Transfer to a Preferred Place of Death

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Abstract

The preferred place of death is an important consideration in end-of-life care, especially when the dying person is definite about their choice. The preferred place of care may well be the same location, but this is not always the case. When the two venues are different, and the patient’s prognosis is poor, a decision has to be made whether to move the patient or not. The expectation to not only transfer the dying person in a timely fashion but also to minimize the time in the current setting often makes the situation a palliative care emergency. However, should the move occur at all? The risk of dying in transit may be high. Furthermore, respecting the wishes of the dying person needs to be balanced with the practicalities of

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safe ongoing care. These are practical and ethical decisions that should be made as early as possible.

How do we facilitate the smooth transfer from one location to another? Coordination and communication are vital in planning the process and supporting the discharge. The provision of the right medications and equipment, relevant information, and strategies for managing future problems should increase the chance of a successful transfer. Sometimes a smooth transfer will not be possible, but patients and family members will usually be happy with a successful one.

1 Introduction

The request to die in an alternative setting to the current venue of care is often stressful, until transfer to the preferred place of death has been achieved. It is not a singular decision but rather a process of considering and reviewing the relevant factors at various points in time. It is important to remember that views may change over time, e.g., due to clinical deterioration or psychosocial issues. Therefore, a careful review of any request is critical.

In order to fulfill the wish of the dying person, the process of transfer is usually deemed an emergency by palliative care teams. The aim of this chapter is to provide a systematic and practical approach for such transfers, considering the needs of all those involved. A multidisciplinary team approach will be beneficial, especially if the prognosis is limited. Last minute requests are complicated by the lack of time but are not uncommon. It may be impossible to fulfill the request of the patient/family in a limited timeframe and provides another reason for earlier referral to palliative care teams for appropriate assistance.

2 The Preferred Place of Death

Most people report that they want to die at home, and 80% do not change their mind as death approaches, although the preference to die at home varies between patients (31–87%), caregivers (25–64%), and members of the public (49–70%) (Gomes et al. 2013). Other research suggests that the views of patients and their carers do change over time, and we need to carefully distinguish between the preferred place of death and the preferred place of care (the venue in which people would like to receive most of their care) (Agar et al. 2008). In planning for end-of-life care (EOLC), healthcare professionals should be encouraged to ask and identify these venues of care; failure to do so is more likely to lead to a hospital admission (Ali et al. 2015).

Despite the desire to die at home, most people actually die in hospitals in the western world. Internationally, comparing 14 countries across 4 continents, we have found that 12–57% of cancer patients die at home and 26–87% die in hospital. The authors attribute these differences to the healthcare resources of the countries and their specific EOLC strategies for cancer patients (Cohen et al. 2015). Many healthcare services have been organized to meet the perceived demand for home deaths, especially in cancer patients, but these figures demonstrate limited success. In people with nonmalignant disease, it is likely that their preferred and actual place of death will differ, due to poor recognition of the terminal phase of disease, not establishing a preference in venue of death, and an inadequate provision of available supportive and palliative care (Billingham and Billingham 2013). Cohen et al. compared people with lung cancer and people with chronic obstructive pulmonary disease (COPD), across 14 countries, and highlighted that those with COPD were overall more likely to die in hospital or in a nursing home (Cohen et al. 2017). Similarly, people with end-stage renal disease are more likely to die in hospital, unless they are not receiving dialysis (Lovell et al. 2017).

Dying at home can be more peaceful for patients and provide less traumatic grieving for families, when compared with hospital deaths, providing the following have occurred: a discussion of the patient’s preferences, the involvement of a general practitioner (GP) who can provide home visits, and the ability for the family to be given time off work to support care at home.
These findings provide some insight into the challenges of dying well at home. Furthermore, societies have changed over the years, e.g., families are more dispersed around the globe than previously. Patients may not have family nearby to care for them, but even if they do, they may not want to be a burden to them. Similarly, some immigrant communities may not have the cultural and supportive networks to remain at home. Societies have also entrusted their health in a predominantly biomedical model and believe in the “rescue culture” of medicine (Poppito 2013). These changes influence the choices about the venue of care and venue of death between the primary decision-makers, i.e., patients, carers, and healthcare professionals. The decisions may favor home, aged care facilities, hospital, or hospice settings at different times; however the impact of family wishes, cultural, and religious beliefs should not be underestimated (Lin et al. 2017; Gott et al. 2013).

From a population perspective, two studies delineate a change in where people are dying. There has been a drop in the number of people dying in hospitals in England and Wales (2004–2014) and in Norway (1987–2011). However, both studies report (during their respective periods) and predict a rise of deaths in aged care facilities (Bone et al. 2017; Kalseth and Theisen 2017). Given the aging population in modern societies, not only will the number of facilities require review, but there will also be a challenge to the provision of optimal EOLC in this sector.

