

16 Community palliative care

Keri Thomas

Few things in general practice are more important and more rewarding than enabling a patient to die peacefully at home. For GPs, district nurses, and others in the primary health care team (PHCT), this is an important and intrinsic part of their work. They deliver most palliative care to patients and generally do this in a sound and effective way, especially when they are backed by appropriate specialist support. People now live longer with serious illness, with most of the time spent living “normally” at home, so providing good community based care is vital. Sensitive facing the reality of dying and making a plan for the final stage of life is as important in end of life care as planning for pregnancy and labour are in antenatal or early life care. Yet this pre-emptive planning is often omitted, resulting in a tendency towards reactive, crisis led care that does not always meet the needs of dying patients. The paradox is that although most of the final year of life is spent at home, and most people would choose to die there, increasingly most people still die in hospital. The excessive numbers of hospital admissions are due mainly to:

- Unresolved symptom control
- A breakdown in provision of home care services—for example, lack of nursing/night sitters
- Lack of support for carers.

Many more patients would prefer to die at home than are currently able to do so, and a hospital death is more likely to occur in particular groups of patients, such as the poor, the elderly, solitary women, and those with a long illness. Many choose to die in hospices (although currently only about 17% of patients with cancer and 4% of all patients die there), and many hospice outreach teams extend specialist support to the home, working closely with community teams.

Increased advanced care planning—supporting more people to cope well at home and improving the quality of palliative care provided by generalists in the community, in hospital, and in care homes—would increase the numbers of people who are able to die where they choose and prevent some unnecessary hospital admissions, thereby increasing inpatient bed capacity.

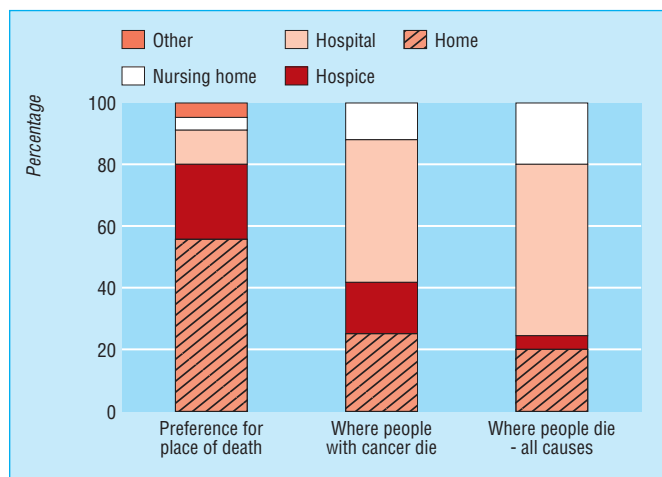
The most important challenge we face in service provision, therefore, is to enable more people to live well and die well in the place and in the manner of their choosing. Practically this means to optimise the quality and reliability of palliative care services provided by all and to reduce crises and unnecessary hospital admissions.

Home care

Ninety percent of the final year of life is spent at home, no matter where the patient eventually dies. Home is a special place, a state of mind, a place to be ourselves most fully. It represents life, activity, self determination, and retaining control, rather than illness, passivity, and the “patient mode” of inpatient care. The preferred place of care may seem to change nearer death; this may be by default—for example, when patients or their carers feel unable to cope, for relief of symptoms, the fear of being a burden, and sometimes conflict between the patient and the carer’s choice. But it has to be questioned whether this is real “choice” or a response to practicalities by default—with better planning and support can a change sometimes be averted? Many people would choose to spend most time at home but to die in a

Key facts around palliative care in the community

- 90% of the final year of life is spent at home
- Most people prefer to die at home, but the number who choose a hospice is increasing
- The home death rate is low (23% for patients with cancer, 19% for all deaths)
- The hospital death rate is high (55% for patients with cancer, 66% of all deaths)
- 21% of those aged over 65 years in care homes (nursing and residential homes)
- Death in hospital is more likely if patients are poor, elderly, have no carers, are female, or have a long illness
- Each GP has about 30–40 patients with cancer at one time
- District nurses coordinate most palliative care in the home
- Primary palliative care is optimised by formalised specialist support
- Less support is available for patients with illnesses other than cancer and their carers and GPs
- Gaps in community care include control of symptoms, support of carers, 24 hour nursing care, night sitters, access to equipment, out of hours support
- Improving community palliative care services (including care homes) has an impact on hospitals and hospices
- The average length of stay in a hospice is now two weeks, 98% of patients have cancer and 50% of patients in hospices will be discharged
- Enabling patients to die in the place of their choice can have a positive effect on the family’s bereavement



Priorities for end of life care in England, Wales, and Scotland (data from Cecily Saunders Foundation and National Council for Palliative Care)

hospice, an appropriate choice for many—yet many of our hospice services would struggle currently to meet this preference, especially for patients without cancer.

