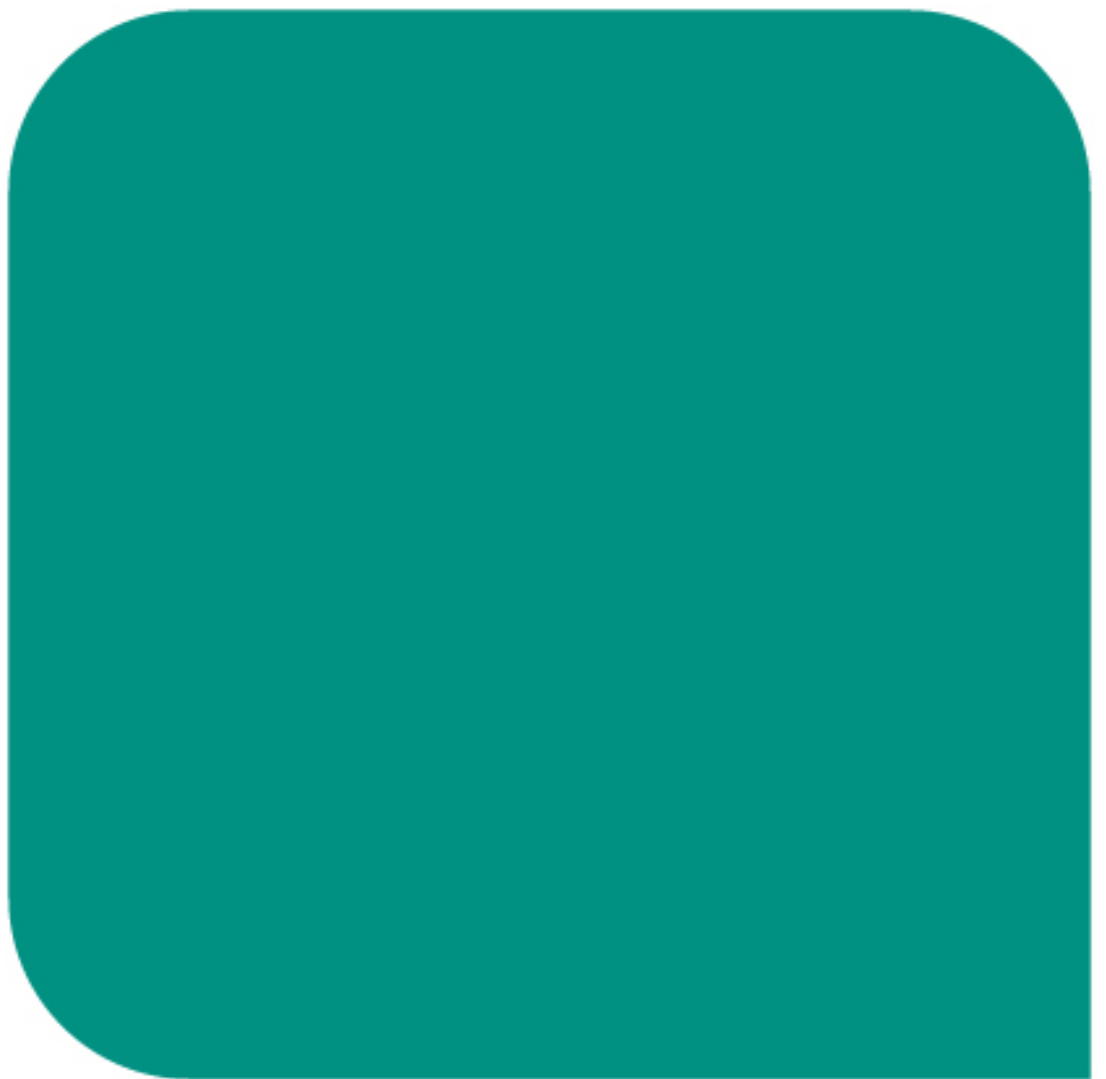




social care
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Dying well at home: research evidence



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Choosing to die at home

Research [2, 3] suggests that between 50 and 74 per cent of people who are dying express a preference to die at home, although this proportion may decline as death becomes more imminent and people want access to more extensive support. However, around 59 per cent of people die in hospital, 17 per cent in a care home and 18 per cent in their own home [3, 4].

Between 50 and 70 per cent of cancer patients express a preference to die at home [4], while just under half of people with advanced, non-cancerous conditions prefer a home death. However, this may change as a patient's condition deteriorates: patients may choose to transfer to other settings, including hospital, out of concern for their family carer, or because they feel that hospital is a place of safety, offering increased hope of survival [4]. Older people are more likely to die in a care home, especially if they have dementia.

The single most important factor that enables people to die at home is a caregiver who is willing and able to provide care at home [4].

The following personal and local factors are also thought to influence the place of death:

- the type of terminal condition (e.g. cancer patients are more likely to die at home while people with dementia are more likely to die in a care home)
- symptoms, and whether they can be addressed in a home setting
- locality (59 per cent of all deaths occur in a hospital, although this figure varies from 46 per cent to 77 per cent between primary care trusts) [2]
- socio-economic status (higher socio-economic status increases the prospect of a home death maybe because people can purchase care, or they live in a more suitable care environment, with bigger rooms) [14]
- type of community (living in a rural (dispersed) community may reduce access to end of life care services that can facilitate death at home) [15]
- age (being of a younger age increases the likelihood of death at home – possibly with parental carers who can support death at home)
- gender (being male increases the likelihood of death at home – possibly because female spouses are more able to provide care at home)
- minority ethnicity (increases the likelihood of a hospital death)
- living alone or being unmarried (increases the likelihood of a hospital death)
- hospital bed availability (increases the likelihood of a hospital death)
- availability of palliative care (increases the likelihood of a home death)

- co-morbidity (having several health problems) (increases hospital deaths, but long-term functional disability is associated with more home deaths – possibly because death is unexpected, or because caring provisions, including bed, equipment and services, are already in place) [4, 5].

For some people approaching the end of their life, there will be clinical reasons for admission to hospital, and for some it is their preferred place of care. However, although there are exceptions, hospitals are generally not well resourced to serve the holistic needs of patients, cannot offer personalised care, respond to individual choice or provide familiar and consistent staff, and a hospital ward can be a frightening place to die [16]. Reducing the number of hospital admissions and the time spent in hospital in the last year of life, irrespective of whether or not people die at home, is generally felt to be worthwhile. In addition, hospitals are expensive places in which to be cared for.

Lack of access to support services in the home

Poor access to care services, and lack of support for carers, may increase the likelihood of people at the end of their life being admitted to hospital, often as an emergency. The absence of 24-hour response services and poor access to advice and medication leads to unplanned admissions. In addition, information on people is not always captured or shared effectively between the different agencies involved in providing care. This can mean that an advance decision not to use cardiopulmonary resuscitation is not known about or recognised by providers such as an „out-of-hours’ general practitioner (GP) or the ambulance service, and may result in an inappropriate admission to hospital.

Most people nearing the end of life will spend some time in hospital during their final year. Therefore another reason why death in hospital may occur is delayed discharge, where the person dies before equipment, home support services and transport can be arranged.

Services that are needed to support people to die at home

A National Audit Office report [2] concluded that the proportion of people who die in hospital could be reduced. Services to support palliative care at home must be locally available. There was evidence of variation in local services, including some areas where no 24-hour palliative care or advice services were available. Section 5 of the report identified the type of services that need to be available.

Some research into hospice at home and other support services [5, 6, 7] suggested that it was not the availability of services, but the timing of referral to these services that was critical to achieving death at home. People who are in the last year of life must be referred early enough to home-based hospice and palliative care services. If referral is not made until the last fortnight of life, it may not be possible to change the course and place of death. There are factors that influence the sustainability of end of life care at home, which include the carer’s ability to cope and the provider’s capacity to provide the service for more than a few months. It may be easier to arrange health and social care support at the right time for a person whose illness has a longer, more stable or predictable disease course.

Influence of health condition or disease on dying at home

Much of the literature has concentrated on services supporting people with cancer to die at home, and some of the services available also focus on such care. Cancer care charities have been proactive in designing and funding support services. By contrast, people suffering from chronic obstructive pulmonary disease (COPD) get far less support [8].

COPD

Dying of COPD is associated with high symptom burden, emotional impact, loss of social functioning, breathlessness and poor understanding of and access to information. Compared with cancer patients, end-stage COPD patients have less access to specialist support. It can be difficult to predict the end stage, so care planning may be neglected until there is an acute crisis, which is likely to end in hospital admission.

People with terminal disease other than cancer lose out, even though „ongoing contact with health-care professionals minimizes anxiety and severity of dyspnoea [breathlessness] in the final stages of life’ [8].

Parkinson’s disease

Parkinson’s disease is associated with a progressive decline in motor abilities and cognitive and sensory functions (which may include dementia), and these effects are associated with emotional and mental ill-health and social isolation [9]. Parkinson’s disease is not considered a terminal illness and so the need for palliative care can be overlooked [10], but it is incurable and progressive. Speech difficulties mean that any care professionals involved have to devote time to communication. In Northern Ireland, hospice social workers confirmed that it was more difficult to get services for people with Parkinson’s disease – in contrast, they were automatically available to people dying of cancer [10].

An interview study [9] of patients and carers of people with Parkinson’s disease found that people did die at home often, without specific palliative support, whether or not they had chosen to die at home. All the 15 former carers interviewed had been caring for more than seven years and were surprised at the sudden speed of death: „I knew he was deteriorating, but I didn’t expect him to die too soon.’ Typically, carers had been isolated and were exhausted. Few knew about hospices or domiciliary palliative care services, assuming hospices were only for patients with cancer.

Specialists were regarded as invaluable but difficult to access because of long waiting lists. In addition, the quality of the interaction was sometimes poor and brief, with little information or signposting to other sources of support. „The neurologist saw him every six months and agreed the tablets: they didn’t have a lot of time’ [9]. There was poor communication between primary and specialist services. All the carers agreed that there needed to be an integrated care package.

Stroke

Stroke is the third greatest cause of death in the United Kingdom (UK), and people who have had a stroke may have high support needs. One study [11] surveyed 53 carers of people who had had a stroke, had been ill for over a month and had lived at home

during the last three months of life. It found that the majority of care (personal care, household tasks, taking medication and night-time care) was provided by carers, 43 per cent of whom had to give up work or make major life changes to provide care. The 2007 Stroke Working Party found that despite progress in the development of specialist stroke services in hospitals, one of the most common complaints was lack of support at home. Three-fifths of informants said that the deceased had had problems in communicating and almost 60 per cent reported that the deceased person had needed help with at least seven out of 10 activities of daily living. Less than 10 per cent of the deceased stroke patients had seen a GP weekly; and very few had had contact with community nursing services or access to palliative care. Sixty-two per cent of the deceased stroke patients were aged 80 or older, while 81 per cent of the carers were aged 50 or older, and a quarter of carers were aged 70 or older.