As healthcare professionals, we should plan ongoing care with the preferred place of care in mind. The preferred place of death will be more difficult to determine, due to the changing views and circumstances of dying people and their families over time (Agar et al. 2008). As a result, sometimes transfers will occur more rapidly than expected. There are excellent patient transfer guides online that may be useful to review, e.g., the “National Rapid Discharge Guidance for Patients Who Wish to Die at Home” (Ireland) and the “Accelerated Discharge to Die at Home” (New South Wales, Australia). In healthcare settings, the transfer destination should provide more appropriate care for the needs of the patient. Implied in the statement is also a view that the setting from which the transfer occurs cannot provide the necessary care to the individual. A further expectation is that the person is likely to improve at the destination venue. In an end-of-life context, we need to reconsider these statements, but there is often an ethical dilemma that exists for all parties concerned.

3 Dealing with the Request to Be Transferred

Palliative care teams frequently receive requests for transfers to another setting. These patients may or may not be dying, but when the reason is to die in a desired destination, the sense of urgency increases. The first response is usually to find out more about the referral, and a phone call may be the first means of triage. The triage process aims to determine the urgency of the referral. A written referral may not include all the relevant information, and so discussing the case with either the referrer or caregiver will help. The tone of the discussion may be enough to decide that the case is an emergency, but we need to know about the patient, their family, and any other reasons relevant to their decision. Perhaps the most common scenario involves a patient wanting to return home to die from the acute hospital ward. In this case, the referral will have been made by a junior medical officer who may, or may not, know the case well. Calling the nurse in charge of the ward may be helpful, as they may have more knowledge of the multidisciplinary team approach to the care thus far.

A similar case may involve a dying person at home, where the family prefer the death to occur in an institution, e.g., they may not want to live with the memory of the death at home, or they may not be coping with caring at home. The person may be conscious, semicomatose, or unconscious. Furthermore, the decision may be in keeping with their wishes or contrary to them. The referral may have come from the GP, or the community palliative care (CPC) team, but once
again speaking to the person with the best overall knowledge of the case will be most helpful.

So, when do these scenarios become a palliative care emergency? There are three main reasons to urgently review the case, assuming the transfer is desired:

- Firstly, if the person has a poor prognosis, e.g., days, then a greater need for action will be required. A delay could lead to death in the current venue of care, which does not meet the patient wishes and may anger the family.
- Secondly, the presence of significant distress in the current setting, from any of the relevant parties, would also increase the acuity for intervention.
- Finally, assuming the dying person wishes to be moved and/or the family are agreeable, then the referring healthcare professionals may be strongly advocating for urgent action.

Ultimately, there is a balance between meeting expectations, minimizing the time in the current venue of care, and maximizing the time in the desired venue of care. In terms of the patient and family, we therefore have a duty of care to ensure the discharge would be feasible, safe, supported, and beneficial. Modern healthcare systems can challenge the decisions we make in these scenarios, e.g., moving someone because of acute hospital bed pressures or requiring the patient to meet the specialist palliative care requirements for a hospice bed (Bergenholtz et al. 2016; Love and Liversage 2014). Overall, palliative care teams aim to respect the wishes of people who are dying as much as possible and support their families through whatever decision is made.

4 Patient Review and Family Discussions

The transition to palliative care should be a process over time, integral to the clinical handover of the patient’s care. However, referrals to palliative care teams are often later than desired, despite evidence of less aggressive EOLC, improved quality of life, and reduced healthcare costs (Scibetta et al. 2016; Smith et al. 2014). The referral marks a move from living with a disease to dying from it. We need to recognize that a palliative care referral often marks a significant psychological step toward death. Patients and families may be at different stages of dealing with the illness, irrespective of the actual clinical status. It is important to establish who is the main spokesperson for the family as early as possible, in order to save time and repetition of information. How these conversations are managed, at such an emotional time, may have lasting repercussions in bereavement (Stajduhar et al. 2017). Late palliative care referrals mark an altered course in the condition and care of the patient, which requires a more rapid adjustment from previous beliefs. Hence, allowing time for people to express their concerns and wishes regarding future care is necessary (Romo et al. 2016; Smith et al. 2016).

The coping mechanisms of the family and staff at the site of care should be considered when deciding upon possible transfers. As discussed above, it is important to understand the situation we will encounter when we review the patient in person. The priority of care should be focused on the patient, and therefore any distressing symptoms should be managed urgently. Advice may have been given over the phone, so a review of the efficacy of the suggested interventions is possible when the patient is assessed in person. The family are more likely to concentrate on their conversation with the clinician, if they see attentive and effective care being given to their loved one first.