With the increase in advanced directives or living wills, it is more important than ever to have these difficult discussions with patients and their families early on and together form an advanced care plan including decisions about their preferences, such as place of care, which should be noted and communicated to others. Other areas to cover include a nominated proxy, do not resuscitate (DNR) decisions, what patients would or would not like to happen, what to do in a crisis, and special requests—for example, organ donation. This enables a greater sense of self determination and control and better planning of care based on the needs of the patient.

Time is short for the dying. Towards the end of life the pace of change may be rapid, and without good planning and proactive management, the speed of events can catch out the best of us. Enabling dying patients to remain at home involves a close collaboration of many people, services, and agencies, both generalist and specialist and, at best, an agreed system or managed plan of care (such as the gold standards framework). A bewildering number of people can become involved, sometimes causing a confusing mismatch of services and adding to the trauma of the dying process. Patients and carers appreciate the continuity, coordination, and ongoing relationship with their primary care team or specialist provider.

So within community palliative care there is a pressing need for active anticipatory management, coordination, and “orchestration” of services to enable good home care for the dying. Although GPs may feel pressurised by time constraints, the primary care team, particularly the district nurses, are in a key role to perform this function, and often they are the mainstay of care at this most crucial time. This is in line with the “cradle to grave” concepts inherent in primary care; knowledge of context and community and of continuing supportive relationship and care of the dying is close to the heart of most people working in primary care. As Gomas (1993) said “Palliative care at home embraces what is most noble in medicine: sometimes curing, always relieving, supporting right to the end.”

The needs of dying patients

Palliative care services should respond to the needs of patients and carers and deliver to their agenda. This requires a holistic assessment, including non-medical psychosocial issues. In general, patients want to remain as free from symptoms as possible and to feel secure and supported, with good information and proactive planning. This allows the continued journeying to other important and deeper levels involved in the dying process—for example, loving relationships, retaining dignity, self worth, spiritual peace. Various studies confirm what is required of healthcare professionals by dying patients and their carers. Good communication and information figure largely—for example, clear advice on what to do in an emergency, what to expect—and also the steadfast continuity of relationships, the “being there,” as “companions on the journey” with our patients. This trusted relationship and supportive role should never be underestimated.

Support from councillors or psychologists is sometimes available, which may smooth the transition and mental adaptation required in coming to terms with dying. Social services need to be involved for advice on financial benefits, continuing care services, respite, and social care. The DS1500

Needs and requests of patients and carers

Requirements of patients and carers at home

- Nursing and medical care
- Good symptom control
- Information—for example, what to expect/who to phone in a crisis
- Practical advice/help/equipment
- Good liaison across boundaries
- Continuity of relationship with clinicians
- Social care—for example, continuous care funding, etc
- Support for carers—night sitters, Marie Curie nurses, etc
- Carers’ needs assessed
- Preparing families for a death
- Information on what to do after death

What patients especially appreciate from their GPs

- Continuity of relationship
 - Being listened to
 - Opportunity to ventilate feelings
 - Being accessible
 - Effective symptom control
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Key components of best practice in community palliative care

Use of the gold standards framework, NICE Guidance on Supportive and Palliative Care, Generalist Palliative Care www.nice.org.uk

