

PALLIATIVE CARE NOTES

A FEW POINTS TO REMEMBER WHEN CARING FOR DYING PATIENTS

- When a patient is dying, their hearing is the last sense to go – be aware that they will hear everything you say. Let their families know this and encourage them to talk to their loved one, as even when a patient is unconscious or not responding, there are opportunities to say what needs to be said, including goodbyes.
- Some relatives enjoy being involved in caring for their loved one – and may appreciate it if you ask if they would like to participate in mouth care or simple hygiene tasks.
- Everyone's contribution to the care of a dying patient counts – no one is more or less important. This includes managers, nursing staff, office staff, PMA's and carers, family members and domestic and kitchen staff.
- Families of dying patients often experience feelings of separation and loss, anger and anguish, apprehension and fear, and remorse and guilt. It is necessary to acknowledge what they are going through.
- Staff have their own strengths and weaknesses, and it is the same with families. Do not judge anyone's actions and perceived feelings– for example, with families, some will want to stay with their loved ones, whereas others find it impossible to sit and watch someone they love die. The same can be said about staff – some are more able to care for the dying than others.
- When a patient has started to deteriorate families may not always recognise the significance of changes, so it is important to alert them to this.

'An awareness of our own attitudes to death and bereavement, acceptance of our vulnerability and need for personal support will help us to approach dying patients and their relatives in a spirit of willingness to listen, to offer support when we can, and to admit that we don't have all the answers to their problems' (Lugton, 1987)



Standard 5 – The primary caregiver(s) is provided with information, support and guidance about their role(s) according to their needs and wishes

Standard 6 – The unique needs of dying patients are considered, their comfort maximized and their dignity preserved

PALLIATIVE CARE NOTES

A FEW POINTS TO REMEMBER WHEN CARING FOR DYING PATIENTS PART TWO RECOGNISING CHANGES

When a patient has started to deteriorate families may not always recognise the significance of changes, so it is important to alert them to what these are.

SIGNS THAT ARE COMMONLY SEEN IN THE LAST 2 – 5 DAYS OF LIFE

- More rapid deterioration, often day-by-day
- Increasing weakness, bed-bound and requiring help with personal care
- Barely able to take even liquids and unable to take medicines by mouth
- Impaired concentration, possible muddled thinking, and difficulty sustaining even the briefest conversation
- Increasing drowsiness

Recognising when the death of a resident of an aged care facility without cancer is imminent is more difficult to determine and staff and families need to be aware that death may occur more quickly than expected. However, immediately before death (within hours to days) several of the following symptoms and signs may be present.

- Peripheral shutdown and cyanosis – causing a mottled, bluish tinge to the skin which can be cold to touch. This doesn't mean the patient is cold or needs extra blankets. It is a normal process.
- Changes in respiratory patterns – this may be slowing down, or even going a lot faster. There could be long gaps between breaths.
- Drowsiness or reduced cognition – sleeping more than usual, and not able to be woken as easily. Less aware of what is happening.
- Uncharacteristic or recent restlessness and agitation
- Retained upper airways secretions – breath sounding a bit 'rattly' or 'gurgling'
- Cardiac – hypotension, tachycardia – generally less well with low blood pressure and fast pulse.



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PALLIATIVE CARE NOTES

A FEW POINTS TO REMEMBER WHEN CARING FOR DYING PATIENTS LOOKING AFTER YOURSELF

Ten commandments for reduced stress

THOU SHALT LEARN TO SAY NO
THOU SHALT NOT EVEN FEEL GUILTY
THOU SHALT NOT BE PERFECT OR TRY TO BE
THOU SHALT NOT SPREAD THYSELF TOO THIN
THOU SHALT SWITCH OFF AND DO NOTHING REGULARLY
THOU SHALL NOT TRY TO BE ALL THINGS TO ALL PEOPLE
THOU SHALT LEAVE THINGS UNDONE THAT OUGHT TO BE DONE
THOU SHALT BE BORING, UNTIDY, INELEGANT AND UNATTRACTIVE
AT TIMES
THOU SHALT SCHEDULE TIME FOR THYSELF AND FOR THY
SUPPORTIVE NETWORK
ESPECIALLY THOU SHALT NOT BE THINE OWN WORST ENEMY, BUT
BE THINE OWN BEST FRIEND

Support Strategies

- Remind yourself you are human, and do not have to know what to do all the time
- Ask for help when you need it. This is a sign of wisdom rather than failure.
- Allow yourself to make mistakes and still feel okay as a person
- Value the relationships you have, saying the things that are important to say
- Have conversations about issues other than work
- Look for opportunities for personal development
- Have regular staff meetings – debriefing or otherwise
- Let off steam emotionally and physically on a regular basis
- Become familiar with your own signs of stress and develop ways to deal with them
- Surround yourself with growing things, with life, colour and creativity
- And most importantly –

GIVE YOUR SENSE OF HUMOUR A REGULAR AIRING!!



National Palliative Care Standards



Standards for Providing
Quality Palliative Care
for all Australians

Standard 13 – Staff and Volunteers reflect on practice and initiate and maintain effective selfcare strategies

PALLIATIVE CARE NOTES

A FEW POINTS TO REMEMBER WHEN CARING FOR DYING PATIENTS GRIEF AND BEREAVEMENT

*When my father died
I never cried
When my plant looked sad
I thought – I know,
I'll ask my Dad
And then I cried (Anonymous)*

Following the death of a loved one, time and support are needed to work through feelings and thoughts, and to adjust to life without the person who has died. Whilst this is certainly true of family and friends, staff and other patients/ residents often share some of the same feelings of loss and grief, especially if that person has been known to them for a long time.