Once the patient is settled, we need to consider what information the family has been given and their current understanding of the situation. Determining the goals of care, e.g., curative/restorative, palliative, or terminal (Thomas et al. 2014), for the patient provides an excellent starting point to plan an ongoing management, as medically the parameters of care should be defined. In consultation with the patient and/or their family, the next step would be to ascertain the preferred place of death and an idea of their advance care plans. Finally, these elements should be considered in discussion with the family and the treating team, to achieve a shared decision about the planned management.
The necessary conversations may have occurred previously, but a quick review of the relevant views establishes current priorities. The condition of the patient informs the feasibility of any transfer. Hence, clinical examination and obtaining a history of deterioration are important to estimate prognosis. In some cases, the person may not be dying, and the consultation provides an opportunity to listen to their wishes. There may be an underlying reversible cause for their deterioration, e.g., infection, opioid toxicity, or hypercalcemia, that requires discussion about potential treatment. In such cases, even though treatment is possible, a decision should be made regarding the appropriateness of prolonging life, according to the individual circumstances.

Prognostication is one of the three important skills in clinical medicine; we have honed our skills in the first two, diagnosis and treatment, but neglected prognostication by comparison (Glare et al. 2008). There may be prognostic tools to help, but in our given situation, reviewing the patient with a corroborative history is key. The family and treating team should provide a trajectory of the deterioration to make a quick assessment of prognosis. Remember that the family knows the patient better than anyone and is a valuable source of information about who the patient is and their life narrative. If there are no reversible causes and the deterioration has occurred day by day, it would be reasonable to assume a prognosis of days. However, if the deterioration has occurred in hours, then a shorter prognosis of hours is likely. Any decisions made in regard to an imminent death should be supported by clinical evidence, e.g., coma, Cheyne-Stokes breathing, and thready erratic pulse. Hui et al. determined some useful bedside clinical signs in cancer patients, to predict impending death within 3 days, i.e., nonreactive pupils, reduced response to verbal and visual stimuli, inability to close the eyelids, drooping of the nasolabial fold, hyperextension of the neck, grunting of the vocal cords, and upper gastrointestinal bleeding (Hui et al. 2015).

Should the prognosis permit a possible transfer home, we need to evaluate the stability of the patient for transfer. A useful way to approach the decision is to review the last routine clinical observations, i.e., temperature, pulse, blood pressure, and respiratory rate. If these measures, or any other clinical concerns under normal circumstances, would prompt a medical emergency team (MET) review, then clinical instability for transfer exists. Review if they have symptoms that need to be managed to facilitate a smooth transfer, e.g., pain, dyspnea, or agitation. Without addressing these symptoms, the patient suffers in transit, and their care may be viewed as suboptimal. The transfer reflects the care we provide to the patient and family; therefore how stable the patient is in transit and on arrival at the destination is a testament of that care. Hence, the decision to transfer a person who is imminently dying is a difficult balance between respecting the views of others and maintaining our professional and personal standards of care.

5 No Transfer Due to Imminent Death

Transfers are unlikely when the prognosis is estimated in hours. In the context of respecting the wishes of a patient and/or their family, delivering such a short prognosis may lead to a volatile situation. There may also be anger about the inability to fulfill the dying wishes of the patient. The clinician should be prepared to encounter and manage any reaction from the family, including potentially violent or abusive behavior. Although we may understand the grief and anger in certain situations, personal safety measures should be implemented as a priority if deemed necessary. Preempting how families may react, after assessment of the situation, may change the approach to the consultation.

The prognosis may be a relief to the family, or at least some of them, but an explanation of the reasoning behind the timeframe and the reluctance to transfer must be clear. Going through some symptoms and signs of dying may be helpful, if appropriate, supported by leaving the family a pamphlet with this information that can be reviewed as needed. Be prepared, and offer, to
repeat any information to the family. Where possible, consultations accompanied by another healthcare professional (e.g., nurse, social worker, pastoral care worker) can help with safety issues, as well as respond to the emotions of family members.

The potential of deterioration in transit should be emphasized and can act as a sobering reminder of the inherent risks of the transfer. Instances do occur where families refuse the advice to remain in the current venue of care. In a community setting, an ambulance may have been called, and the decision rests with the ambulance crew. Without prior warning, the scenario is difficult for ambulance staff that will invariably try and adopt the best approach for the patient and the family. In ward settings, the family may carry the person to their vehicle and request the help of staff to aid them. As traumatic as these events are for staff, keeping the focus on the family can sometimes diffuse the situation. Should a hospital discharge occur against medical advice, then liaison with the GP, community services, the CPC team, and other family members may provide the required support in the community.

We do have a primary duty of care to the patient, and so emphasizing that ongoing care will be provided to support family can be helpful. It may be useful to point out how comfortable the patient is at present and that moving them is likely to disrupt their stability. If possible, allay any feelings of guilt or failure in the family, and positively reinforce the efforts they have already made. Emphasize that the patient will be less aware of their actual location but may be more responsive to family around the bedside. It is a time for the family to come together and be present for the patient, as well as each other. It is perhaps more a time for them to be family, rather than adopting the additional roles of nurses, doctors, and pharmacists. Reassure them that it will be our responsibility as healthcare professionals to ensure the patient’s comfort and to support their grief. Enquire how we may best support them spiritually or culturally, and do not make any assumptions. Be present, be human, and be kind – many situations will be diffused with this approach.