- Patients with needs for palliative care are identified according to agreed criteria and a management plan discussed within the multidisciplinary team
 - These patients and their carers are regularly assessed with agreed assessment tools
 - Anticipated needs are noted, planned for, and addressed
 - Needs of patients and carers are communicated within the team and to specialist colleagues, as appropriate
 - Preferred place of care and place of death are discussed and noted, and measures taken to comply when possible
 - A named person in the practice team orchestrates coordination of care
 - Relevant information is passed to those providing care out of hours, and drugs that may be needed left in the home
 - A protocol for care in the dying phase is followed, such as the Liverpool care pathway for the dying patient
 - Carers are educated, enabled, and supported, which includes the provision of specific information, financial advice, and bereavement care
 - Audit, reflective practice, development of practice protocols, and targeted learning are encouraged as part of personal, practice, and primary care organisation/NHS trust development plans
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The term “psychosocial” care includes the psychological, social, spiritual, and practical needs of the patient and carers, all of which need to be assessed and addressed where possible

ABC of palliative care

attendance allowance form should be used by primary care teams to enable speedy additional funding for those in the last six months of life. Spiritual needs may be hard to assess and personally challenging but vital to enable people to move towards a peaceful conclusion of their lives. Referral to the appropriate spiritual advisor and awareness of ethnic differences in this diverse multicultural nation is all part of good care. Practical needs include equipment such as mattresses, wheelchairs, commodes, syringe driver, and home modifications such as external key boxes and handrails, etc.

Primary care team response

Working as a team, the PHCT can provide continuous and coordinated supportive care in the community. Early referral to the district nursing service is preferred, allowing time for a full assessment of the needs of the patient and carer, early referral to other services, ordering of equipment, and time to develop a relationship with the patient and carer as advocate and “key worker” before later deterioration.

Out of hours care

Particular attention should be paid to improving the continuity of care out of hours, which accounts for about 75% of the week. Without this vital aspect, all the good work of primary care can be instantly dismantled, and the patient can be admitted to hospital in crisis, possibly to remain there until death. In the UK, changes in the contracted out of hours cover might threaten the continuity of care for dying patients. With better proactive management and the use of an agreed protocol, a handover form, and good access to drugs, however, these situations could be avoided.

Support for family and carers

Support for the family and carer can be one of the most important aspects of the holistic care provided by primary care teams, backed up by hospice support if available. Carer breakdown is often the key factor in prompting institutionalised care for dying patients. Carers should be included as full members of the team, enabled, forewarned, informed, and taught to care for the dying patient to the level desired. This has consequences for the carer in bereavement, with a greater satisfaction that the patient’s final wishes were fulfilled and fewer “if only . . .” regrets later. The toll of caring for a dying person can be considerable in both physical and emotional terms; many carers are elderly and infirm themselves and there is an increased morbidity and mortality of carers in bereavement.

In some surveys of both patients and families, the carer’s anxiety is rated alongside the patient’s symptoms as the most severe problem. There is resounding evidence that without support from family and friends it would be impossible for many patients to remain at home.

This is one issue where evidence confirms that primary care can make a real and valued difference. Many carers, however, feel that GPs do not understand their needs, and in turn many GPs and district nurses feel they lack the relevant time, resources, and training to take a more proactive role. The primary care team, however, is in a key position to help, both personally and in coordinating services. Separate assessment and practical support for carers is therefore required and, with support from social services and self help groups, carers are then more likely to be able to withstand the pressure. Those without carers may struggle even more, and they present particular difficulties for primary care in an age of increasing solitary living.

Carers need time to ask questions, to discuss decisions, to help relieve their anxiety, and to create a better understanding

A protocol for out of hours (OOH) palliative care

- Communication:
 - Handover form to OOH provider
 - Inform others—for example, hospice
 - Does the carer know what to do in a crisis?
- Carer support:
 - Coordinate pre-emptive care—for example, night sitters
 - Give written information to carers
 - Emergency support—for example, rapid response team
- Medical support:
 - Anticipated management in handover form
 - Crisis pack, guidelines, etc, and ongoing teaching
 - 24 hour specialist advice available—for example, from hospice
- Drugs/equipment:
 - Leave anticipated drugs in home
 - Palliative care bags available
 - On-call stocked pharmacists

Improve access to palliative care drugs

Suggested list of drugs to be left in the home of every palliative care patient

- Diamorphine
- Cyclizine/haloperidol
- Midazolam
- Hyoscine butylbromide/hydrobromide/glycopyrronium

Adapted from Thomas K, *Eur J Pall Care* 2000;7:22–5.

