

section 4.2.5: home for end of life care

specific considerations for the patient and family

Only a small percentage of patients die at home even though many prefer to do so.¹ There are a range of advantages when compared with death in a hospital, including of a sense of normality, choice and perceived comfort and dignity.² The choice for place of death often alters as the demands on the caregiver, the availability of respite options and the symptoms and needs of the patient increase.

Despite the challenges of accessing equipment, resources and medications, coordinating services, and providing education and experience in personal care to family, in what may be an extremely limited window of opportunity, every effort to accommodate a patient's expressed preference to die at home will be made.

Planning is likely to involve staff from a range of disciplines and community support agencies making coordination a priority. A flexible approach is crucial as the patient's condition may change dramatically and rapidly, either prior to discharge home or immediately after arrival at home. Counselling family about the possibility of change is essential – this helps in preparing them for all possibilities, including an understanding that despite all efforts, discharge may not be possible and home care may not be sustainable.

essential components of care planning

In addition to the requirements specified in Section 4.2.1 – *Discharge to home in metropolitan Adelaide*, the following aspects of care must be considered:

Discussion with patient and family/caregivers

- frank, open discussion with the patient, family and caregivers, treating medical consultant and the specialist palliative care team is essential
- contingency plans for an alternative site of care are necessary should terminal care at home no longer be possible

Provision of hands-on care

- identify a caregiver/s who is available, willing and able to provide 24 hour care
- explore respite options
 - within the family and their informal network
 - in the formal network of hospital avoidance schemes or home nursing funded by private medical insurers

Coordination of home-based care

- input from many staff and a range of agencies is frequently required to support patients in the terminal phase at home
- input and coordination of resources by the specialist palliative care team staff may provide valuable assistance
- the treating medical team should contact the patient's General Practitioner to provide a summary of the patient's current status, recent treatment and decisions made, likely symptoms or complications on discharge and the plan of care to be put in place at home
- request that the family arrange a GP home visit prior to discharge from the acute care facility

Equipment

- what is essential and is it available?
- many patients will require a hospital bed and pressure relieving mattress to be provided
- is access to suction apparatus required?

Transfer

- will transfer via SA Ambulance be required?
- does the patient have ambulance cover?
- is access to the home for ambulance officers made more difficult by a steep driveway or an upstairs residence?

Clarify personal care requirements with caregivers

- in this phase particular attention to mouth care, pressure area care and continence management will be the priority – education for family and caregiver/s will need to focus on these areas
- details of personal care are included in Section 2.8 – *Care of the imminently dying person* and Section 4.3 – *Including caregivers in discharge planning*

Medication regimen

- discharge medications need to be ordered with consideration for predictable but new symptoms arising in the terminal phase, and availability on the PBS in the community
- does the patient use and need oxygen – will it be required on discharge? if required, then a prescription from the respiratory physician or the palliative care physician will be necessary and liaison with the respiratory nurse to make the necessary arrangements. See Section 5.1.1 – *Accessing resources for care – community based resources*. In some instances oxygen supply may be negotiated with the local specialist palliative care team, but access varies significantly across the metropolitan region.
- the possibility that oral medications may not be tolerated or able to be given will need to be considered by prescribing medical staff:
 - ask: “is the medication necessary for this particular patient and in the context of their disease? can the drug be ceased without adverse effects? is it necessary for the patient’s comfort?” to guide management
 - if a particular medication is necessary, is there a parenteral option available or will drug substitution be required? ease of management, availability of the drug and known safety of the route will determine whether subcutaneous, sublingual, transdermal, rectal or intravenous (if an intravenous line is in place) routes can be used
 - contact the clinical pharmacist for assistance in determining routes of administration
 - contact the specialist palliative care medical staff if advice regarding symptom management is required
- management of specific symptoms, including use of pharmacological means is dealt with in *Therapeutic Guidelines – Palliative Care, Version 2*³

Planning for likely symptoms

Symptoms arising may be caused by the particular disease itself or from the physical effects of the terminal stage of disease. Planning will need to take effects of both processes into account.

In addition to the patient’s current medication regimen it is suggested that terminally ill patients be sent home with a “back up” supply of medications (plus written authority for community nurses to administer) for potential symptoms such as:

- terminal restlessness
- terminal secretions
- changing or potential for newly developed analgesia requirements.

If the patient is currently on long acting per oral opioid, consider providing a back up supply of opioid using alternative routes eg subcutaneous, plus written nursing orders for either regular 4-hourly administration or for a continuous infusion via a Graseby syringe driver plus an as necessary analgesia order.

Even if patient has no current/infrequent analgesia requirements, then still consider supply of as necessary subcutaneous analgesia and the potential for newly developed antiemetic requirements due to nausea.

If a continuous infusion is going to be required at home check the hospital's procedure manual for details and contact the local palliative care service to assist with providing the Graseby syringe driver.

Timing of setup may need to be coordinated with the community nursing services schedule.

For advice on sending patients home with subcutaneous medication requirements, see Section 4.5 *Medications in the Community*

Caregiver contact procedures

Ensure that the caregivers have contact numbers for primary healthcare providers and encourage them to contact them in the following order:

1. local General Practitioner and/or locum service
2. relevant home nursing agency involved, eg RDNS who provide a 24 hour contact number for clinical support, advice, and capacity to negotiate a home assessment, depending on staff availability
3. local specialist palliative care service – see Section 5.1.1/ 5.1.2 – *Accessing resources for care*

Funeral arrangements

- family and caregivers will need to consider which funeral director they would like to engage
- exploring arrangements prior to death can avoid the necessity to do this during what can be an emotional and stressful time following death and this may also reduce anxiety for family knowing that they have attended to these details
- note that some patients also wish to be involved in this planning

Procedure following death

Ensure that the family is aware of the process when an individual dies in an expected manner. The family/caregiver needs to contact:

- the community nursing team, who can provide assistance with washing and caring for the body and support for family
- the General Practitioner or locum doctor to pronounce death
- the funeral director, to arrange collection of the patient's body plus attend to other practical issues regarding the funeral

Given that this is an **expected** death at home, and is not less than 24 hours after discharge from a hospital or emergency department, the family do not need to contact the ambulance service or the police after the person has died.

Should there be caregivers or family members who are identified as at risk of complicated grief (see Section 7.2 – *General guidelines for dealing with bereaved people*) then a referral to the closest specialist palliative care service can be made.

Deaths, which must be reported to the coroner

- if the **death has occurred in within 24 hours of discharge** from hospital or having received medical assessment at an emergency department (even in the case of expected deaths) – the police will normally attend to this
- preparing the family in advance that the police may attend their home in the event that the person has died within 24 hours of discharge from hospital may reduce anxiety and distress – the family must also be advised that the person's body will become the responsibility of the coroner and may be transported to the city mortuary

references

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- ¹ Hunt R, Fazekas B, Luke C, Roder D (2001) Where patients with cancer die in South Australia, 1990- 1999: a population based review. *Med J Aust* 175: 526- 529.
 - ² Hudson P (2003) Home-based support for palliative care families; challenges and recommendations;179 (6 Suppl) S35-S37
 - ³ Therapeutic Guidelines-Palliative Care Version 2 (2005), Therapeutic Guidelines Ltd, Victoria, Australia.