There are some instances when the clinical needs of the patient would automatically preclude the possibility of transfer. Examples include patients who would die soon after extubation, patients requiring high-flow oxygenation, and patients who require ionotropic support to remain clinically stable. Often these patients would be on intensive care units, and weaning or ceasing life-supporting measures occurs after a consensus decision. A period of 24h usually provides some evidence of stability for transfer if still desired. Practically, the options for venue of care/death would be, in order of clinical preference, a ward in the hospital, the palliative care unit (PCU), or home. However, there are cases where patients have been extubated at home (Unger 2016; Mann et al. 2004). The extent to which services are prepared to help home deaths can often be admirable, especially in pediatric cases (Needle 2010). However, many more cases miss the opportunity to facilitate a home death due to late discussions, referrals, and coordination of care.

6 Transfer Options

Once the decision to transfer a patient has been agreed upon, the organization of the transfer can begin. The palliative care team is often required to coordinate efforts to ensure the smooth transition from one care setting to another. A checklist can ensure that nothing is forgotten but also streamline the process and reduce the time for transfer, especially when busy. These checklists can be sent to community teams, to ensure all tasks have been completed and education continues. The Liverpool Care Pathway for the Rapid Discharge Home of the Dying Patient provided effective guidance in EOLC (Murphy et al. 2004; Ahearn et al. 2013) and has been incorporated in other EOLC guidelines, e.g., Te Ara Whakapiri: Principles and guidance for the last days of life (the New Zealand EOLC guide).

Ambulance crews can be very helpful and flexible with transfers to the preferred place of death. Importantly, a “do not resuscitate order” is vital for the transfer. They will usually need to know about access to the house, if the venue is home, in
case they need an extra person to assist in the transfer. If any charges are incurred for ambulance trips, then families should be notified of the cost. It is also important to notify the ambulance crew and the family of what should happen if death occurs in transit. The standard advice is that they should continue to the final destination, alerting those who may be awaiting their arrival. Here the family can be supported and the necessary arrangements made to manage the deceased.

Once a discharge to the community has occurred, some palliative care services have a rapid response team, allowing the enhancement of care alongside existing services. They may provide a short period of care until the CPC team can takeover or provide support for EOLC at home or in aged care facilities (Gage and Holdsworth 2015). It may also be possible to optimize EOLC in aged care facilities post-discharge using hospital subacute services that visit them. A collaborative and educational approach between palliative care, elderly care, and aged care staff can ensure patient wishes are respected.

In the following sections, we consider each possible transfer and the role of the palliative care team in facilitating the urgent relocation.

7 Transfer from Ward Facility to Designated Home Setting

A meta-synthesis of qualitative studies over 25 years (1990–2015) provides seven themes that patients viewed as important for EOLC in acute hospitals. These are expert care, effective communication and shared decision-making, respectful and compassionate care, adequate environment for care, family involvement, financial affairs, and maintaining a sense of self. Apart from the last theme, family members shared the previous six perspectives. However, the same study also found four themes specific to the views of family members. They believed that maintaining patient safety, preparation for death, bereavement care, and enabling patient choice at the end of life were important to EOLC in acute hospitals (Virdun et al. 2016). These findings perhaps give an idea of what needs to be achieved in acute hospitals to optimize EOLC. They also provide an insight into why patients and families may want to leave hospitals at the end of life.

If a transfer is deemed appropriate from a ward setting, then a hospital palliative care team (HPCT) can assist in the discharge. As stated earlier, the timing of the referral can affect the urgency and the ability of the HPCT to meet expectations. The lead clinical team on the ward should be guided in the tasks needed to transfer care to the community. Liaising with the CPC team or the district nursing team, as well as the GP, will be critical in ongoing care at home. Discharging someone home without the support in the community to continue care only increases the chances of readmission and burdens the family with unwanted stress. Early notification to the relevant community nursing services will allow the service to better prepare for the transfer home. It is often reassuring for families to know when these services will be visiting. A GP who can visit, as mentioned earlier, is integral to the network of healthcare professionals who will contribute to the EOLC at home and fulfill the lead medical role in the community.

The lead team on the ward may have notified members of the allied health team appropriately, but the HPCT should ensure that the right individuals remain involved in EOLC. These may include:

- Case managers (with essential knowledge of the patient, family, and clinicians involved in the patient’s care in particular conditions, e.g., motor neurone disease patients)
- Pharmacists (both hospital and community pharmacists – to ensure appropriate medications are in place)
- Occupational therapists (to maintain daily activities as much as possible for both patients and carers, e.g., via equipment/aids to facilitate ongoing care).
- Physiotherapists (for mobility reviews if needed, soft tissue and therapeutic massage, and advice on passive movements and positioning)
• CPC teams (especially the nurse that will visit the home post-discharge)
• Music therapists (to provide support and symptom relief)
• Home-based care programs (either to cease or increase their involvement)
• Social workers (for patient and family advocacy, counseling, loss and grief support, family support, and social services support)

The involvement of these allied health professionals contributes to the holistic goals we aim to achieve in palliative and EOLC. Furthermore, there may be some continuity of care provided by these members of the healthcare team who have supported a patient and family over a number of previous hospital admissions. Their support and knowledge of the patient and family, and how they have coped with the episodic deteriorations, can provide valuable insights into EOLC.