Carer breakdown is a crucial and sometimes unrecognised issue, and carers have their own separate needs for assessment and support. This important factor must be addressed if any impact is to be made on home based palliative care (see chapter 14)

Supporting carers—what primary care can do

- Acknowledge carers, what they do, and the problems they have
 - Assess health and welfare of the carer as well as the patient
 - Treat carers as you would other team members and listen to their opinions
 - Include them in discussions about the patient
 - Flag informal carer’s notes, so other health workers are aware of their circumstances
 - Give carers a choice about which tasks they undertake
 - Provide information about the condition
 - Provide information about being a carer and support and benefits available
 - Provide information about local services available for patient and carer
 - Ensure that services and equipment provided
 - Liaise with other services—be an advocate for the carer
 - Ensure staff are informed about the needs and problems of informal carers
 - Respond quickly and sympathetically to crisis situations
 - Give or arrange training—for example, in lifting and moving, giving medication, etc
 - Confide in and listen to patients/carers—let them express their needs and support them
 - Suggest coping strategies, both internal (faith, positive attitude, etc) and external (social networks)
 - Development of a bereavement protocol and raising awareness of bereaved patients in practice teams
 - Assemble a list of local contacts for bereavement support
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of what is happening. It is often helpful to rehearse with the carer what to do in certain situations, such as if the patient has uncontrolled symptoms or when the patient dies.

Together with the provision of back up 24 hour contact details, this will enhance a sense of security and confidence and reduce the chance of crisis calls. Management plans, advanced directives, and do not resuscitate decisions need to be discussed and communicated to others—for example, ambulance staff—to prevent the sad situation of inappropriate and failed resuscitation attempts. Supporting carers in bereavement is a key role of primary care, with planned visits, consultation alerts by tagging of notes, pre-emptive supportive care, and referral to local bereavement support groups.

Other settings and patients without cancer

In assessing comprehensive palliative care services in a locality, other care settings must be considered. About 20% of people die in care homes and the end of life care provided for such people is important, though sometimes of variable quality. There are specific issues about care homes, such as their independent ownership, clinical governance, staff needs, multiple pathology of these patients, variable primary care arrangements, etc, which make this issue complex, and, despite best efforts, too often patients may be given suboptimal care and admitted to hospital in the final stages. Some care homes develop educational initiatives and specialist inreach and local guidelines, such as the use of pathways and frameworks, but this is an issue requiring further work to produce a more consistent high quality standard of care. Patients in private hospitals and community hospitals can sometimes be excluded from generalist and specialist palliative care services and provision may be suboptimal. Practices and procedures need to be agreed with the relevant staff and authorities to maintain high quality care for dying patients, such as symptom guidance, referral criteria, accessing specialist drugs, and support, etc.

The current provision of palliative care services in the UK still largely favours patients with cancer. Meanwhile, those with other common end stage diagnoses such as heart failure, COPD, renal failure, neurological disease, and dementia, who have equally severe symptoms with similarly poor prognoses, may have reduced access to services or specialist advice, especially in the community—for example, lack of specialist support, Marie Curie or Macmillan nurses, reduced access to advice or equipment etc. “Do I have to have cancer to get this kind of care?” is a natural response from patients with non-malignant but equally serious conditions. The improvements in management for patients with cancer by community providers need to be transferred to patients with other conditions. As an approximation, each year every GP has about 20 patients who die, of whom about five have cancer, five to seven have organ failure such as heart failure or COPD, and six to seven have old age comorbidities, frailty, and dementia, with one to two sudden deaths. The less predictable trajectories of illness in the group with organ failure mean greater hospital involvement and more difficulty predicting the terminal stages and introducing supportive care. For all patients with end stage illnesses, irrespective of the diagnosis, it is still important to apply palliative care principles, to recognise deterioration, and to include such patients in service provision—for example, specialist advice on accurate assessment and control of symptoms, respite care, access to equipment, information transfer, and handover forms.