Practice Example 10 outlines a process known as the Amber Care Bundle which supports people at the end of life following a stroke.

Dementia

End of life care for people with dementia is also neglected, despite the increasing number of people dying with dementia. It can be traumatic for a person with dementia to be transferred to an unfamiliar hospital setting.

Unlike cancer, there are few specialist services for palliative care at home for people with dementia. One study [12] evaluated a dementia community support service that had been started six years previously in response to carer demand. The evaluation was not strong in terms of evidence, and involved a very small sample of 14 carers, although it did highlight the difficulties faced by people trying to care for people with dementia at home, many of whom had additional health problems. Eight of the people cared for by the 14 carers died at home, and six in hospital after brief admissions. Issues raised included the following:

- There was no consistency among care home staff coming into the home : „We tried social services’ carers for six weeks. In that time, 21 different people came.’
- There was a lack of support and guidance. Carers had to work out how to provide physical care, despite their own frailty.
- There was insufficient access to specialists. Carers commended the support given by Old Age Psychiatry as „indispensable’ and reliable. Eight carers said that their GP’s support was adequate, but others said that they did not visit, or only came in a crisis, whereas a regular visit would have helped. Three reported that district nurses were indispensable, but four had no input from them at all. Social workers had been involved in six cases. There were repeated concerns about access to services: „With social services, as K was less than 65, she did not fit into a box. So she was not helped.’ ‘Social services had excuses all the time.’ A repeated theme among carers was the need for an identified care professional who would visit regularly. Only two of the patients had access to palliative care services. Most carers would prefer to have access to funding so as to select, and enforce their own standards on, paid carers.

- There was poor access to equipment such as hospital beds and hoists, continence pads and sheets, commodes, wheelchairs, pressure-relieving cushions, Zimmer frames, shower/bath aids and toilet raisers. One said that they were not told that they could apply for free continence pads through the National Health Service (NHS).
- Carers experienced difficulty in managing distress and symptoms.

There was a strong feeling that hospital admission was to be avoided if possible. Several carers cited the distress the person with dementia suffered when in hospital.

„A person with dementia in a normal hospital ward: they just don't go together. One time he was in the hospital they kept calling me again and again to go up there, as they could not cope with him ... The first time he was so disruptive they called security, poor bloke was terrified. He was only frightened and trying to get out.'
(Carer [12])

A research-based literature review [13] on community services for people dying with dementia at home or in care homes highlighted particular issues for care in the community:

- Uncertainty around approaching end of life – It was often unclear that people with dementia were approaching end of life. „Little consensus was found about the value of prognostic indicators for people with Dementia' [13].
- Palliative symptom management for people with dementia – Services and quality of life were found to be poorer than for people dying with other conditions. People dying with dementia were more likely to experience persistent, untreated pain even where they had been assessed using a recognised tool such as the Abbey Pain Scale or the Pain Assessment in Advanced Dementia (PAINAD) Scale. Facial expression, vocalisation and body language were the three indicators felt to be most valuable in identifying pain.
- Decision making at the end of life – In a survey of 84 older people living at home or in transitional care, 75 per cent did not want aggressive interventions, including tube feeding, if they developed dementia. Carers valued advance care planning, but no studies demonstrated the impact of this on outcomes for people at the end of life.

Awareness of specific conditions

The care of people with specific conditions is an issue for commissioners, providers, patients and carers. Carers who attended the SCIE workshop [16] said that they were sometimes shocked by the lack of specialist knowledge about the patient's condition: „What I needed was expert advice on the care of a person with *this* condition.' This is a real problem for generalist and specialist palliative services, and probably best addressed by liaison with specialists.

Limitations of this guide

The SCIE Project Advisory Group highlighted groups of people whose needs had not been considered in this work and so were not present in the research analysed. These included:

- frail older people (who are more likely to live alone, and may gradually decline with no support needs identified)
- people with learning difficulties, who may die earlier than other adults
- people already living in institutions such as prisons and long-stay hospitals
- Traveller communities
- homeless people.

Dying a good death

From the patient's perspective, the national End of Life Care Strategy (2008) defines „a good death' as:

- being treated as an individual, with dignity and respect
- being without pain and other symptoms
- being in familiar surroundings
- being in the company of close family and/or friends.

There is little research evidence directly reporting the concerns and views of people who wish to die at home. There is, however, a wealth of evidence from informal and family carers, who act as advocates for patients. In one study, families commented on some professionals treating the patient as though they were „not all there' or just not there. A patient commented: „They talk to you like you're an imbecile ... I have all my faculties, I just can't walk.' Assumptions were made about abilities and disabilities, yet the Mental Capacity Act 2005 has made it unlawful to discriminate or stereotype people on the basis of a diagnosis. Different staff also did things differently (e.g. ulcer dressing), and were not prepared to be challenged by the patient or a family member [17].

While wishing to die at home, people and their carers found it hard to have a number of different care professionals into their homes; this often reduced continuity of care. Carers from the SCIE workshop [16] and Project Advisory Group said they did not feel they were respected as equal partners or experts within the care team. Some carers made it their business to understand their rights (which are enshrined in section 4 of the Mental Capacity Act 2005) and became „almost qualified' but professionals were still likely to dismiss them. They were concerned that „they will get labelled as the difficult family'. Carers acting as advocates were acutely aware of their own lack of power and dependence upon professionals: „You feel you can't say too much in case you are perceived as someone who is creating too much fuss and they don't want anything to do with you' (Monique, wife of deceased [17]). Another said: „It is too much, you have no privacy, no control over what is happening and if you have control, you have to fight for what you want.'

People approaching the end of life should still be able to take part in valued activities and relationships and to remain in control of their lives. The College of Occupational Therapists has published policy [19] on supporting people at this stage of life based on a „strengths and abilities' perspective. People should be encouraged to make decisions about daily routine and recreational activities.

Access to transport and wheelchairs may make a significant difference to a person's ability to prolong a good quality of life. Having access to the internet can also be a huge benefit for frail people, enabling them to keep in touch with old, and make new, friends and supporters [16]. Initiatives to raise awareness and promote community involvement with people who are dying and their families include **Compassionate Communities**.

Volunteers and neighbours can be invaluable in helping a person who is dying to continue doing what they want to do, and take on activities such as dog walking, so that they can keep a beloved pet. Friends who spend time with the person offer social stimulation and interest, and potential respite for carers. Bereaved family members told us that some „friends’, made uncomfortable by the fact of dying, avoided them; while others made a substantial and lasting contribution to the family’s welfare and ability to support „a good death’.

Identity and diversity

Every person is unique, and care should reflect and respect the individuality and lifestyles of people who are dying and their carers. However, there was no literature on diversity, for example, for people of Romany origin being supported to die at home or the particular needs of younger people who are approaching death. A recent systematic review [20] considered the experiences of lesbian, gay, bisexual and transgender people who were approaching end of life or caring for their partner during end of life. One included study [24] found a preference for care at home among lesbian, gay, bisexual and transgender people, partly motivated by discrimination experienced in other care services, and a high use of advance decisions and statements of wishes, especially where relatives disapproved of relationships.

Patients talked about assumptions made by professional staff at all levels, and by „peers’ in patient and carer support groups. Some people of gay or lesbian identity did not feel that they should have to discuss their sexual orientation with health professionals or to be placed in the difficult position of „colluding’ with assumptions made. „Going into the hospital the first time for the pre-op visit, and having the anaesthesiologist come in, and call me Mrs ... it just made me feel invisible. I’m going to be treated based on assumptions.’ Some patients found that doctors were unwilling to regard partners as primary carers and people to be consulted. „My doctors will discuss information with my partner, but they are less willing to provide her with support. For example, after my latest surgery the doctor didn’t even speak to her. She’s a nurse herself and was shocked ... very shocked’ [20].

This review [20] did not consider end of life care at home, and no other evidence was found on this topic, but good care delivered in people’s own homes should be sensitive to and accepting of all personal choices, identities and lifestyles. There is a clear need for research and guidance on supporting good end of life care within different cultural traditions.

Need for spiritual care and support

One of the reasons that professionals find it difficult to discuss end of life care is uncertainty around the meaning of end of physical life. Beliefs are obviously highly variable. An evidence summary on spirituality and ageing, published by the Institute for Research and Innovation in Social Services (IRISS) in Scotland [21], concludes that there is no agreed definition of spirituality, although the term may often be used to „refer to the deepest values and meanings by which people seek to live’. Although some may perceive it as underpinned by specific systems of faith or religion, it is also a secular concept. In health and social care policy, the authors suggest, „spiritual care is usually

given in one-to-one relationships, is completely person centred and makes no assumptions about personal convictions or life orientation' [21]. Supporting spiritual needs demands that people are non-discriminatory in their approaches, and strive as much as possible to allow the person who is unwell, or at the end of life, to be cared for in a manner consistent with their own beliefs, and religious and cultural traditions.

One research study consulted people about their spiritual needs, and found a lot of agreement, although not everyone had a religious faith or a belief in God. The spiritual needs that people say matter to them are:

- need for support in dealing with loss
- need to transcend circumstances
- need to be forgiven and to forgive
- need to find meaning, purpose and hope
- need to love and serve others
- need for unconditional love
- need to feel that God is on their side
- need to be thankful
- need to prepare for death and dying
- need for continuity
- need for validation and support of religious behaviours
- need to engage in religious behaviours
- need for personal dignity and sense of worthiness
- need to express anger and doubt (Koenig et al, 2001, quoted in [21]).

Merseyside & Cheshire Cancer Network offers an **overview of religious practice** for practitioners working with people from diverse cultures. The extent to which people observe religious traditions, and the meaning and purpose of observance, vary. However, culture involves more than religious belief.

Practice Example 9 describes a culturally appropriate domiciliary homecare service for the Bengali community in East London. There is a **SCIE Social Care TV film** on this service.

The IRISS summary concludes from the limited evidence base that carers can all offer spiritual care by „careful listening ... In intentionally listening to another, the gift of time and attention is offered, as well as support for the spiritual work of hope, meaning and purpose' [21]. In health and social care, „spiritual care' is often used as a short-hand for

person-centred care, and this is borne out by commentary from hard-pressed staff, who lament that they are often driven to include only the basic physical tasks in their care of people who are dying. Listening is closely linked to attributions of dignity and value to the person being cared for.

