from under a dressing on his neck but soon it started to gush. I applied some pressure which gave him enough time to communicate that he was aware that this was the end and asked me to sedate him before I let go. This was all written down by him of course. His pregnant wife was present and while I was applying pressure he "said" all his goodbyes, telling his wife how much he loved her, where the will was and what to name the baby. Although I heard all of this I was not part of it. When he was ready we gave him IV midazolam and the last thing he wrote down was that it was not as bad as it looked. We lead his wife out before we let go.

This experience was needless to say had a profound and long lasting effect on me. To witness such intimacy from people I had only met minutes before was a privilege. I felt that just being there and doing a simple thing of stemming the blood flow, allowing these two people the precious time to say goodbye to one another, was probably the best thing I could do.

4c. Convulsions

While an isolated convulsion may not even require any medication, recurrent or persisting fits do. There are, however, several interesting alternatives to the usual iv benzodiazepam. Rectal diazepam has been advocated for a long time. But it takes quite a while to be effective and may be difficult to administer in an adult.

An alternative is buccal midazolam (between the teeth and the cheek). It is rapidly absorbed and is very suitable for children or adults when the iv route is not easily available. Its bio-availability is 75% of the iv dose. (Midazolam can also be given intra-nasally using an atomiser. Half the dose is given into each nostril.) The usual dose is 10 mg in adults and 0.2-0.6 mg/kg in children. It is effective within 5 to 10 minutes and lasts up to an hour. Clonazepam drops (2.5 mg/ml = 0.1 mg/drop) can also be used but the onset of action may be a bit more delayed.

For more persistent fits, carbamazepine CR 200 - 400 mg 12 hourly per rectum.

"Twitching" or myoclonic jerking may also occur. In patients with poor renal function or severe dehydration, morphine metabolites may accumulate and cause neurotoxicity.⁹ Reduce or stop the morphine. A benzodiazepine may be added if the jerking is severe. If the patient begins to experience pain after stopping morphine, a fentanyl transdermal patch (Durogesic) can be applied.

4d. Airway obstruction

Like massive haemorrhage, complete airway obstruction is a frightening situation for all. Rapid sedation with iv midazolam is the most appropriate management. Struggling to resuscitate or doing nothing are both inappropriate options.

5. Dilemmas regarding food and fluids in dying patients¹⁰

As they approach death, many cancer patients are unwilling or unable to eat or drink much. Should they be left to eat only what they fancy or should they be encouraged to take more? If things really get

bad, should hydration and nutrition be maintained by artificial means? This is a highly complex and controversial topic.

Think of the following scenario:

A 32 year old woman is dying of advanced breast cancer. She has failed to respond to chemotherapy and all active anti-cancer treatment has been stopped. She is deeply jaundiced, confused, has grossly oedematous legs and a very swollen abdomen due to ascites. She is passing concentrated urine and has a dry mouth. Her medication includes a transdermal fentanyl patch and a mild sedative. She is taking small amounts of fluid and yoghurt by mouth. She has a 4 year old son and a very caring husband. What would you do?

Adding to the concerns of the doctor caring for such patients, is the uncertainty of the exact prognosis, how long will she still live? How should you manage the last days of her life? What is the expectation of her husband, her parents and the nursing staff? What do you do if everyone doesn't agree on what to do?

Most doctors feel the need to "do something." Doing "nothing" sounds like neglecting a person in need and yet there is also a nagging fear that one's overzealous efforts may actually be prolonging the suffering of a dying person. Most people have a fear of an impersonal death stripped of all dignity in a high-tech setting with tubes emerging from every orifice, monitors beeping and one's family restricted to visiting hours only. Does dying with one's electrolytes in perfect balance compensate for all that?

In dealing with the dying person, comfort must be the prime goal. The risks, benefits and burdens of any proposed action needs to be carefully weighed up before embarking on any course of action.¹⁰

Ethical issues:

Food and fluids are such basic necessities for life, such strong symbols of care and love, that many people and even some doctors would suggest that to deny them to a dying person is a form of neglect, euthanasia or worse still, even torture.¹¹ As one man said to me, "I don't mind my mother dying of cancer but I don't want her to starve to death."