End of life care is important (reproduced with permission of Samuel Ashfield/Science Photo Library)

Care needs for different disease trajectories

Predictable trajectory—for example, for patients with cancer

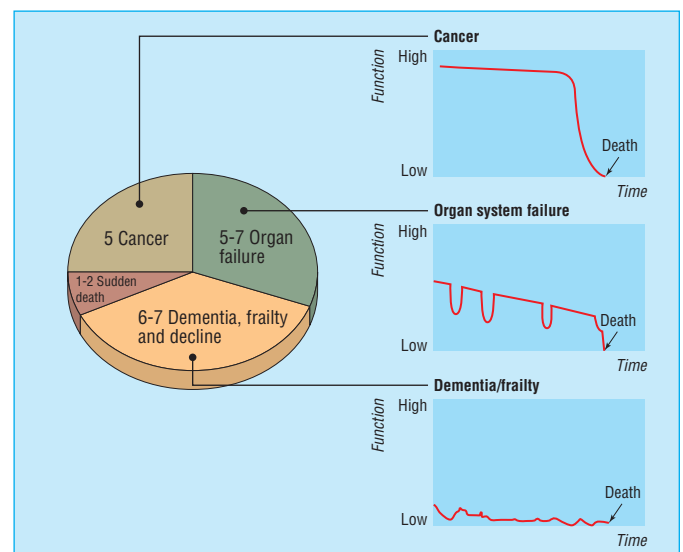
- Family support
- Symptom control
- Continuity of relationship
- Life closure
- Adaptability to rapid changes

Erratic trajectory—for example, for patients with organ system failure, heart failure, COPD, renal failure

- Preplanning for urgent situations
- Life closure
- Prevention of exacerbations
- Decision making about benefits of low yield treatments
- Support at home
- Prepare family for “sudden death”

Long term gradual decline—for example, for patients with dementia and frailty

- Endurance
- Long term home care service and supervision
- Helping carer to find meaning
- Avoiding unnecessary lingering
- Keeping skin intact
- Finding moments of joy and meaning for the patient



Workload of general practitioners, with illness trajectories for patients with cancer, organ failure, and old age, frailty, dementia, and decline

Multiprofessional teamwork

Specialist palliative care services, largely funded by the voluntary sector, have enhanced the quality of care given to dying patients throughout the world and improved our level of knowledge and understanding of the art and science of palliative care. The multiprofessional specialist palliative care team adds expertise and support to the generalist professionals in the community and to the patient and carer. Such support includes hospice outreach and hospice at home, respite admissions, clinical nurse specialists or Macmillan nurses, Marie Curie nurses providing hands-on nursing in patients' houses often overnight in the last days of life, day centres offering social support and activities and also complementary therapies, and much more.

Clinical challenges

Control of symptoms, particularly pain management, can be difficult in the community and is often poor, and better assessment, use of guidelines, and cworking with specialists can improve this. Education must be targeted and accessible and should include care of non-malignant conditions. For those in primary care, there may be some clinical conditions they rarely meet and may feel less confident to manage. Seeking specialist advice and reassurance that the best care is being provided can be invaluable, while maintaining the continuity of relationship provided by the primary care team. Some drugs often used in palliative care are not specifically licensed for that use and may be unfamiliar to GPs, so advice should be sought.

For many patients, including those with diagnoses other than cancer, development of "self care" and maximising of internal resources can be helpful, and the use of psychological or psycho-oncology services can help people to cope better.

Legal issues

The responsibility for notifying a death to the registrar lies with the relative or other person present at the death. A doctor who attended the patient during the last illness will normally issue a death certificate or report the case to the coroner. In the light of the Shipman inquiry, however, these procedures are currently being re-examined and some radical changes made. For more details consult the BMA website on www.bma.org.uk or your local primary care organisation.

Optimising home care—some models of good practice

So how can the best quality of care in the community and the best collaboration between generalist and specialists be ensured? Two complementary models are in current use in the UK to improve community palliative care—the gold standards framework for the last months/year of life and the Liverpool care pathway for the dying used in the last days of life.

The gold standards framework (GSF)

The GSF is a common sense, primary care based approach to formalising best practice, so that good care becomes standard for *all* patients *every* time. GSF users find it affirms their good practice, improves consistency of care so that "fewer patients slip through the net," and improves the experience of care for patients, carers, and staff. This work is underpinned by best available evidence, fully evaluated (recommended in NICE Guidance and by the Royal College of General Practitioners), and is extensively used by primary care teams across the UK.

The framework is easily used for patients without cancer nearing the end of life, and adaptations are developing for care homes, hospitals, and other settings.



