

## Helping Patients and Families Plan for an Expected Home Death: The GP's Checklist

The GP has a critical role in end of life care for patients who wish to die at home. This checklist is designed to guide the GP through decision-making about care, to help them support the patient and family, and to identify the need for appropriate supports early. It flags issues which may need to be addressed ahead of time.

GPs managing patients dying at home usually share care with other services, including palliative care and home nursing. This checklist can act as a planning tool for shared care, and a trigger to help clarify how care will be organised between those involved.

Patient name/ID: \_\_\_\_\_ Date: \_\_\_\_\_

### 1 Clarify expectations and support

Has the patient indicated they want to die at home?

Actions needed: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Do those who live with the patient know about and share that wish?

- Has the plan been discussed within the family?
- Consider – young children, others with care needs in the household

Actions needed: \_\_\_\_\_  
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Are there enough people to share the care?

- Consider practical, hands-on availability for round the clock care. Suggest a roster to support carer and provide time out.
- Consider specific services that can support families caring for someone who is dying at home, e.g. night nursing services or volunteers – the local palliative care service can advise.

Actions needed: \_\_\_\_\_  
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- Review the patient's prognosis, in order to help the family plan ahead. E.g. is care likely to be needed for days, weeks, or months?

Actions needed: \_\_\_\_\_

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- Is there a back-up plan if either the patient or the family find it difficult?

- Clarify and document a plan and ensure that it is realistic, and understood by all involved.
- Where appropriate, provide a letter (or Ambulance Plan) describing the palliative goals of care in case of a triple zero call, clearly state that the patient is dying and cardiopulmonary resuscitation is not appropriate, where agreed.

Actions needed: \_\_\_\_\_

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## 2 Assess the home situation

- Will the patient be able to be cared for safely and comfortably in the home?

- Refer to home nursing services, and ask them to teach the family about how to provide care safely (transferring and moving the person, eating and drinking, giving medicines). How much nursing support is available? Specifically, how many visits can the patient have?
- Are there complex nursing needs that will be difficult to manage at home e.g. difficult wounds, fistulas, spinal analgesia?
- Consider equipment for nursing a bed-bound patient. They will need a hospital bed, mobility aids, commodes and personal care equipment, wheelchair, pressure mattresses, etc. Consider a palliative care referral for OT and/or physiotherapy assessment to advise on and organise equipment.
- Discuss the option of an in-dwelling catheter to reduce the care burden for a bedbound patient.
- Encourage the family to think about practical arrangements to make caring easier or safer – e.g. moving a patient's bed to a different room, or patient moving in with a family member (remember though that moving to a different address can disrupt eligibility for services – so do this early if possible.)

Actions needed: \_\_\_\_\_

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### 3 Plan for symptom management

Review long-term medications – cease any that no longer contribute to patient’s comfort.

Actions needed: \_\_\_\_\_

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Discuss with the family how the patient’s symptoms will be reviewed and managed, e.g.:

- How often GP visits will occur
- What the home nurses will do
- What the palliative care service will do
- Arrangements to provide prescriptions

Actions needed: \_\_\_\_\_

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Plan for predictable, common symptoms that occur at the end of life:

- Dyspnoea / terminal secretions
- Delirium
- Pain
- Nausea

Actions needed: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Ensure emergency medications are available in the house for when they are needed. This is best done well in advance as deterioration can be unpredictable.

- Remember – dying patients cannot take oral medications
- Subcutaneous medications are preferred to ensure continuing symptom control, with bolus medications via sc butterfly needle, and/or a syringe driver with a 24 hour infusion
- Family members should be taught how to give breakthrough doses by palliative or home nurses
- Check that medications are available at a community pharmacy, and that the caregivers have an adequate supply to get through after hours and weekends in particular

Actions needed: \_\_\_\_\_

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- Consider whether a plan is needed for high risk problems such as major bleed, airway or bowel obstruction.
- If care needs are complex, or a high risk problem exists, seek early advice from a palliative care specialist.

Actions needed: \_\_\_\_\_  
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#### 4 Information that families need

- Are the carers fully prepared for the fact that the dying person will be dependent and bedbound?

Actions needed: \_\_\_\_\_  
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- Do the carers need information about eating and drinking in the palliative care situation, for instance:
- That loss of appetite is a common and predictable feature of advanced disease?
  - That swallowing deteriorates with the approach of the terminal phase?
  - Do they need ideas about what , and how much, to offer the patient to eat and drink, and how to do this safely?

Actions needed: \_\_\_\_\_  
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- Do the carers need information about physical changes that occur as a person is dying, including:
- Changes in breathing patterns, including the possibility of terminal secretions (“death rattle”)
  - Changes in skin colour and temperature
  - Changes in level of consciousness, including the possibility of terminal delirium

Actions needed: \_\_\_\_\_  
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- Ensure that the family has access to twenty four hour phone advice about symptoms or changes in the patient's condition, which everyone providing care knows how to contact.

Actions needed: \_\_\_\_\_  
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- Do the caregivers need information about what to do after the patient dies? E.g.
- Encourage them to think about choosing a funeral director
  - Reassure them that there is no urgency to ring anyone straight away after the patient dies
  - Ensure that they know which doctor has agreed to certify death, and the arrangements for contacting them.

Actions needed: \_\_\_\_\_  
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\_\_\_\_\_

Facility name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

For more information visit CareSearch GP Hub [www.caresearch.com.au](http://www.caresearch.com.au)  
There are family resources you can order and give to patients and carers.