A research study [25] explored what nurses consider to be „a good death’. As one component of a good death, spirituality seemed to mean taking an active role in discussing the significance of the death and „peace of mind’. „Wellbeing is essential, give them chance to off-load their past experiences positive and negative, it’s nice to just listen.’ ‘A good death is where the patient has come to terms with the fact they are dying, they are at peace with themselves’ [25].

A review of spiritual care [26] found that few studies addressed the need for education, training and reflection among professionals working with people at the end of life. A number of UK models described in the review used open core questions, such as: „When life is hard, how have you kept going? Is there anyone or anything that has helped you keep going?’ Some studies have focused on spiritual distress, said by hospice nurses to arise from the loneliness of dying and the person’s struggle to accept dying, but also if there has not been reconciliation with significant others. UK guidance says that spiritual needs should be assessed [26] but does not say how they should be addressed. A retrospective audit for the national End of Life Care Strategy of documents completed for the Liverpool Care Pathway record found that only 50 per cent of conscious patients had their spiritual needs assessed, 42 per cent of whom had an identified religious affiliation [26]. Much of UK practice is about not offending against or contravening religious practice.

There is very little research on the health benefits of spiritual care [26]. There is general agreement that health and social care staff can and should be trained to recognise spiritual and/or religious needs, and that work on spirituality should make links with other initiatives, such as Dignity in Care and Compassion in Practice.

Ascertaining patients’ wishes: advance care planning

Anyone expected to die within 12 months should have a care plan that covers arrangements when the person is unable to communicate. An advance care plan is important for people wishing to die at home. Part of the purpose of the plan is to ensure that services are provided in the home, and to steer professionals away from actions that jeopardise the person’s desire to end their life at home. The advance care plan should be drawn up with the service user (while they have capacity), and with the family and primary carer(s), and at least notified to the GP and other professionals. It is, however, a living document, and may change when a person’s condition or wishes change.

The plan may include preferred place of care, preferred place of death, whether and in what circumstances the service user might wish to be admitted to hospital and whether they have made any advance decisions to refuse treatment and/or a lasting power of attorney for health and welfare decisions. To be effective, the care plan should be available to all those who have a legitimate reason to access it. All systems for coordinating end of life care, including the Gold Standards Framework and end of life locality registers (such as electronic palliative care coordination systems – EPaCCS – or

palliative care registers in Northern Ireland) should include these aspects of the service user's wishes, and consent should be sought from the patient to share this data with those who need to know. In reality, however, it can be difficult to ensure that up-to-date electronic records are adequately maintained and accessible at all hours of the day or night. Social care staff and ambulance crews may rarely be able to access them, so patients and carers might like to keep one to hand (see Practice Example 6). A member of the SCIE Project Advisory Group frequently changes her plans, and keeps an updated copy with her at all times.

Advance care planning may also include legally enforceable commands:

- advance statements to inform subsequent „best interests' decisions (sometimes called „statements of wishes')
- advance decisions to refuse treatment, which are legally binding if valid and applicable to the circumstances at hand
- the appointment and registration of lasting powers of attorney („health and welfare' and/or „property and affairs') [22].

An advance decision to refuse treatment may include the choice not to undergo cardiopulmonary resuscitation (a DNACPR notice – do not attempt cardiopulmonary resuscitation) in the event of a future cardiac arrest (heart ceasing to pump). Locums and ambulance staff attending an emergency home visit may not know of the existence of an advance decision, or may be unsure as to whether it is valid and applicable. In order to be valid, such a statement should do the following [27]:

- It must be made by someone aged 18 or over who has mental capacity. (Those under 18 can make a statement of wishes, which will carry weight in any best interests decision making.)
- If the person is refusing life-sustaining treatment, it must be written, signed and witnessed, and it must include the statement: „it is to apply even if life is at risk'.

Advance statements of wishes and care plans are highlighted in policy literature as essential to patient choice and dignity during the last days of life (including the Gold Standards Framework, National End of Life Care Programme publications and Liverpool Care Pathway). It is in the interests of professionals to establish the patient's preferences, and any professional engaged with the dying person is encouraged to ensure that preferences are established. However, there are many examples throughout the research literature of service professionals – from GPs to domiciliary support workers – who find it difficult to initiate the conversations that will elicit the wishes of the person who is dying. It is also reported (see below) that some patients do not want to admit that they are approaching death, and do not want to discuss end of life matters. It is then relatively easy for staff and patients to collude in avoiding difficult conversations.

One qualitative research study [23] consulted GPs and district nurses about establishing preferences around death and found the following:

- People's views were often ill-defined or poorly formed and frequently changed over time. Choices were „often' expressed as an inclination rather than categorical preference. People might change their minds to spare suffering of families, or because they had had respite care in a hospice and were minded to remain. In some cases, patients would not discuss issues as they had not accepted the prognosis.
- Preferences were often said to have been inferred by the health professional, without direct questioning or receipt of definitive statements from the person.
- GPs and nurses found it easier to discuss if patients referred to their own death, otherwise they felt wary of denying the hope of recovery. Sometimes it was „impossible, unethical or potentially damaging to the doctor–patient relationship' [23] to discuss preferred place of death.
 - „Undoubtedly, there are some people who need to keep going by denial and, you know, they don't want to talk about it.' (GP [23])
 - „The patient's convinced that the treatment ... is going to make them better ... you wouldn't dream of talking to them about where they want to die.' (District nurse [23])
- Inherent uncertainty challenged the practicability, usefulness and value of recording a definitive preference. People's choices changed when symptoms became unmanageable, distressing to them and carers, or carers seemed unable to cope. Some respondents recalled cases where death at home was impractical, for example if there was no family carer. In crisis situations, „earlier preferences tended to disintegrate and patients were often unable to form or communicate new ones' [23].
- Professionals did admit to personal inhibition about opening the discussion:
 - „I must admit sometimes ... I chicken out and leave it for [the home care teams] to do because it's one of the questions that they'll ask when they do their assessment.' (District nurse [23])
 - „I find it very difficult, still ... It's an easy cop-out to say the nurses are much better at it ...' (GP [23], who also implied that GP visits are too short to get around to such matters)
- Enabling people to die at home if they choose to is used within the Gold Standards Framework as a proxy for the effectiveness of palliative care delivery. Interviewees thought that recording preferences could be misleading if people changed their minds at a later point – and at times changed the record so that audit figures „were fairer'!
- Macmillan and other specialist palliative care nurses do not report the same reluctance in themselves, or in the people they care for, to talk about death,

and it seems likely, as one GP admitted, that professionals are „chickening out’ of having these conversations. Carers who attended the SCIE workshop [16] commented:

- „That’s a great skill the Macmillan nurses have. They enabled us to have the conversation [about what the person dying wanted their funeral to be like].’
- „We were able to ask what would happen.’
- ‚I can’t understand why the NHS can’t pick up practice from the voluntary sector.’

Training staff to initiate difficult conversations while remaining sensitive to the patient’s response is important. People’s willingness to discuss death is likely to vary over time. Recording a person’s wishes for care, death, funeral arrangements, gifting of belongings, and involvement of family members is unlikely to be established during one discussion.

People who are dying may also want to make wills, send messages to friends and family members, arrange pet care, set up provisions for care and funding for children, and generally ‚tie up loose ends’. These areas are less likely to concern health and social care practitioners but may involve social workers. These issues may be vitally important to the person’s ability to die in peace. Family carers, friends and neighbours, as well as befriending schemes staffed by volunteers, may provide invaluable support and advocacy in these circumstances. Practice Example 1 illustrates a volunteer befriending service.

Meeting carers' needs

In this guide, we have used the term 'family carer' to mean a person or people identified by the person dying (where possible) as important to them, and it is intended to cover a spouse, partner, child, other relative, friend or supporter who cares for, and cares about, the person who is dying. Where a person is dying at home, the primary meaning of 'carer' is a person who delivers everyday care to the dying person. NICE guidance on cancer care defines carers as: 'lay people in a close and supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management' [34]. This definition is equally applicable for the purposes of this guide.

The choice to die at home is often judged unrealistic without the input of family carers [28]: having a live-in carer to assist the person dying is probably the most important factor in enabling the person to die at home if they wish [4, 5]. There are currently estimated to be around 500,000 carers in the UK supporting people with a terminal illness [28], and the need for carers will increase as more people die later in life and with more complex needs and there are fewer informal carers (such as spouses) to support them.

Paid support staff such as housing support workers [35] and visiting nurses and healthcare assistants can deliver adequate cover to support a person living alone to remain at home if that is their wish.

Dying at home can have consequences for the bereaved family. The home or parts of it may be a continual reminder of the person who has died. This may be positive or negative. It may make it difficult for the family to sell or move away from the home (16, SCIE Project Advisory Group, dying person). People dying and their carers may change their minds about their preferred place of death during their last days of life due to limited or poor support in the home.

The value of informal care

The support provided to frail and disabled people by family carers was estimated to be worth £71 billion to the health and social care economy in 2007 (Carers UK, quoted in [3]). However, the nominal value of informal or unpaid care is rarely taken into account in studies that consider the relative costs of dying at home, in a hospice or (more expensive still) in hospital. This is unfortunate, as all our sources (published evidence, SCIE workshop [16] and expert sources) suggest that carers often do not receive adequate support and assistance, which could be paid for from these savings (see Costs of dying alone, page 52). Research, and carers who attended the SCIE workshop, suggest that most carers are motivated by love and commitment, and they are ambivalent about expressing their own needs at the time of caring.

The views of carers on end of life care services

Given the frailty and common communication difficulties of people who are dying, the views and observations of carers on end of life care services are often the closest substitute for those of the dying person. This guide also provides details of carers' views on services in the appropriate sections on services and staff.

Practical and information needs of carers

The SCIE workshop with carers [16] concentrated primarily on the difficulties experienced in getting adequate, if not high-quality, care to the person they cared for. Their first priority as a carer was to understand how they could provide good care, and how they could access professional specialist care and advice. Their own needs, for example for emotional support, tended to be subsidiary to this main focus, although the obstacles encountered in procuring care and equipment substantially added to the emotional and mental stress they experienced. For this reason, this section considers first the practical support carers need to provide good care to the people they are caring for.

A sample of district and specialist palliative care nurses [36] considered that family carers were often unprepared to take on the 24-hour care of a loved one when they left 24-hour hospital care. Some carers initially expected community services to be available at all times, and even expected to be able to return to work, and this may not be an unreasonable expectation for a person who has no experience of NHS and social care services provided in the home. The burden of caring was particularly difficult if the illness was lengthy, although „where you have got big families, where there is more resources in terms of care input from the family, people are more likely to remain at home’ (community nurse specialist [36]). The involvement of a wider family group could, however, raise conflict in how and where the person should be cared for.