While we all accept that death is inevitable, modern medicine has the skill and the facilities to delay its arrival. By means of central lines and hyperalimentation we are able to "feed" someone even if he/she is unable to take anything by mouth. Should such means be used to sustain the lives of dying cancer patients?

What if such heroic measures fail? If one starts along the route of active intervention, is it ethically justifiable to discontinue the IV infusion, remove the NG tube and turn off the ventilator?

Does an individual have the right to refuse such treatment? Should we be encouraging more patients to draw up an advanced directive (Living Will)? Should we be looking at providing a more humane alternative to the over medicalized nightmare described above? While there are no easy answers, I believe there are options which are ethically sound, medically appropriate and patient friendly.

The Process of Dying:

It may be helpful to briefly review the process of dying. Many cancer patients develop weight loss, lethargy, weakness and increasing immobility. Reduced food intake causes reduced gastric contractions and leads to reduced hypothalamic stimulation and anorexia. With the lack of glucose and protein from the diet, the body will turn to the metabolism of fat stores. The resulting raised level of ketones further suppresses hunger and thirst. The use of fat as the main energy source may lead to the sparing of muscle breakdown, greater endogenous water production and a reduced need for fluid intake. Diminished urea production means that less water needs to be excreted by the kidneys.

Eating actually reverses this metabolic process and may cause increased hunger, thirst and muscle breakdown. Some studies have even shown reduced survival in those on more aggressive nutritional support due the complications of therapy and possible enhanced tumour growth.

McCann and colleagues from Rochester University (NY) investigated the frequency of symptoms of hunger and thirst in dying patients and whether these could be relieved without the use of forced feeding or parenteral nutrition. They found that 63% never experienced any hunger, while another 34% only had mild symptoms initially. Similarly, 62% experienced no thirst despite grossly inadequate fluid intake. All of those who did experience thirst, could be made comfortable with sips of water, sucking crushed ice and lubrication of lips. Patients only ate when they felt like it. Those patients who ate more to please their families, experienced increasing abdominal discomfort and nausea.¹²

“Unwanted nutritional support and hydration through intravenous or enteral routes may not only be ineffective in reducing morbidity in advanced cancer, but may even be associated with an increase in medical complications and reduction in quality of life.”¹³

In a study looking specifically at dehydration and the dying patient, Ellershaw demonstrated that thirst and a dry mouth were not proportional to the degree of dehydration but were often due to local causes or prescribed drugs. In such cases artificial hydration would be futile.¹⁴ The National Council for Hospice and Specialist Palliative Care Services of Britain in a policy document concluded that as artificial hydration neither improves survival nor symptom control, it may even constitute an unnecessary intrusion.¹⁵

Dying is seldom easy. It evokes strong feelings and sometimes very negative emotions. As death approaches, patients often withdraw and may seem depressed. Many terminal patients become delirious. Surely this is due to dehydration? Surely IV fluids would correct this? The available evidence, however, does not support this approach.^{16,17} Apart from occasional nausea, the gradually developing dehydration of the dying cancer patient appears to be remarkably asymptomatic. In addition there are several disadvantages of parenteral hydration. Increased urine output may result in incontinence or the need for an indwelling catheter. IV canulas are uncomfortable and can cause infection. The drip impedes mobility and creates a barrier to the family and makes nursing more difficult. It may also create the wrong impression about the patient's chances of recovery. Care gets focused on the drip rather than on the patient. Increased respiratory secretions may cause a troublesome 'death rattle'. Fluid overload may precipitate pulmonary oedema.

Conclusion:

Let us briefly return to our patient. She was cared for at home. Her general condition gradually deteriorated. With the reduced intake of fluid, her oedema and ascites subsided substantially, and she did not require a catheter. Careful mouth care and spraying regularly with water kept her oral mucosa moist and comfortable. She died peacefully at home without the need for a drip or artificial feeding.

I believe a strong case can be made out for a radical rethink of the approach to the use of fluids and food in the dying patient in hospital.

NB: “A doctor has neither a duty nor the right to prescribe a lingering death.”¹⁸

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For advice:

Contact your local Hospice.

<http://www.hospicepalliativecaresa.co.za/>

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