The physical needs of the patient may require several pieces of equipment for home care. For example, a hospital bed and air mattress will aid EOLC for patients and their families; an oxygen concentrator will be required for hypoxic patients, where dyspnea is distressing. During the coordination of the transfer home, the delivery of equipment will require a family member to take responsibility to permit entry into the house and inform of access and location for the equipment. Occasionally, families may be so keen to get home that they may not wait for equipment, e.g., hospital bed, and prefer to let the person sleep in their own bed. It may be a small detail, but hospital beds are not invariably double beds that may allow the intimacy of a couple sharing their last few nights together. A pragmatic approach should be adopted, where advice should be documented, but we work to facilitate the transfer home as the main objective. Waiting for the safest transfer, at such a critical time, may jeopardize the goal – most families will wait for deliveries or pick equipment up once the patient gets home.

The family should be aware of the care that will be required at home. Although nursing a bedbound patient is often deemed easier in practical terms, performing personal care for their loved one may still cause distress. An early family meeting, involving a social worker, can clarify and inform the family of the undertaking ahead and determine if a transfer will occur. It can be helpful to highlight the shifts of professional carers involved on the ward each day, so that family and friends can be prepared for what is required once at home. The discussion should not aim to dissuade the family but to provide an informed decision about the transfer.

While on the ward, families should be given the opportunity to learn and participate in the nursing care. Pressure injury prevention, with associated safe positioning of the patient, e.g., tilt and turns, should be taught by the nursing staff, and the family should be observed in their practical involvement. Mouth cares, hygiene cares, and feeding will all be areas for education. For some families, these tasks may deter them from going ahead with the transfer. By contrast, larger families may accept and share the tasks to facilitate their planned move. Equipment for hygiene care will need to be provided, and urinary retention should be excluded. The consideration of an indwelling urethral catheter may prevent distress, readmission, and inappropriate medication usage.

There may be times when the coping mechanisms of the family, or their social supports, are not sufficient to provide optimal care from our professional caregiver perspective. At these times, the multidisciplinary team involved need to make a decision about pursuing the transfer, especially if the patient is deteriorating. Families may be adamant that they will cope, either out of a sense of duty or determination to respect the wishes of the patient. In these circumstances, challenging their decision may not be helpful. It may be better to document that there are professional concerns, which the family has been advised of, but they remain steadfast in their views. Planning for the failure of the discharge may also help the family, e.g., to know that they can return to the ward or have a direct admission to the PCU, should the care become too problematic at home is reassuring. Community teams and other services, e.g., PCUs, should be advised of all important discussions, in order to support the discharge as much as possible and coordinate care as needed in a crisis.
Syringe driver orders, breakthrough medications, and emergency medications are all likely to be required via the lead medical team. Often, junior doctors will be unsure of the right medications and lack confidence in prescribing the right doses. In such instances, the HPCT can educate and support junior doctors, either via their usual practice or in conjunction with EOLC guidelines. It is also important to instill and demonstrate an ethos of holistic care, and the provision of EOLC provides an opportunity to highlight the necessity for an individualized approach. Discussions about artificial hydration and nutrition will need to be completed, also explaining the rationalization of medications due to reduced oral intake. Some deaths will need to be reported to the coroner. It is the lead medical team’s responsibility to ensure that this information is conveyed to the family, as well as the process involved. However, the HPCT should check the completion of this task and also ensure the GP and community teams are advised.

Pastoral care and cultural liaison workers, if available, should address spiritual and cultural needs, respectively. There may be instances when these considerations are critical to the transfer. For example, there may be a desire for a blessing or cultural ritual prior to the transfer to ensure a safe passage or accommodate for a death in transit. Bereavement support should also be highlighted as a future service, so that families know who will be contacting them and when. Hence, as in all care, the holistic approach can be a powerful factor in demonstrating a respectful approach to the patient and the family if the right conversations are undertaken.

Patients returning to aged care facilities may require a higher level of care than they had previously. In some countries, there may be a requirement to reassess the current level of care required before the patient can return to the facility. Here, allied health assessments are essential if the diagnosis of dying is not so clear. Even under these circumstances, many facilities will need support from GPs and CPC services. Usually staff from these facilities are eager to continue the care of their patient and keen to learn about palliative care skills to help them. As with families caring for a loved one at home, the symptoms and signs of dying may need to be reiterated, with instructions to call the GP or CPC team if needed.