A systematic review of caregivers’ practical needs in providing home-based end of life care to people with cancer was undertaken [29]. The authors concluded that the emotional needs of carers have been extensively researched, but their practical needs with respect to the provision of physical care are yet to receive systematic attention. The review brought together research on carers’ experiences, and focused on all aspects of physical care, nutrition, medication and symptom control. It concluded that:

- Carers delivering palliative care are the primary carers, but they often lack the information to help them provide palliative care, and therefore adopt a „trial and error’ approach.
- Day-to-day palliative care (for people with cancer or other conditions) typically involves incontinence care; diet, hydration, feeding and swallowing; access to specialist services or equipment; general patient comfort, including positioning and lifting, medication and symptom management. The carer at home needs information on all these areas of care.
- Carers frequently said that health professionals seemed reluctant to provide informal caregivers with adequate information and guidance. At the same time, „health providers often retain unrealistic expectations regarding the extent to which family members may be comfortable undertaking these practical nursing tasks’ [29].
- Informal caregivers wanted education and training, ideally from either being directly involved in practical tasks carried out either on wards before discharge or by visiting nurses and professionals.

- Learning should be supported by clear written material and telephone access to help in day-to-day caring and in the event of emergencies.
- Any educational initiative needs to take into account the effects of the physical and mental strain of caring, distracted attention and a poor capacity for memory on a carer's ability to learn.

The review demonstrates the additional pressures and anxieties that carers experience when they are not supported in caring tasks.

However, this review does not entirely reflect the struggles that the carers who attended the SCIE workshop went through in order to get services to provide support and equipment. Battles for equipment and funding were common: „The sheer bureaucracy [of getting equipment installed] really inhibits people who want to help' [16]. Carers highlighted awareness of systemic issues – not only did they not know how to access equipment: professionals also appeared not to know. One participant had support from a sympathetic social worker, but „she could not influence health services because they are not integrated'. These battles are undertaken from a standpoint of ignorance of services, and people do not know what is available, or what they or the person they care for may be entitled to. „I was 45 years old before I had any dealings with health services; you cannot assume any knowledge of how things work' [16].

Carers at the workshop said they did not know how to recognise when death was approaching, and might not know when palliative care was needed, but having to „push' for it meant that they had to make judgements. They also had little specific information about the last days before death: „Not knowing what to expect from the dying process. If we tackled this in education, would it help?' Professionals going into the home were often focused on tasks, and did not take a long-term view: „The [nursing] agency sent 14 different people in the space of two months. If they'd sent the same person, they would have spotted the differences as he deteriorated.'

The Marie Curie Cancer Care publication „Being cared for at home towards the end of life' [30] is an excellent guide on some of the practical issues that carers and patients need advice on, including practical illustrated tips on handling and turning, likely indicators that death is near, and sources of further support.

Communication between family carers and care professionals

Research with carers was undertaken to underpin the 2012 guidance from Marie Curie Cancer Care [1], and to provide content for the award-winning [Healthtalkonline website](#), which is designed to improve public and professional understanding of people's experiences of health and illness. The guide emphasises carers' need for honesty and information from professionals. Carers felt that:

- GPs were often not honest about the severity of the patient's condition
- professionals gave test results and did not take the time to explain them in detail

- professionals needed more training to understand the support needs of people at the end of life.

One carer said of her experience: „It felt like I was on a treadmill and I had to find out everything as I went along’ [1].

Carers generally do not feel that their expertise and observations are valued. Professionals going into the home often do not listen to them, nor involve them in planning the care that they themselves may have to deliver. Carers may also be forced into advocating for and coordinating care, as they may be the only people who liaise with all care providers. Carers want better coordination and information sharing between providers „to save carers telling the same story over and over again ... and to prevent contradictory advice’. „They [providers] should organise themselves into a coherent team’ [16].

But doctors and care staff do not necessarily see the carer as someone who needs information about the cared-for person, never mind as a partner in care. Carers who attended the SCIE workshop [16] found that some providers used „patient confidentiality’ and „data protection’ as a reason not to involve carers and family members:

„There is a real barrier to good care in “patient confidentiality”, which prevents GPs, for example, from informing carers. This is not in the patient’s best interests.’

„I had to make an appointment to tell my father’s GP what was really happening as he would only talk to my mother. She was in denial: the account I gave him changed my father’s treatment.’

The patient should be encouraged to nominate a person who can share care information (as applies in the United States). Although spoken consent to share care information is valid, this may best be recorded in writing with the patient’s signature before they lose capacity. If the patient consents to information being shared, there is no barrier to doing so: should they wish to exclude any family member from having personal information, this is an opportunity to say so. Care professionals should alert patients to the need for specific consent to share information with family carers if they intend (often incorrectly) to invoke patient confidentiality as a reason not to share information. At some point, patients may lose capacity to give consent, in which case professionals must act within the Mental Capacity Act 2005 [37], which says that decisions must be made in the person’s best interests. Excluding family carers from information important to the person’s care and wellbeing is likely to be unlawful, particularly if the family member is the person’s main carer.

Carers at the SCIE workshop [16] said that they were sometimes expected to make decisions on life and death issues, for example whether to take the person to hospital or let nature take its course, with no acknowledgement of their own need for information and emotional support. Carers said that there was little acknowledgement of the fear they might experience.

Financial support and benefits advice

The review did not reveal any research concerning carers' need for financial and benefits advice, both for themselves and for the cared-for person. Some carers said they gave up paid employment in order to care. They struggled to claim benefits, which arrived too late:

„It came back as the middle rate, and I knew at the point at which it came back at the middle rate, that actually, he was no longer, his circumstances had changed and, actually, he was eligible for higher rate. So I then had to, not appeal, but then I had to do a change of circumstance form and we got the decision about the high rate DLA [Disability Living Allowance] on the Saturday and he died on the Monday.’ [1]

A carer who attended the SCIE workshop said: „It was six months before we got any financial support. Our petrol bill quadrupled (with clinic appointments and other essentials); we are only just recovering financially’ (five years on) [16].

Wider needs of caregivers

A systematic review of 123 papers [31] assessed the needs of carers supporting a person at the end of life using questionnaires to which a numerical value was applied to answers, for example, a high score was given for symptoms of poor mental health. This approach is considered more „objective’ than personal accounts. The review found that the following impacts and needs were demonstrated:

Psychological difficulties:

- depression and anxiety
- feelings of powerlessness and helplessness
- low caregiver esteem
- physical and emotional stress
- psychosocial difficulties.

Financial and occupational difficulties:

- financial strain; need for financial support/advice
- occupational disruption
- activity restrictions
- social dysfunction and relationship challenges.

Patient care difficulties:

- need for direct help or guidance regarding practical aspects of care

- being unable to leave the person unattended.

Dealing with the physical demands of providing care:

- need for respite care
- need for help with household tasks
- need for communication and information
- physical health impacts and challenges
- sleep disturbances and insomnia
- fatigue.

The same research team identified 105 qualitative research articles reporting the expressed views of carers of people at the end of life [32]. In summary, these articles highlighted the following:

Difficulties of caring:

- intense, negative, conflicting and difficult emotions (fear, guilt, hopelessness)
- patient suffering and deterioration
- stress of physical demands, including sleep disturbance
- lack of information on personal and physical care and symptom management, including from formal providers
- lack of support for the caregiver
- feelings of inadequacy, insufficiency and uncertainty about their abilities
- lack of information about disease and its course – inconsistency of information from different providers
- bereavement, which can herald more distress, remorse, haunting images of suffering
- social isolation
- desire for „normalcy’ – some engagement with normal life (possibly through respite care).

Relational aspects of caregiving:

- The care recipient (the person at the end of life) may continue to care for their carer.

- The caregiver may view their role as a natural extension of the marital or son/daughter role.
- The caregiver may have to negotiate with the dying person to accept services.
- Family conflicts may need to be dealt with.

This review [32] also used interviews and focus groups, which allowed caregivers to comment on what helped with caring:

- They said that it helped to have a good relationship with the person dying (and with other family members): when the dying person appreciated their care, they had a more positive experience of caring.
- They emphasised that trusting relationships, support networks and sharing tasks contribute to security, reassurance, comfort and manageability, and mitigate anxiety, stress, uncertainty and feelings of abandonment.
- They appreciated provider services that are competent, adequate, flexible, coordinated, with information and advice and caring staff who they can enjoy good relationships with.

Some findings „emphasise a need to recognise caregiver expertise and ability and affirm their self-worth’ [32].

Studies also found that caregivers were ambivalent about saying what their own needs were against a background of lack of information about rights, lack of time and discomfort in confiding in strangers [32]. Caregiving may be perceived either as a loving or conscious choice, or as an obligation. Commitment and satisfaction with caring provided greater resilience to stress and burnout.

These reviews also identified rewarding and meaningful outcomes of caring for a loved one. Carers who attended the SCIE workshop [16] were committed to providing love and care, despite the difficulties and frustrations. Research suggests that the quality of care that loved ones receive and the „quality of death’ are extremely important to the experience of bereavement. Carers gained comfort from the knowledge that they helped a loved one to die comfortably, and the final days spent at home were remembered as rewarding:

„You could feel it in her and it was the remarkable increase, again, in her spirits and that’s all I can say. So, no, I had no hesitancy in agreeing, well, it wasn’t agreeing, in saying: “Yeah, you can come home.” And, as it turned out, it was a wonderful development’ [1].

After a person dies, a carer who has been supported by health and care practitioners can miss the contact and feel very alone:

„I missed them. I really missed them because I just didn’t see them. I see one of them up at the pool and we, you know, we have a chat now and again. But you’re ... the wife of a patient and they’ve got loads of other patients so obviously, they move on to

the next person but it was so quiet when Bill had died and my son had gone. Nobody dashing in at nine o'clock and half past to wash him and see to him. No care manager ringing. No Macmillan Nurse coming in and I really missed them all. It was just very, very strange. I think that's quite a common thing.' [1]

Evaluating support for carers

A systematic review [33] considered psychosocial interventions for family carers of palliative care patients. The approaches considered were varied and not well described. They included: a pain management training intervention; a counselling and support group for carers of people with Alzheimer's disease (which had a positive effect on depression); and a brief behavioural sleep intervention, which showed some improvement in sleep and depression scores. An intervention promoting self-care had no effect on carers' wellbeing, possibly because full-time carers do not have the option of prioritising self-care. There were positive results for programmes designed to prepare carers and families for end of life care, but it was reported that carers found it difficult to attending educational and support programmes outside the home. Even telephone support did not work for some people who could not find the time to take part. „On the job' training in care did not require the carer to leave the person they cared for, and ensured that all the practical aspects of care could be done in a specific home setting.