During grief people can experience some or all of the following, all of which are manifestations of normal grief:

- Shock – present in normal grieving but especially with a sudden death
- Numbness – often in early grieving. Probably occurs because of a number of overwhelming feelings
- Relief – particularly after a long or painful illness
- Anger – may be due to the feeling that nothing could be done, or because the person has gone away
- Helplessness – related to anxiety, often early on in the loss
- Anxiety – can range from feeling insecure to panic attacks
- Guilt – either over something that happened or was neglected. Takes time to realise that this is irrational
- Sadness – most common feeling – not necessarily shown by crying
- Yearning – a normal response that may diminish in time
- Loneliness – frequently expressed by those who have lost a partner and were used to a close relationship
- Fatigue – a measure of mood disturbance. May be experienced as apathy or listlessness
- Emancipation – a positive feeling. A normal response to changed status

Access to bereavement support is available for families and friends, and information is available in folders that can be given out.



Standard 8 – Formal mechanisms are in place to ensure that the patient, their care-giver/s and family have access to bereavement care, information and support services.

PALLIATIVE CARE NOTES

A FEW POINTS TO REMEMBER WHEN CARING FOR DYING PATIENTS PRACTICAL NURSING CARE

MOUTHCARE

- Glycerin/ lemon mouth swabs are not recommended, the glycerin dries the mucosa and the lemon stings. Instead use regular sod. bicarb mouthwashes (teaspoon per cup) every few hours to clean dead cells from the mouth. Follow with water (such as on a sponge swab) to refresh the mouth as sod bic leaves a nasty taste
- Use Orobase – helpful when mouth breathing
- Use lanolin by all means but sparingly!

TURNING

- If a patient is bed-bound and on a 'special' mattress they may not need turning very often (some turning is needed as the joints can become stiff and painful)
- Otherwise moving the patient about every 4 hours is usual.

SUCTION

- Oro-pharyngeal suction is not encouraged particularly, as it can be traumatic and distressing.

GENERAL CARE & HYGIENE

- Dermalux washes are particularly appreciated by patients who are bedbound.
- It is always good to remember that someone's physical appearance is still important, and perhaps even more so now – families will always remember the last few days in particular. The emphasis is on good general hygiene e.g:
- Shaving patients daily (female patients as well perhaps?)
- Attending to toenails and fingernails
- Facewashing, including eye toiles

BOWEL CARE

- Patients need to continue to have their bowels opened even when they are no longer eating. Constipation can be a huge source of discomfort and will make even an unconscious patient restless.
- It is recommended that suppositories are still given if they have a full rectum and they are uncomfortable. It is not advisable within the last 1 or 2 days however.



Standard 3 – Ongoing and comprehensive assessment and care planning are undertaken to meet the needs of and wishes of the patient, their caregiver(s) and family.

Standard 4 – Care is co-ordinated to minimize the burden on patients, their caregiver(s) and family.

Standard 6 – The unique needs of dying patients are considered, their comfort maximized and their dignity preserved

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The principles of using breakthrough medication in Palliative Care

- Many people with pain experience intermittent flares of pain that can occur even though they are taking analgesic medications regularly for pain control. This pain is called 'breakthrough pain' because the pain "breaks through" the regular pain medication.
 - ⇒ While breakthrough pain flares may vary in length, intensity, or cause, the typical episode reaches peak intensity in as little as 3 minutes and lasts an average of 30 minutes
 - ⇒ Breakthrough pain episodes are often unpredictable, brought on by something as simple as swallowing or coughing, or when carrying out a specific activity like walking
 - ⇒ People may also experience breakthrough pain as they reach the end of their dose of persistent pain medication
- Breakthrough pain is different from persistent pain and requires different treatment. Breakthrough pain treatment is prescribed in addition to long-acting medication (usually an opioid) taken around-the-clock to maintain control over persistent pain.
- The ideal treatment for breakthrough pain is a short-acting opioid that works quickly but stays in the system for a shorter time and therefore cause fewer side effects.
- Breakthrough pain medication is taken on a prn basis as soon as symptoms are experienced (prn is as required, not prn 2hourly or prn 4 hourly)
- Whenever possible the breakthrough dose should be the same short –acting opioid as the patient is taking regularly for baseline pain. Using the same drug makes it easier to identify the source of any potential side effect.
- Without treatment, breakthrough pain can harm a person's sense of well-being, interfere with daily activities, interrupt disease-related treatment schedules, and even make it more difficult to treat persistent pain
- Breakthrough medication, prescribed on a p.r.n basis, is typically 1/6th of the total 24hour dose. Therefore:
 - ⇒ For a patient on MS Contin 60mg bd the breakthrough dose is 20mg of immediate release morphine prn.
 - ⇒ For a patient on a syringe driver with 90mg of s/c morphine over 24hours, the breakthrough is 15mg s/c prn
- A point to remember when increasing a regular dose of a long- acting opioid, is to increase the breakthrough dose correspondingly!



National Palliative Care Standards



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Standard 11 - the Service is committed to quality improvement and research in clinical and management practices