8 Transfer from Hospital Ward to Palliative Care Unit

The transfer to a PCU is often managed by a HPCT. However, in the absence of such a team, admissions are arranged directly with the PCU using admission criteria. PCUs vary between those that accommodate more acute cases and those that operate solely for the imminently dying. In the USA, the latter PCU is termed a “hospice.” Although PCUs differ in practice across the world, the common grounds for admission may restrict some patient transfers. For example, a family may want to continue intravenous fluids and antibiotics due to preferences for their loved one, but some hospices may not facilitate such treatment. Admission to the PCU may be dependent upon the cessation of the intravenous management and appropriate conversations with the family, hence delaying the transfer.

There are many issues to consider in these transfers. The lead clinical team on the ward will value a transfer based on their assessment of the patient, their confidence in caring for a dying patient, the family expectations, the acute bed status of the ward, and the empty beds available in the PCU. These are all valid considerations, but often the acute hospital is unaware of the demands on the PCU from community patients, as well as other hospital campuses.

PCUs should provide specialist palliative care services to those patients admitted to its care. Hence, the question often raised by the PCU staff is whether the admission from the acute hospital requires specialist palliative care management. EOLC guidelines, such as the Liverpool Care Pathway (LCP), were developed to help manage the nonspecialist palliative care deaths occurring in acute hospitals or in the community. However, misuse and media interpretation of the implementation of these guidelines has undermined the intention to improve the standard of EOLC outside PCUs. In services where a HPCT exists, many patients can be supported in
the acute hospital setting via the collaboration with acute teams. For many clinicians, the ability to continue caring for patients and families familiar to them is both personally and professionally rewarding.

Organizational imperatives, such as patient flow, are more prominent when the PCU is part of the acute hospital system. Within such organizations, the movement of patients to the most appropriate ward is a priority, and PCUs are often considered the best site for EOLC. Tensions can arise when seemingly all deaths are referred to the PCU, irrespective of their need for specialist palliative care. Determining the urgency for transfer on the basis of patient or family need should be the PCUs objective, but it can often be challenging. The organizational need for an acute bed may be the main factor behind a referral and can be difficult to defer when PCU beds are empty. Once again, a HPCT can clarify the need for transfer and ensure supportive care until the move can occur. When PCUs are not governed by the acute hospital organization, referrals can be reviewed without the same pressures and therefore ensure the appropriate patient cohort for the PCU.

Another important factor in transfers from acute hospitals to PCUs is the distance between the two facilities. The movement of a patient in the terminal phase of their illness is affected by the transit mode and duration of the transfer. The HPCT will need to decide if the person is likely to survive the trip, whether by ambulance, helicopter, or airplane. The same issues apply with regard to the comfort of the patient during transit, as discussed earlier. The balance between the stabilization of symptoms and the goal of preferred place of death often means a compromise. Pre-transfer medications are usually given to ensure comfort, but the longer the trip the riskier the transfer becomes in terms of comfort or death in transit. Hence longer trips may not be sanctioned by HPCTs.

A family meeting, led by the social worker, is the best initial process to ensure all parties understand what is happening. A member of the HPCT should attend the meeting not only to hear the discussions and meet the family but also to demonstrate a clinical handover of care. The HPCT can clarify the workings of the PCU and arrange the transfer at the most appropriate time. Some family members may not accept that death is imminent for their loved one. Acute care interventions, delayed decisions, and the fear of the PCU may all delay the transfer. Many family meetings may be required to gain a consensus plan, but transfer without such agreement will only cause more problems on the PCU.

9 Transfer from Designated Home Setting to Ward Facility

If most people want to die at home, then community services are tasked with the challenge to keep people at home, under difficult circumstances. A recent review of the essential components of quality community palliative care reports six vital requirements: integrated teamwork; management of pain and physical symptoms; holistic care; caring, compassionate, and skilled providers; timely and responsive care; and patient and family preparedness (Seow and Bainbridge 2018). These are the elements that all healthcare organizations strive toward, but the aging population remains a challenge that will increase demands and place community healthcare under immense strain.

There are two major settings to consider as a designated home for people. The first is the usual private residence, recognized as home, and the second is an aged care facility. Each has their problems in the transfer of patients into a ward, whether acute or subacute in nature. Subsequently, we shall consider them separately in the following discussion.

9.1 Transfers from Home

People dying at home may, or may not, be known to a CPC service. GPs and district nurses can usually provide support to carers at home and obtain advice from CPC services as needed. Dying at home remains difficult in the cities of the western world, as discussed earlier. In many cases the social networks are less prominent than in former years, prompting a movement for
“compassionate communities” and EOLC as a focus for public health reform (Kellehear 2013; Sallnow et al. 2017). The concept is growing from a public health perspective, to better support carers in the community and recreate links within our societies based upon compassion. Many rural and traditional communities have operated in a similar fashion for years, due to the close-knit relationships and traditions over many generations (Sallnow et al. 2010).