There is a large body of research on carers' needs, and on the adverse impact of caring, but little on the experience of specific groups, such as male carers, young carers and parent carers of people who die at a younger age. There is little published research on support that will address these carers' needs [28].

The focus of carer interventions is repair (when carers cannot cope) and reacting to crises, rather than proactively trying to avoid crises [28]. Early and timely advice and support could prevent hospital admission: „A little low-level timely advice and support could avert a crisis. You're only allowed paid help if you have substantial needs – so there is no prevention' (carer [16]).

Carers' assessments

It is not known whether and how local authorities, and health and social care trusts in Northern Ireland, carry out statutory carer assessments, and whether these assessments are followed up with appropriate support. „In Community Care Act, there is carers' assessment, so it is already in law: it should be offered, but it isn't happening. And the assessments I had very rarely resulted in any action at all. Every carer should have an action plan' (carer [16]). Assessments should therefore result in action plans to support carers, and which are implemented: this should also be a statutory right, since assessments are pointless if they do not address need.

Carers who attended the SCIE workshop [16] did not necessarily identify themselves as carers, with their own needs and rights, and this may affect help seeking: „I didn't class myself as one until I started volunteering [as an expert in caring, after his daughter's death]: I was her father.' 'I felt the same: I was his wife.'

What do carers think had helped them?

Carers who attended the SCIE workshop [16] did not look for „interventions’, nor necessarily for respite. Above all else, they wanted better services that they did not have to fight for, alongside the exhausting process of caring for the loved one. They had a clear view of what had helped them, and what would have made a difference to them. The following is a selection of written comments from the group.

What helped?

- Discussion about choices in all areas.
- Support which reduces isolation and fear.
- Sensitivity from professionals so people can come to terms with facts.
- Trust in professionals.
- Providers having listening skills.
- Support from neighbours (including someone who would sit with the person to give carer a break; volunteers to walk the dog)
- A cancer charity’s befriending scheme.
- Alzheimer Society’s carer support worker (sympathetic, but could not influence services).
- Direct payments to choose own carer, reducing the worry about quality of care given, though they might need expert training
- Social worker to help with practical area such as direct payments, but also able to give emotional support.
- Comprehensive support through a lead professional:
 - „Our District Nurse was incredible – on the day [our daughter] was discharged as incurable, she arrived an hour after we got home. She said, “I know [hospital-based nurse] and so I know about you: what can I do to make you comfortable?” We had a pressure mattress and a bath chair within 24 hours.’

What would have made a difference to them?

- Communication, communication, communication with professionals: „Absolutely vital ... Carers are the key workers, so it is very important for professionals to listen to them.’
- Better professional skills & knowledge, and better basic nursing care.

- 121 support: „Having one named person who will “walk the walk” with you.’
- Having support from a significant other in addition to me, and for me.
- Continuity of support (a particular issue with agency staff).
- Respect for cultural differences.
- Mature, open, adult conversations with professionals (not being talked down to, patronised).
- Time from care professionals for carers themselves, to listen and advise them.
- Person-centred training for professionals.
- Informal support networks.
- Greater integration of health and social care.
- Palliative care teams for conditions other than cancer: „I had previously cared for my Mother, and the palliative care nurses were brilliant: but they said palliative care nurses were only available for cancer.’
- Professionals should „think family’ and consider needs of family: paid carers getting to know the family well.
- More community participation to reduce family’s isolation:
 - „We don’t know, as a society, how to talk about death. We lost friends, they didn’t know how to talk to us.’ ‘People want you to be “fixed” quickly. This last Christmas, five years later, was the hardest yet.’

The main message from the carers’ workshop [16] was that primarily they wanted better services:

- higher quality of care
- care delivered with respect by people committed to caring
- continuity of carers
- explicit involvement of family carers by professionals.

Although their own needs were secondary, it is clear that carers felt isolated and unsupported. Befriending schemes that coordinate volunteer support to people dying and their carers may be invaluable. Practice Example 1 outlines an example of such a scheme, developed by a hospice.

Available research does not confirm whether more concrete interventions or programmes might be useful to carers, or whether individual or group support is preferable, although it is likely that their caring responsibilities would not allow group

attendance before the death of the person they care for. At this point, the impact of the caring role may leave them psychologically, physically and financially diminished.

It was not possible to cover post-bereavement services and interventions in this guide, but it is clearly important that support after bereavement is provided to carers so that they can achieve whatever recovery, resolution or comfort is possible for them. Caring for, and losing, a loved one is a traumatic and life-changing experience; with the right support, it can also be a positive one [16].

Coordinated care

A person who is dying at home may receive support from a range of health and social care staff. They may include:

Health:

- GPs and their out-of-hours services
- district and community nurses
- healthcare assistants
- specialist nurses (cancer care or palliative care) providing hospital or hospice services at home
- ambulance paramedics
- occupational therapists.

Social care:

- social workers
- domiciliary (home) care workers.

Some of the services available to people expecting to die at home are provided by people with „specialist’ training in palliative care, but more commonly care at home is delivered as part of the general workload of health and social care staff. Specialist palliative care is:

„The active, total care of patients with progressive advanced disease and their families. Care is provided by a multi-professional team who have undergone specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support.’ (Tebbit [40])

In the home, care may also be described as delivered by a „team’, including hospice at home and rapid response teams. Generally, the team is represented by a single nurse or healthcare assistant with specialist training, who should have access to specialist support and advice from a consultant or senior clinician.

Approximately 70 per cent of the 500,000 people who die each year need palliative care. Only about half of these people receive it in any location (hospitals, hospices, care homes or at home). The majority of these will have advanced cancer, but those with end-stage organ failure, neurodegenerative diseases and advanced dementia also need timely access to such care. Specialist palliative care is not available to all who may need it and health and social care services may have to prioritise those referred to them with the most complex needs. There are no national criteria for receiving these services, so who gets them may vary locally [40]. Some specialist services (e.g. Macmillan

nurses, Marie Curie nurses and hospices) are provided by charitable third sector organisations, largely for people dying of cancer.

This review did not find any evidence of good liaison and support of people dying at home by specialists in specific diseases who are hospital based although some patients attend hospital outpatient appointments. Carers [16] highlighted the need for themselves, generalist and even specialist palliative care professionals to have more information on disease-specific symptom management and the likely course of particular terminal diseases.

General practitioners (GPs)

End of life care in the home is led by GPs and much of it is provided by district nurses. There is not a lot of published evidence about GPs' views on, or experience of, end of life care.

Seventeen GPs and 16 community nurses were involved in a study [23] exploring their experience of establishing preferred place of death with terminally ill patients. The strongest message conveyed by the participants was that preferences could vary as symptoms, and the perceived 'burden' of caring, changed: „and they will say, “well, I'd rather be in a hospice and not cause stress at all” ... so you can't always get a yes/no answer in these kinds of situations'. Choices were „often' (but not always) expressed as an inclination, rather than a categorical preference, and might change over time.

Carers have suggested that GPs are reluctant to discuss the patient's dying status [1] and this is borne out by GP commentary from other studies [23]. In some cases, GPs and nurses said that patients would not discuss, and had not accepted, the prognosis. „I don't ask them their preferred place of death. I'd ask them, “how are you managing, how are you getting on, is there anything ...” (GP [23]). Sometimes it was „impossible, unethical or potentially damaging to the doctor–patient relationship' to discuss death: „Undoubtedly, there are some people who need to keep going by denial and, you know, they don't want to talk about it' (GP [23]).

A small interview study [38] of 10 GPs involved in caring for dementia patients in the community found that, with this patient group, it is very difficult to define when to stop active treatment: patients could, for example, recover the ability to eat. Familiarity with the person was helpful:

„It's much easier to look after somebody with dementia if you've known them for years and years ... you've seen them gradually decline and you sort of know yourself that they're slowly dying.'
[38]

Another suggested:

„What you try and do is to get a flavour from the people who have responsibility for their care as to what it is they would have wanted ... if you can't get it from the person themselves.' [38]

GPs felt that there were no guidelines to help them determine when end of life was near, but the issue they were most concerned with was difficulty in finding out what the

patient might have wanted. GPs in this and other qualitative studies did not seem to recognise the provisions of the Mental Capacity Act 2005.

Comments from nurses working in primary care settings [42] suggested tensions in the relationship between them and GPs. They described strategic moves to get what they considered the best care for the patient. „If you have got a foot in the door at the hospice with a patient, if the situation with the GP unfortunately breaks down, there are other avenues ... that sounds like we are all playing games ...’ (palliative nurse specialist). Nurses said that GPs did not call in nursing services sufficiently early in the decline of a patient, and this could mean they were less effective in the palliative stage. Nurses’ comments suggested that they felt they had to make a good impression on GPs, but GPs did not seem to share this perspective: „In good practices, the GP obviously plays quite a leadership role in actually helping to ... bring people together and discuss and facilitate discussion ... I think the district nurse is far more knowledgeable than the average GP’ (GP [42]). Most of the GPs interviewed in this study said that they held the opinions of community nurses in high esteem: „They see patients more often, I think they’re a bit more proactive than I am, so they tend to see, they tend to pick up problems that I’ve not identified’ (GP [42]). However, a researcher noted of an observed meeting:

„The meeting was dominated by the GPs who took the lead in deciding which patients to discuss ... The district nurse appeared to know most of the patients discussed, but only participated to volunteer information when asked, not of their own volition.’
(Researcher [42])

A study conducted on the impact of the Gold Standards Framework in primary care [43] concluded that hierarchical doctor–nurse relationships persist, but that the best-functioning teams use a mixture of formal and informal „meetings’ and a non-hierarchical working style.

Some of the SCIE Project Advisory Group members said that GPs tend to transfer patients to hospital because they are „risk averse’ and have professional ethics that put preservation of life first, even when the patient has expressly chosen to refuse treatment. It is also likely that, as suggested above, they are not confident in making a judgement that the end of life is near, and may not have found a way to discuss the wishes of the dying person.

There are particular difficulties for GPs providing out-of-hours cover. Unless they are briefed by the practice, they may know little about the person they are called out to treat. This review found no direct evaluation of the role of out-of-hours GP response services in end of life, although anecdotally [16] and scattered throughout the literature (e.g. [41]), there are references to out-of-hours GPs having no information on the patient, being unwilling to prescribe palliative care drugs and tending to admit the patient to hospital as a risk reduction strategy. Having information about the patient’s diagnosis, prognosis and, crucially, their wishes for end of life care is vital if regular, locum and out-of-hours GPs are to support people wishing to die at home. The introduction of an electronic palliative care coordination system (see the section „Commissioning’) should enable these data to be accessed, but only if GPs or other

general practice staff can initiate the conversations needed to record the patient's preferences in this database.

