



Home Care for The Dying Patient Reflections from Hospice Klang

<https://www.hospiceklang.org>

Choosing to Go Home?



Home can be either the very best or the very worst place to die

- Patients wish to spend time at home to settle affairs and have the family together but often these wishes are not met for many reasons
- Some of these factors are due to misconceptions and under preparedness about home care on the part of doctors, providers, or families themselves

Critical Issues For Home Care



Deciding when and where

Place of care

Place of death



Managing home care

Symptom control

Team and family communication

Caregiver burden

Handling Visitors



Managing the terminal phase



After a home death

Choosing home care- Advantages



- Advantages of home care include:
 - Feeling secure
 - Flexible routines
 - Reduced medical intervention
 - The patient remains part of the family
 - Control (professionals become the visitors)
- Even if a patient lives alone, it is still possible to offer home care if neighbors, friends and community volunteers can agree to a roster of daily responsibilities.
 - However, it is best for one person (a neighbor or friend) to assume primary responsibility for liaison with the home care team, and for scheduling.

Choosing Home care – Disadvantage



- At the same time, there are disadvantages to home care
 - Isolation
 - In extreme cases, patients may suffer from neglect
 - Even in the best cases, family and caregivers may be unavoidably absent for long periods during the day, leaving patients without supervision or interaction
 - Poor control of difficult symptoms
 - Lack of training or support for caregiver
 - Becoming a burden to their family
 - Relatives not spared death's last moments

Making the right choice for care



- The *prime* factor is the patients wish
 - It is important to listen carefully to the patient
- However, it is not the *only* factor
 - need for expert care
 - Practical issues such as coordinating professional and volunteer support
 - Attitudes and availability family members



Choosing the place of death

Death is a social event, not a medical event.

- Professional carers need to ask gently and at the right time - “If the time comes for you to die, where would you like to be?” eg through discussion about a living will.
- Dying at home is usually straightforward - with preparation
 - As the disease advances, many families are unsure of whether they can continue to cope, but appropriate encouragement and support may enable them to do so.
 - At the same time, changes in plans should be anticipated and facilitated

Symptom control at home



- Excellent symptom control is almost always possible in the home, given **willing carers** and a **competent team**.
- it is sometimes assumed that some treatments are not suitable for home care, but we need to question whether these beliefs are related to tradition or to practicality.
***There is no justification for sending patients to the hospital for simple procedures like insertion of a urinary catheter**
- A common & difficult condition to manage at home is **confusion**
Other difficult problems e severe diarrhea, heavy bleeding or seizures, intestinal obstruction or terminal dehydration can still be managed medically in the home

Preparing the space



- The ideal sick room is light and airy with the following
 - A comfortable bed, a high armchair, a pleasant view, a convenient telephone, remote-control TV and bathroom.
 - A V-shaped pillow and a light, colorful quilt
 - In hot weather, air-conditioning (or at least an electric fan)
- Home care can be made considerably easier by the use of simple aids and appliances as advised by the care team
 - Rental is usually preferred to purchase while some hospices and home health organizations maintain an “equipment closet” for free borrowing
- **Complicated (and often expensive) medical equipment requiring frequent professional interventions should be avoided.**

Most important of all, the sick room should be one in which the patient feels at ease, and which is not isolated from the rest of the house.

Preparing the family



- Home care providers' support and experience is critical to enable the patient and family to plan ahead for foreseeable events and changes at every stage as well as contingencies
- A well-prepared family will have fully discussed their worries and concerns about care and management
- Providers should anticipate that families may react badly or be unduly stressed by the reality of progression or death, especially if accompanied by common yet disturbing signs e.g. vomiting, difficulty breathing
- Advance preparation may help the family remain as calm and peaceful as possible

Checklist:

A prepared family should be able to answer these questions well in advance

- What will happen at each stage?
- Will we cope?
- What about the children?
- How will we know he's dead?
- Whom do we contact if we need to?
- What do we have to do afterwards?

Care team communication



Good communication between the home care team and family members (to explain and reassure) provides the enabling foundation for home care, and includes the following five elements

Inclusive

- Family members should feel like part of the caring team

Reliable

- Failure to keep their promises to patient and family (about the date and time of the next visit, for example), or to respond promptly and courteously to telephone calls, destroys trust.

Timely

- Home care can break down if simple reassurance is lacking at a critical moment

Coordinated

- Conflicting advice (especially about prescribing) destroys trust.

Anticipatory

- The experience and training of the home care team is the key resource for families to help anticipate problems

A simple comment from a member of the home care team (“We think with our help you will manage very well.”) can give a family enough confidence to continue

Managing caregivers



Carers are often (implicitly or explicitly) expected to cope with complicated problems, such as:

- Giving medications
- Monitoring symptoms
- Nursing tasks
- Learning new skills (such as lifting and moving the patient)
- Living on a reduced income
- Adapting the home
- Adopting new roles (highly stressful)
- Emotional pressures
- Explaining to others
- Allowing anticipatory grieving

- It is essential for families to organize their own schedule of caregiving, recognizing the needs of caregivers
 - Physical exhaustion is common and also leaves less energy for emotional problems
 - Family carers suffer from emotional exhaustion (“burn out”) as well as professionals.
- Carers need to rest, and to leave the house from time to time.
 - Hospice day care and brief inpatient respite care can be important resources

“Nobody ever asks how I am. I could scream every time the phone rings!”

As death approaches...



Patient comfort and management

- Maintain analgesia
- A subcutaneous infusion can very useful (e.g scopolamine to dry up secretions and control bubbling)
- Indwelling urinary catheter or urinary condom may be needed
- Advise family members not to dial 911 as death nears, to preclude unnecessary resuscitation efforts or ambulance transportation to the hospital emergency ward

Family preparation

- Rehearse emotions and procedures.
- Teach the family to recognize the signs of death, while explaining that even nurses and doctors are not always sure of the moment death occurs.
- Explain that the body need not be removed immediately
- Certification of death is not always necessary in Malaysia

- Key points for ensuring continuous support and communication
 - Scheduling caregiving continues to be important, as an expected 24-hour vigil can turn into a long week of waiting.
 - 24-hour telephone contact to the home care team is very important, and rarely abused.

After a home death



- A death at home can be a sad but profoundly moving experience which paves the way to eventual healing and growth for the family
- Families often have a sense of achievement. (“We are so glad we were able to keep him at home.”)
- This is usually a comfort in their grief, and facilitates the normal grieving process

“I was dreading this last part, but every day has been a memory to treasure.

- Mrs. G.T. (whose husband was dying at home)