CPC services vary around the world in terms of personnel, provision of care, and funding. The aim may have been to facilitate dying at home, but more modern services are aware of the changing needs of the population. People may want to be admitted to a hospital or PCU for a number of reasons, and CPC teams should recognize the choices made regarding the venue of death. Early recognition of deterioration can trigger discussions about transfer from the home environment. Usually, CPC teams liaise with PCUs for an admission as early as possible. However, a PCU bed may not be available when required and hence an urgent admission via the hospital system is necessary. The emergency department (ED) should preferably be avoided, but families usually value being rescued from a crisis situation at home even if an admission must occur via the ED. There is still merit in these admissions, e.g., there may be continuity of care with the lead treating team, reversible causes of deterioration can be reversed, and patients who refuse a PCU admission can be reviewed and followed-up by the HPCT if they get admitted.

Once again, the assessment of the dying patient is critical. Home visits often encounter families who have been struggling for days to maintain the level of care required. These later reviews may find an imminently dying patient, who is too unwell to transfer. However, community teams facing such a scenario need to act calmly and quickly to deal with the situation. Families who are keen for a transfer to occur may pressurize the visiting clinician for an admission; similarly the clinician may also feel the least risky decision is to admit. Both the needs of the patient and the family can underpin these decisions, but invariably a PCU bed will be sought if possible. It should be noted that community palliative care staff might walk into unexpected scenarios of despair and distress. The consultation may be the first with the family about the seriousness of the situation, and establishing a quick rapport can be difficult. Subsequently, the clinician receiving the call from the CPC nurse should recognize the predicament the patient, family, and CPC nurse is facing.

There are times when some admissions to a PCU do not match the specialist palliative care criteria for entry. These referrals may emanate from the community, where the home option is no longer viable due to the level of care and support that are required. Recognizing this fact, PCUs prioritize community referrals above hospital referrals, where the clinical teams are available and can be supported in delivering palliative care. Clinicians triaging these referrals often understand the community situation and accept the referral, even though it may be deemed “inappropriate” for a specialist unit. The quicker the decision is made, the sooner the referring clinician can inform the family and organize transfer.

9.2 Transfers from Aged Care Facilities

Aged care facilities are the homes for many frail people in our population. In many countries they may be divided into high-level (nursing homes) and low-level (residential homes) care facilities. People with higher nursing care needs are more likely to require palliative care services; however not all facilities are served by CPC teams. CPC support may be provided for the staff at aged care facilities but may not be as “hands-on” as desired. Staff would certainly benefit from, and appreciate, the clinical experiential learning from CPC teams.

Medical support is also required. GPs may be associated with the patients by virtue of the facility or via an ongoing relationship that began before admission to the facility. Patients who want to die in the facility should be known to the GP and linked in with the CPC team. Out-of-hours care may involve locum medical staff, where acute decisions may not be underpinned by patient or family wishes. Here again the
importance of advance care planning is highlighted for those out-of-hours visits. Locums will refer people to hospital, if they are unsure of the clinical plan for the patient or the wishes of the patient/family under certain circumstances.

Ideally, patients admitted to aged care facilities should be asked about their wishes at the time of their admission to the facility. Conversations at this time, involving substitute decision-makers, will inform future care planning. Although these conversations may seem straightforward, how they are performed and updated require careful consideration. Firstly, the circumstances of the admission to the facility should highlight the more vulnerable and frail nature of the patient. A review of their deterioration can give an idea of their disease trajectory, but their comorbidities also factor into the prognosis. The GP has a major role in these conversations, to guide and coordinate the views of patients, families, and specialists in an advance care plan. How these conversations occur will determine the effectiveness of the plan created. Medically the goals of care need to be clear, and the patient’s wishes need to be woven into the management plan. Conversations about death and dying may need to occur, at a time when functional change is traumatic for both the patient and members of their family. However, these conversations cannot be delayed.

Once an advance care plan is achieved, there should be accompanying medication changes to deal with the immediate care and future care. De-prescribing allows a streamlining of medications, but planning for emergencies may prevent an unnecessary admission. An awareness of potential modes of deterioration should be in the forefront of the clinician’s mind when reviewing the patient. Are they likely to have a catastrophic event, e.g., massive gastrointestinal hemorrhage, or massive hemoptysis? Is a clinical deterioration in condition likely sooner or later? If so, these are further conversations that should occur with the family and staff of the facility.

A completed advance care plan will need to be reviewed and appropriately updated. When should this occur to remain up to date? Certainly, after an acute admission to hospital, there should be a review of the plan. However, it may be prudent for the staff of the facility, the family, and the GP to meet periodically to review the patient’s progress and to plan for any deterioration. There may be a presumption that the patient and/or the family will prefer conservative management in the aged care facility. Once again, assumptions should not be made, and possible transfer options should be discussed. If the patient and family wishes are clear that a hospital admission should be made, then staff can respond appropriately if deterioration occurs.