District and community nurses

Community nursing is provided most commonly through district nurses who work within primary care teams. District nurses work in the community with GPs, who refer patients to their service. A larger service will consist of community nurses and healthcare assistants, led and supervised by a senior nurse with a specialist qualification in district nursing. District nursing teams provide most hands-on nursing in community and end of life care, and may be supported in this work through advice from clinical nurse specialists in palliative care. They are generalist rather than palliative specialists.

District nurses visit patients in their own homes to carry out a range of nursing tasks. They are very likely to be involved in providing care at the end of life. Studies identify a tension between holistic and task-oriented nursing: where nurses prioritise routine physical tasks over psychosocial support for patients and carers, they may be reflecting both the emphasis in nurse training, and their large and varied caseloads, which leave them little time to do more [8].

A review of district nursing [42] suggests that district nurses do not quite know what their role in end of life care should be. Patients also report not knowing, for example, whether district nurses can help to liaise with other agencies to coordinate care. District nurses are trained to deliver physical care, but may struggle with psychological aspects. Despite some emphasis on the importance of personal relationships, they may distance themselves from patients and families to avoid confronting issues around dying. District nurses may also describe relationships with other professionals as poor, suggesting that their expertise is undervalued.

In some areas, district nurses work with community nurses, often in a supervisory capacity. A qualitative study of 51 community nurses across four London primary care trusts [39] found that district nurses did feel they had a central role in delivering palliative care, and coordinating care (e.g. with GP, Macmillan nurse), and that this included emotional support and counselling. This holistic role was not recognised by other professionals, who seemed to see community nurses (with or without the district nurse qualification) as being everyone's 'gofer'. They felt they had lower status than nurse specialists in palliative care [39].

Workloads, and the number in need of end of life care, were unpredictable: „for a few months, we'll have nothing, and then all of a sudden we have ten or fifteen ...'. This impacted on the ability to provide holistic care, even when they wished to. Sometimes they had known and cared for patients with long-term conditions for years: „You would like not to have to rush off; you would like to do the little things that just make that person's life a little bit more variable ... and that's heartbreaking when you're having to drive away ...' [39].

In addition to a very wide range of nursing tasks with patients at different stages of illness, most community nurses described a backlog of paperwork and overflowing in-trays.

One study explored what community nurses thought contributed to „a good death’ [25]. Eight themes emerged:

- Symptom control

- „A good death is where the symptoms are managed proactively and not reactively.’

- Patient choice

The choice to die at home needed to be understood by everyone involved in care.

- „The GP couldn’t understand why the family didn’t want her admitted, so it became a battle.’

- Honesty

- „The family were aware at every stage of all the possible things that could happen and they took it on board. There were no surprises for them.’

- Spirituality

This meant taking an active role in the significance of the death for everyone, with particular reference to „peace of mind’.

- „Wellbeing is essential, give them chance to off-load their past experiences positive and negative, it’s nice to just listen.’
- „A good death is where the patient has come to terms with the fact they are dying, they are at peace with themselves.’

- Good interprofessional relationships

Nurses said that this was challenging, as some GPs did not communicate well with nurses, and did not understand the emotional dynamics. Out-of-hours locums would often refuse to prescribe opiates. Communication between out-of-hours and day staff was problematic, with a formal handover offering the best guarantee of continuity of care.

- „Communication between nurses and GPs is not friendly ... they are not emotionally involved, but we are.’

- Effective preparation

- „The most beneficial thing I found was having the drugs in the home, to be able to administer when you need to, instead of going through the OOH [out-of-hours] service and having to wait for drugs.’

- Organisation
 - Timely access to pressure-relieving mattresses, syringe drivers, hoists and commodes was important.
- Provision of seamless care throughout

Many found closure in staying at the patient's home for a short time after death.

- „We laid the husband out together, got a rose and made him look peaceful and nice.’

The Gold Standards Framework in primary care

The Gold Standards Framework (GSF) is a systematic, evidence-based approach to optimising care for people nearing the end of life with any end-stage illness in any setting. The purpose of the Framework is to help people live as well as possible when they are approaching death. In primary care, the framework aims to enable and improve palliative care in the community, helping more people to die at home if they choose. Box 1 lists the seven recommended processes in primary care for end of life care. Strategies for improving coordination of care and teamwork include the keeping and sharing of registers of patients at the end of life, team meetings and strong communication to promote coordination and continuity of care [43]. Non-hierarchical relationships and mutual respect are thought to foster good teamwork [43].

Box 1: Recommended processes for end of life care in primary care: the seven Cs

- Communication – Maintaining a supportive care register of terminally ill patients, regular multidisciplinary team meetings, patient-held records.
- Coordination of care – Practice coordinator to ensure the smooth running of palliative care procedures. Named GP and district nurse for each patient.
- Control of symptoms – Holistic assessment of symptoms. Use of symptom assessment tools.
- Continuity out of hours – Sending details for terminally ill patients to the out-of-hours provider. Leaving drugs in the home that can be anticipated as being needed (e.g. diamorphine for a syringe driver).
- Continued learning – Audit of palliative care delivery, practice/patient-centred learning, including significant event analysis.
- Carer support – Identifying carers' needs. Keeping a carers' register. Offering practical, emotional and bereavement support.
- Care in the dying phase – Use of a protocol or a pathway to ensure good practice.

Source: Adapted from Mahmood-Yousuf et al (2008) [43]

In other studies, researchers have also concluded that „effective primary palliative care appears to require good team relationships and robust processes’ [43].

A discursive evaluation of the GSF in primary care settings [43] explored the views of district, community and Macmillan nurses from 15 primary care practices on relationships between GPs and nurses. Nurses said that the framework had encouraged GPs to refer patients earlier for end of life nursing care: „I think GPs are much more aware now across the board that we [district nurses] are there to see them when they are well, and they don’t hang on to them until they are really poorly’ [43]. Early referral enabled nurses to establish a rapport with patients and their carers before the person became too debilitated, and it was more likely that patients could communicate social, spiritual or other needs. They also found that the framework stimulated more partnership or team working between nurses and GPs:

‘[Prior to adopting the framework] a lot of the care was just managed by the district nurses and there was very little involvement from the GP ... But since the GSF was introduced we’ve had very good relationships where we’ve done joint visits with the GPs and seen patients and discussed them.’ [43]

Some of the practices found the „tranche after tranche’ of paperwork off-putting, and a disincentive to follow the framework. For some, tickboxes were useful aide memoires, while for others they interfered with GP–patient or nurse–patient contact: „It makes it very formulaic ... box ticking. I spend most of my time on consultations tapping my piano, my keyboard, rather than being able to look at a patient and have good eye contact’ (GP [43]). Some practices said that they followed the framework without doing all of the paperwork.

Team meetings governed by the GSF were said to be now much more about people rather than administration: district nurses would also be invited and Macmillan nurses would be told when the register was to be discussed. „GPs ... after their surgery they’re rushing off to do visits ... You can’t pin them down, whereas a meeting is ... time out isn’t it?’ (district nurse [43]). However, some practices had difficulty getting everyone together, which may not be worthwhile in a small practice, and GPs seemed to be more satisfied with the quality of communication than nurses were.

Training community nurses in palliative care

Recognising the role of district nurses in palliative care, the Department of Health initiated a palliative care education and support programme to train 10,000 district nurses over three years in the NHS Cancer Plan (2000). The programme was designed to improve the knowledge and confidence of district nurses in palliative care practice. It was evaluated through a self-reported postal survey, sent out before the training to capture existing knowledge, and a year later after the training had been delivered [52]. The evaluation survey asked about confidence in pain control, control of other symptoms, emergencies and referrals, assessment and support, and included case studies with attached questions. Three hundred and seventy-four nurses returned questionnaires in both years and were included in the final analysis. The results showed that the training had achieved a small but significant increase in confidence in palliative care competency and knowledge. Nurses and healthcare assistants without the district

nurse qualification, and who had never worked in specialist palliative care, showed the greatest improvements from the training. Thirty-nine trainees were also interviewed. Some said that they were more likely to ask if a person was in pain, as they knew how to respond. Nurses said that they were more likely to communicate with carers as they felt able to respond knowledgeably. They also appreciated learning with, and from, peers in group sessions and felt more confident about working with GPs and requesting drugs to be left in people's homes. By March 2004, 12,700 district nurses had taken part in the training programme.

Supporting community nurses

Marie Curie Cancer Care's Delivering Choice Programme initiated a Complex and Palliative Continuing Care Service (CAPCCS), a community-based support service designed to support district nurses in their care of home-based patients approaching the end of life. The evaluation [46, 47] addressed aspects of service delivery and integration impact on patients and families along with training implications. This initiative was designed to deliver additional palliative support to community clients by employing health and personal care assistants (HPCAs), supervised by district nurses. The service is an example (possibly common, but rarely recorded) of direct collaboration between NHS (primary care and district) nurses and third sector palliative staff. Marie Curie Cancer Care nurses, like Macmillan nurses [53], see their role as both achieving the best outcomes for patients in any given episode, and raising care standards generally in hospital or community services, acting as change agents. This role is consistent with the widely held view that these nurses exemplify good practice in palliative care. „I can't understand why the NHS can't pick up practice from the voluntary sector' (bereaved carer [16]).

The aim of the CAPCCS service [46, 47] was to increase choice at the end of life and support those with very complex needs for continuing care, preventing inappropriate admissions. It was designed to fast track referrals for nursing support by joining up and taking referrals directly from primary care staff. The pilot service started in May 2008 with £340,000 funding, providing HPCAs trained by Marie Curie staff to take on routine medical and caring tasks for people thought to be approaching death. District nurses could access the service when they had identified need that they had no capacity to address. HPCAs were recruited, often without experience, and given a month-long induction process, including shadowing other HPCAs, and formal induction on end of life care. Training in moving and handling, medications, hygiene, catheter care and so on was included.

In general, carers (who provided evaluation data) appreciated the personal and caring nature of HPCAs (who often had no clinical qualifications, and were recruited primarily for personal attributes). Carers said that HPCAs were skilled in communication, and could be relied upon to take up issues with their supervisors (district nurses) or other professionals when they did not know the answer to carers' queries. Having a service that would deliver both personal and medical care with continuity of staff was important to carers: social services had tended to send agency workers, who did not have the same generic skills or commitment. Many carers said they couldn't have coped with keeping the person they cared for at home without this service. On the whole, the supervisory structure worked well.