Marie Curie nurses provide hands-on care within the patient's home during the last days of life (with permission of Marie Curie Cancer Care)

The gold standards framework

The **gold standards framework** aims to develop a practice based system to improve and optimise the organisation and quality of care for patients and their carers in their last year of life. It can be summarised as follows:

- *One* gold standard for all patients nearing the end of life
- *Three* processes: identify, assess, and plan
- *Five* goals of the gold standard to enable patients to die well:
 - Symptoms controlled as much as possible
 - Living and dying where they choose
 - Better advanced care planning information, feeling safe and supported with fewer crises
 - Carers feeling supported, involved, empowered, and satisfied with care
 - Staff feeling confident, satisfied with good communication, and team working with specialists
- *Seven* key tasks—the seven Cs:
 - Communication
 - Coordination
 - Control of symptoms
 - Continuity and out of hours
 - Continued learning
 - Cover support
 - Care in the dying phase

For more details and resources, see www.goldstandardsframework.nhs.uk

The three central processes of GSF all involve improved communication

- *Identify* the key group of patients—for instance, using a register and agreed criteria
 - *Assess* their main needs, both physical and psychosocial, and those of the carers
 - *Plan* ahead for problems, including out of hours—move from *reactive* to *proactive* care by anticipation and prevention
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The Liverpool care pathway (LCP)

The LCP was developed as a framework to enable generalist staff on hospital wards to care better for uncomplicated dying patients and later extended to the community, care homes, and hospice. An abbreviated form is integrated into the GSF as “C7.” It allows standardisation and benchmarking of care to ensure consistency of care in the last few days of life. It is recommended that new areas in the community begin with GSF but later add LCP, while hospices and hospitals use LCP first.

Within England, the NHS Modernisation Agency and more recently the NHS End of Life Care Programme (www.modern.nhs.uk/cancer/endoflife) support these two established models of generalist care for patients with and without cancer. Advanced care planning tools are also recommended to promote choice and early planning discussions with patients, communicate decisions to others via a patient held record, and ensure more care focused on the patient. One example is the preferred place of care document that is in the early stages of use in England. Together, it is hoped that use of these tools will enable a better quality of palliative care to become mainstream within the NHS, with the “skilling up” of generalists, with fewer hospital admissions and more patients being enabled to die where they choose.

Conclusion

Good home care is vital. We now have the new situation of a population growing old and unwell more slowly than in previous generations—this is a new “epidemic” that we have not previously met or dealt with. With the demographic changes of ageing populations, better treatments and chronicity of end stage illnesses, fewer inpatient beds, and rising costs, there is a growing imperative to provide good home care for all seriously ill patients. Key issues include enablement of generalists, advanced care planning to determine need and preference, application of successful developments to patients with diseases other than cancer and in other settings, enhanced carer support and self care, high quality 24 hour clinical management and service provision, and good communication across boundaries.

As we rethink our palliative and supportive care services in response to this burgeoning need, the holistic approach of primary care is well placed to meet the challenge, if it is enabled to do so. Primary care teams in the community can deliver excellent palliative care for their dying patients and enable patients to die well where they choose when complemented by good access to specialist services, support, and expertise. As demand for community care increases in future, it is important to maximise the potential of primary palliative care and the use of frameworks or protocols with good collaboration with specialists.

Best practice in the last hours and days of life

(See for example, the Liverpool care pathway, www.lcp-mariecurie.org.uk)

- Current medications are assessed and non-essentials discontinued
 - “As required” subcutaneous medication is prescribed according to an agreed protocol to manage pain, agitation, nausea and vomiting, and respiratory tract secretions
 - Decisions are taken to discontinue inappropriate interventions, including blood tests, intravenous fluids, and observation of vital signs
 - The insights of the patient, family, and carers into the patient’s condition are identified
 - Religious and spiritual needs of the patient, family, and carers are assessed
 - Means of informing family and carers of the patient’s impending death are identified
 - The family and carers are given appropriate written information
 - The GP’s practice is made aware of the patient’s condition
 - A plan of care is explained and discussed with the patient, family, and carers
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A death dominated by fear, crises, inappropriate admissions, overmedicalisation, and poor communication can be a tragedy and a failure of our medical system; enabling a peaceful death at home can be a great accomplishment for all concerned

Further reading

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