Another option may be the admission to a PCU. Often, these admissions are firstly discussed with the CPC teams. Support may be provided to the facility staff and GP, but two triggers may change this approach. Firstly, the patient may display specialist palliative care needs, e.g., uncontrolled pain, dyspnea, or terminal delirium. Secondly, the family or staff may decide that care needs are not being adequately met in the facility. In the latter cases, an admission to either an acute hospital or a palliative care unit may rescue the situation sufficiently to minimize suffering and potential bereavement complications. Once again, the timeframe to plan the transfer to another venue of care can be limited.

Generally, the ambulance transfer can occur rapidly once the decision has been made. The hope is that the decision is a well-informed one and reflects the wishes, values, and expectations of the dying person concerned.

10 Transfers from a Palliative Care Unit to the Acute Hospital

Admissions to a PCU usually have a specific goal of care in mind. End-of-life care is often the main goal of care, but in the modern hospice setting, other goals may exist. For example, the admission could be for symptom management and then discharge home. For some patients, a period of assessment may be required. In such cases, the patient may eventually go home, require placement in an aged care facility, or enter the terminal phase of their disease. Time often allows the inpatient palliative care team the ability to review the prognosis and plan care accordingly.
However, in modern PCUs there may be a need to transfer the patient back to the acute hospital. A family meeting, led by a social worker, is often the best forum to discuss the transfer and prepare appropriately, if possible. There may always be the potential for the patient to die before the transfer, but the team should prepare and advise according to the discussion above. Further coordination is required with the hospital teams, in order to facilitate the best support for the patient and family.

Families may be keen for a transfer, as they may have not understood the philosophy of the PCU. Hope can be maintained by a transfer, as "more can be done" in the hospital. Some family members will find it difficult to leave the PCU, especially if they believe the decision to leave is wrong. Families often struggle with the emotions between the devotion to the dying person and their wishes, the practical issues of coping with the decisions, and the safe haven of the PCU.

Another factor to consider is the relationship the patient and family may have with their treating team in the acute setting. Many patients with chronic diseases will have developed a strong bond with the multi-professional team on the acute ward. Examples include patients with end-stage renal disease or end-stage chronic obstructive pulmonary disease. The relationship may also be reciprocal with the acute care staff, as often displayed by their willingness to care for these patients at the end of life (Gott et al. 2013).

In the current healthcare system, patients and families often have a misperception of palliative care. Without time to process the need for palliative care, it is not difficult to understand the reluctance of some patients and families to stay in the PCU. The familiarity with the acute hospital team and the environment is one factor, but the kind of medicalized care provided is another. The mismatch of expectations and experiences can prompt a request for a transfer back to the acute hospital. Sometimes the transfer may be difficult to facilitate, due to organizational systems, but invariably an understanding can be reached from a patient-centered approach.

Once in the acute hospital, the HPCT may be able to monitor the progress of the patient, collaborate with the lead clinical team, and support the family as required. Abandonment of the patient and their family can be an important factor in the delivery of care, during the terminal phase of an illness (Smith et al. 2016). Even if the HPCT is not required, the supportive role can remain significant for all concerned. The lead clinical team will require a handover, due to the complexities of care. In both scenarios, the HCPT should be involved and relevant to the supportive processes.

### 11 Conclusion

Transfers to a chosen venue of death require planning, clear goals of care, and empathic communication in order to facilitate a smooth transition of care. The knowledge of the patient and family wishes, as early as possible, is critical to allow the coordination of required services. The introduction of more systematized advance care planning in our communities, and increasing societal conversations about death and dying, provides useful opportunities to plan care. Ultimately, under difficult circumstances, we are trying to honor the wishes of a dying person. For those people whose goal we achieve, there is much satisfaction and gratitude. There may be instances where the goal was achieved, but how we were successful was less satisfactory. Finally, there will be times when we failed to achieve the goal and there is disappointment and anger. In each case there is an uncertainty to accept and a reflection to learn from, but how we fought to realize someone’s preferred place of care and then death will live with families as a memory of our respect for their departed.

### 12 Summary

The preferred place of death remains an important factor in good EOLC but may not always be the home setting we are led to believe. Many people prefer other venues of death, for many reasons including societal, cultural, and psychological considerations. A recent systematic review of the
barriers and facilitators to dying at home provides a succinct overview to facilitating the preferred place of death. The facilitators include coordinated care, skilled staff, effective communication, and support for patients and HCPs. On the other hand, the barriers included a lack of knowledge, skills, and support among informal caregivers and HCPs; informal caregiver and family burden; recognizing death; unfavorable social circumstances; inadequate discharge processes; condition-specific discrepancies, e.g., the inequity of access to palliative care for people with nonmalignant conditions; and poor planning (Wahid et al. 2017).

Whatever the setting of care, the early knowledge about the wishes of the patient is important. Only then can we plan and realistically obtain a smooth transition to the venue of death. Prognostication adds to the complexity of the situation, amidst the current standards of healthcare communication. These decisions cannot be made lightly but are often made in emergency situations. Taking the time to understand the decisions of patients and the families can ensure the right choices are made in the timeframe available. The coordination of services, reduction of adverse risks, and compassionate communication help achieve the best outcomes in these situations.

References