Some systemic difficulties arose, particularly in the speed with which the electronic system governing referrals, service input hours, change in condition of the patient and end of service could be updated. Sometimes, HCPAs or district nurses were not informed if the person was admitted to hospital. CAPCCS could be withdrawn, for example if the patient's condition improved, without telling the relevant joint care managers – but social services said they then needed 28 days' notice to reinstate domiciliary care. Some health staff referring into the service questioned the limitations of being able to refer only through district nurses (who might be out themselves for most of the day). Training and selection of HPCAs was seen as very important – they needed to have the right approach and professional attitudes and skills.

Communication between HPCAs and district nurses was generally felt to be good, and district nurses acknowledged the willingness and helpfulness of the HPCAs.

A small qualitative interview study [47] supplemented the main evaluation [46] by interviewing participants in the project, and family carers. Interpersonal qualities of the HPCAs (a major criterion for recruitment) were much appreciated by family carers: „It was the tenderness they showed her. They always went out and gave her a kiss, “see you tomorrow [patient name]” [46]. Carers also found the HPCAs receptive to questions about any aspect of care, even if they didn't know the answer: „I could say I'm a bit worried about this ... I didn't have to do any more, they would say “well I think we'd do this ... and if it hasn't worked by the time we're going ... we'll pass it upstairs” [47]. Carers saw the service as an example of integrated care provision, flexible and supportive, „like family'. They believed that they would have had difficulty getting the nursing care required for the dying person without the HPCAs: their help revolved around basic nursing care, included turning, washing and changing nightwear and bed linen, and adherence to complex medication routines. HPCAs could refer to district nurse supervisors for additional support or information as the need arose. „My husband said to me that he had never felt so comfortable and well cared for as he did then ... most of it was because of the expert care he received from the CAPCCS team who went to great lengths to ensure that he was comfortable' (carer [46]).

The performance of the HPCAs relied on rigorous selection processes, aptitude for the role and related job satisfaction.

„It's like a privilege to be able to go out to people. You know for the end of their life that you're giving them the care and they're able to stay in their own homes ... they've got that choice ... I don't class this as a job. It's something you've got to want to do.' (HPCA [46])

Specialist palliative care nurses: Macmillan and Marie Curie nurses

Macmillan and Marie Curie nurses and hospices are predominantly funded and managed by voluntary sector organisations. Very often, Macmillan and hospice services have been seen as much more supportive than NHS staff:

- „That's a great skill the Macmillan nurses have. They enabled us to have the conversation [about what the person dying wanted their funeral to be like].'

- „They asked, and how are you? We were able to ask what would happen.’
- „I can’t understand why the NHS can’t pick up practice from the voluntary sector.’ [bereaved carers [16])

We found one qualitative research study [53] on Macmillan nurses. Macmillan nurses appear to work relatively autonomously, determining caseload priorities, and using their time flexibly.

„We do have a line manager but really day to day decisions we make ourselves ... we need to have a degree of autonomy in what we want to do and how we spend our time ... We shouldn’t need someone watching over us and saying what we should be doing.’
[53]

This may be a real difference from the experience of district nurses, who may lack confidence in their skills and judgement regarding end of life care and may have little control over their work schedules.

Macmillan nurses can also exercise control over referrals and discharges: „If the referral policy was too narrow we might actually be missing out on people if the assessments of the people referring isn’t great ... Often people don’t know why they are referring ... they have a vague idea of what we do’ [53]. Macmillan nurses may also „dip in and out’ of contact with patients: „I’m reluctant to discharge them because they have got an ongoing often progressive disease and they will need you at some point’ [53]. An informal policy of telephone support was followed, providing reassurance to patients and carers that they can easily be reached when circumstances change.

Domiciliary care workers and healthcare assistants

We found one review of the published literature on home care workers and their role in supporting people at end of life [50]. Although the review did not define what it meant by home care workers, it suggested that they may take on social care, domestic tasks and some healthcare tasks, and do not on the whole have nursing or other care qualifications, including specific training in end of life care. We suspect that agencies and services deploying home care workers have difficulty in agreeing workers’ roles: either these are well prescribed and inflexible or they are not well defined, in which case the workers may be overloaded by the degree of need encountered in a household supporting a person who is in the process of dying. People who attended the SCIE workshop [16] and the Project Advisory Group considered that relatively unqualified health and social care home care workers could, and in some cases did, make a significant contribution to patient and family carer support.

In the review on home care workers [50], users and carers reflected on the limited availability of home care services, lack of continuity of care, time constraints, lack of flexibility and poor communication with other services. Users and carers rated the quality of home care support by the:

- nature of services (continuity, reliability and responsiveness)
- nature and demeanour of staff (disposition, competence)

- nature of the process (quality of relationship, awareness of needs, flexibility)
- continuity of care worker (seeing the same person over time).

From their own perspective, workers reported heavy caseloads, having to cover absent workers' cases, not feeling supported in emergencies, feeling isolated and having unclear role boundaries.

Dissatisfaction with the quality of support provided in the home has been identified as a strong predictor of psychological distress for caregivers, who may feel a loss of control over caring, heightened by poor communication and reluctance of home care workers (at all levels) to provide instruction in caregiving skills [50]. Home care workers are a source of support to older people and carers, but can also be seen by the recipients as a threat to their autonomy.

Home care workers may be trained to carry out basic nursing tasks, including wound care, infection control, continence care, moving and handling. As one outcome of training, they become increasingly confident in liaising with community nurses and GPs. The organisation and supervision of home care workers is sometimes provided by the local authority (or health and social care trusts in Northern Ireland), although they may „work alongside' community nurses. Further work is needed to identify what they can contribute to palliative/end of life care, and what their training needs are.

Home care or domiciliary workers are now often employed by agencies, as local authorities (and health and social care trusts in Northern Ireland) have outsourced services, and some people self-fund their own care by buying directly from agencies. A consultation of patients and carers receiving end of life care from a primary care trust (a commissioner of services) [17] found that recent privatisation of adult social care services in (an unidentified) borough appeared to introduce more uncertainty in how domiciliary care was organised. One GP commented that tendering out „loosens the connection between patient and practice', and that increasing reliance on agency workers meant less predictability in who would turn up to care.

The National End of Life Care Programme [54] has published guidance on the involvement of domiciliary care workers in end of life care. This acknowledges the potential role that they can play, which is strengthened if other health professionals involved with the dying person and their family recognise how well placed the workers are to identify change and need.

The guidance prompts domiciliary workers to be proactive in engaging with the needs of the dying person, to ask (patients, carers and other workers) what their role should be, and be aware of medications, equipment and so on (without taking responsibility for them). Organisations they work for should have good liaison with local healthcare providers. Workers should be well informed about who may be dying, their care plan and how they are involved, and how they can discuss both death and care with the service user (including who can provide more specific advice). Workers can offer to find out about and share any preferences or advance planning, with the service user's permission, with appropriate professionals, and can help to review the care plan. Domiciliary workers may be the first to recognise the final stages of life and can alert Macmillan or district nurses. Their employing organisation needs to provide appropriate

training and support to them after the death of a client. The guide provides useful sources for organisational and personal assessment by care workers, and shows how the suggested standards link to the Care Quality Commission's essential standards in England.

Practice Example 2 describes a training initiative developed by local authorities in partnership with adult education services to equip domiciliary workers for end of life care.

Occupational therapists

Occupational therapists (OTs) can offer a valuable and specific contribution to end of life care [19] and may work in many settings. They often comment [19] that their training means that they can offer comprehensive interventions, taking into account people's physical, social, psychological and functional needs, but that frequently their role is reduced to assessment for equipment and discharge planning. OTs are in short supply, but patients may be able to see an OT during a hospital stay or at a hospice. In relation to dying at home, OTs are ideally placed to offer assessment of the person in their own home, and may accompany the person home from hospital to build a comprehensive picture of their needs and abilities.

The OT on the SCIE Project Advisory Group highlighted the role of OTs in facilitating optimum function and quality of life, for example by looking for ways to support continued participation in activities that are important for the person dying. Supporting people to live well was not very prominent in the literature on dying at home, but a vital aspect of dying well is to live well as long as possible, especially when the actual end of life may be a year or more away.

The specific intervention, exercises or equipment recommended to a person near the end of life will depend on the specific activity they want to achieve, but could involve assistance to remain at work, maintaining independence in self-care, continued involvement in leisure activities or visiting a particular place or person. The OT assessment builds on the strengths and abilities of the person, enabling them to live as well as possible during their remaining time. Helping people to cope with physical incapacities, and focusing on what they want to achieve, enables people to be self-reliant in some activities of daily living, and maintains dignity and control. OTs can also offer psychosocial support, group support, training in relaxation and energy conservation. They are skilled in moving, handling and posture management – providing assistance and advice to the individual, carers and families.

Community multidisciplinary team support

There are a number of specialist teams that have been commissioned and evaluated in local settings. However, most accounts given are descriptive, and rely on „before and after' measures, such as the number of people who die at home, rather than comparing two groups (those people receiving the team support versus those not receiving it). This is probably because it is unethical to not provide a service that is almost certainly going to help people who are isolated and vulnerable. But it means that we cannot compare different types of service for „what works best'. Specialist teams often focus on a

particular aspect of care – for example out-of-hours rapid response or discharge – so we have highlighted these in the discussion below.

Hospice at home and palliative team responses

The Marie Curie Cancer Care organisation provides a number of services, most notably night-time nursing cover. Its Delivering Choice Programme was an additional initiative set up to see whether more people could be enabled to die at home. Two features, both of which were piloted and evaluated in Boston, Lincolnshire [45], were:

- a Rapid Response Team, which makes emergency and planned visits and gives telephone guidance to patients and carers from 3 pm to 10.30 pm, and out of hours from 10 pm to 7 am. This service aimed to reduce emergency hospital admissions, which may often happen when there is no one (or no one who knows the patient's details) who can be contacted outside „normal' service hours.
- a Discharge Community Link Nurses Team, which entailed two nurses based in an acute hospital setting who could arrange fast discharge from hospital, liaise with community services and might accompany patients home from hospital to settle them in. This team originated from the observation that people often spend time in hospital in the last year of life, and although active treatment may be over, and further time in hospital unnecessary, they may be held up, and eventually even die in hospital, while awaiting discharge because community support has not been arranged.

The aims of the evaluation of these services were to see whether more people died at home, to see whether use of health and social care services varied after the new services were introduced, and to identify changes in costs. Results overall did show an increase in all home deaths in the area from an average of 19 per cent in 2005–06 (before the services) to an average of 23 per cent in 2006–07, but for those who accessed one or other of the services, the increase was to 42 per cent, and 54 per cent for those accessing both services. The services then did make a difference, but clearly were not available to everyone dying at home (hence the different rates of change in dying at home). Unfortunately, the effects of the different approaches cannot be assessed separately, and there were some cost increases associated with the Discharge Team, but lower hospital (acute care) costs – associated with fewer admissions – for the people using the Rapid Response service. These services did address two major impediments to dying at home: round-the-clock care and speed of discharge.

Hospice at home

Another third sector initiative, the Sue Ryder rapid-response hospice at home initiative, was described in the research literature [44]. This was a very small-scale pilot service, in which 17 patients were seen, intended to support people in their own homes in the final stage of life. It was initially thought that a 72-hour service would be offered, but in some cases, where it was difficult to predict the time of death, support continued for up to eight days. Although the article that described the initiative did not demonstrate what

might have happened without the service, it did detail some of the equipment and services (managed by nurses and healthcare assistants backed by a doctor) during the final days.

The team doctor (having negotiated access with the GP) „prescribed anticipatory drugs to be kept in the patient’s home until needed, including diamorphine and other painkillers. Having the necessary medication to hand meant there was no need to ring GPs at short notice, and also reduced the risk of emergency hospital admissions’ [44]. The team provided sedatives for the final stage if people became agitated, and the nurse set up syringe drivers and sat with families, talking about the Liverpool Care Pathway and other issues. If the service were re-commissioned, they would want it to offer overnight nursing care, and respite care for family carers to take a break.

Hospice at home services are being developed across England, but are generally not well publicised. Bradford District Hospice at Home for cancer patients was evaluated [41] through questionnaires sent to GPs, district nurses and family carers of the 570 patients who used the service at home. A relatively high response rate for a postal survey was achieved (78 per cent of GPs, 89 per cent of district nurses and 51 per cent of bereaved carers. At the outset of the service in 2001, the hospice team comprised one nursing sister, two staff nurses, six healthcare assistants who were Marie Curie trained, plus agency nursing staff. The service took GP referrals, and was supposed to be for cancer patients predicted to die within six weeks.

The evaluation reported that carers highly valued the opportunity to fulfil the wish of the dying person to die at home. Some said that the agency nurses and out-of-hours cover (by locum GPs) provided within or alongside this service was not of high quality: they needed briefing and did not always understand the patient’s condition. GPs also criticised the out-of-hours locums, who might admit the patient to hospital, rather than provide opiates in the home (see Accessing equipment and services, Pain-relieving drugs and syringe drivers, page 48). GPs noted the value of having (nurses) trained in palliative and end of life care to support them, but all parties recognised a shortage of Marie Curie nurses to sit with people at night. The service did not achieve its stated aims of reducing hospital deaths, and was flawed because it excluded cases where the patient was transferred to alternative care services, including hospital – that is, the very people who might be dissatisfied with this service. However, the evaluation did highlight positive development:

- more full-time Marie Curie nurses were employed
- a stricter specification for agency nurses and out-of-hours locums was set up
- GPs were encouraged to carry injectable opiates.

GPs clearly valued the service; however, they began to refer people who did not have cancer and whose prognosis (length of life) was uncertain (who therefore did not meet the criteria).

Specialist palliative care teams operating in community settings may not be referred to as „hospice at home’. Practice Example 5 describes a 24-hour support and coordination

service – Partnership for Excellence in Palliative Support (PEPS) – which provides palliative care support accessed through a single contact point.

Hospice daycare

Although we found little material on this, hospice daycare can also be a very important support to people who are living at home and their carers (patient of Peace Hospice, Watford). Hospice daycare provides assessment and ongoing monitoring, a wide range of therapies including relaxation techniques, and enjoyable and stimulating activities and social contact. Transport to and from home is usually part of the package, and carers are then free to spend the day as they wish. Specialist palliative care professionals are readily available. Attending the hospice gives patients and carers the reassurance of a weekly review of their needs, and the opportunity to discuss and seek advice on anything they are concerned about. If for any reason the plan to die at home becomes difficult, contact with the hospice reassures patients and carers that there is another option. However, hospice places are limited, and depend on charitable contributions.

A review of hospice services [55] identified no quantitative studies of hospice daycare in the UK and only four qualitative reports on general hospice use. Users and carers were positive about the support received from hospice daycare: „When I did come [to hospice day care] it was lovely, brings you out of yourself, you talk about things’ (dying patient). Patients reported feeling less socially isolated, and having renewed interests (in gardening, the arts and so on) and a sense of belonging.

Discharge planning services

A discharge planning team such as the Marie Curie initiative described above [44] places a lot of attention on speedy discharge and handover to primary and community care services. Since most people identified as within a year of dying will have at least one hospital admission, facilitating rapid discharge and arranging for palliative care at home are likely to enable more people to die at home.

Rapid discharge may be part of a total service configuration in a local setting to increase the number of people facilitated to die at home. One study [48] identified all patients from a single Scottish GP practice of 11,000 people who were at high risk of admission. An „anticipatory care plan’ and a team of primary care workers, plus a case manager and an occupational therapist, were assigned to set up services to enable early discharge. The aims of the team included:

- ascertaining patients’ wishes around preferred place of care and death, and resuscitation
- preventing hospital admission where appropriate
- promoting early discharge in the event of admission
- mobilising support from the primary care team
- installing aides to promote independence

- signposting people and their carers to Citizens Advice Bureaux to maximise incomes.

This service was not directly targeted at people thought to be at the end of life, but the number of people who died in hospital was reduced. Furthermore, a 'before the service/after the service' comparison showed more than a 50 per cent reduction in both hospital admissions and length of time in hospital for the people using the service, and hence a significant reduction in cost (as hospital care is far more expensive than primary or community care).

An interesting aspect of this approach was that ambulance services were notified that some patients had made a decision not to be resuscitated, as this is identified as one route through which people at the end of life who call for support are taken to hospital and given treatment they do not want. A scheme based in South West London was set up to increase the number of people dying in their preferred place of death [49], whether home, hospice or care home. This was a funded fast-track discharge scheme providing seven day a week fast discharge from hospital to community, with hospital staff acting as coordinators, ensuring that the right medications were dispensed and equipment at home was set up. Before the discharge scheme, ward staff had handled discharges, and had no protocol for those at the end of life.

Initially only those who expressed a wish to die in their own home or care home who had a prognosis of two weeks or less to live were accommodated by the scheme, but it was found that patients awaiting continuing healthcare funding were dying in hospital after a lapse of more than two weeks, so the service was extended to those expected to die within six weeks. As part of service, a specific 'end of life' transport category was agreed with the ambulance service (as previously these patients had been seen as low priority and transport was subject to cancellation). The palliative care nurse specialist accompanied each patient home, and handed over to a community professional. Outside the hospital setting, it was agreed that continuing care funding would be in place at discharge, including funding for larger equipment (although the article discussing service did not describe how the assessment for funding was speeded up). It was agreed that drugs and healthcare equipment, including syringe drivers, would be provided by the hospital. A protocol for communication with the family, along with a discharge checklist, is given in the article [49]. This includes:

- working with the family to ensure appropriate bed space, with electric sockets nearby
- checking on DNACPR (do not attempt cardiopulmonary resuscitation) status and communicating this to the ambulance service
- arranging prescription of oral and subcutaneous opiates
- provision of a 'lock box' for drugs
- supplying carers with a leaflet with the title 'The Last Few Days or Weeks at Home' and a list of useful telephone numbers
- faxing GP and out-of-hours GP services with discharge summaries.

A total of 110 discharges were facilitated, almost all within 72 hours and around 20 per cent within 24 hours. Sixty-six per cent (68 people of 110) of discharges were to people's own home and (despite unpredictability of cancer survival in particular) 55 people died at home (with only three readmitted to die in hospital). Only 21 of the original 110 patients died in hospital: 18 before discharge could be completed and three when readmitted. Here and in other services (e.g. see [46]), communication and coordination between both secondary (hospital) and primary care staff, and NHS and third sector services, is challenging. It was found that the decision to discharge a patient had to be reviewed daily, as patient and carer wishes could change. Readmissions and staying in hospital were mostly related to the sudden deterioration of the patient: in these circumstances, people may be unsure that they can cope at home. Other important factors included working with pharmacists to draw up and dispense at short notice the common medications; and the need to prevent other staff misusing patient transport by making the team's palliative nurse specialist the only person who could categorise and prioritise the patient as „at the end of life’.

Ambulance services and clinicians

The response of ambulance services or paramedics is sometimes identified in the literature as a „factor’ preventing people from dying at home (or in other chosen settings, such as care homes). This is usually because they are the only out-of-hours service that can reliably be accessed quickly at any time of the day or night, and their general aim is to provide resuscitation and transport to a safe environment where patients’ lives can be prolonged. It is suggested in the general literature (though no systematic research or audit was found) that ambulance paramedics are not well trained in, or made aware of, end of life care priorities and choices and advance decisions refusing resuscitation.

A study involving a single Scottish GP practice of 11,000 patients [48] identified ambulance services as key players in efforts to reduce admissions. The practice notified ambulance crews of documented wishes for care and preferred place of death. (Scotland has different legislation from that in England: the Adults with Incapacity Act 2008.) The study of a fast-track discharge scheme in South West London to promote ability to die at home [49] also engaged ambulance services as key partners. In this scheme, ambulance services allocated enhanced priority to patients awaiting discharge from hospital to home to die. This group of patients had previously been seen as relatively low priority for ambulance transport, and might deteriorate and die in the hospital setting before they were taken home.

Authors of a more in-depth article on ambulance services [56] agree that the role of transport is crucial to determining whether a patient’s wish to die at home is honoured, while further questions have been raised about the risk of terminally ill people dying in transit. In the UK, ambulance services must respond by law to emergency calls, doctors’ urgent admission requests, high-dependency and urgent inter-hospital transfers and major incidents. Ambulance staff must then transfer patients at the end of life in and out of hospital as requested by other clinicians, or by carers calling 999, but they do need to assess whether such transfer is desirable, feasible, timely and safe. They also face the dilemma of judging whether an advance decision to refuse resuscitation is valid and applies to the current situation.

Four areas of concern were highlighted in the study [56]:

- Where there is an urgent need for transport due to a rapid change in a patient's condition. Examples would be falls, uncontrolled bleeding or loss of consciousness. The response of the out-of-hours GP service or the 999 operator could determine where the patient died. One out-of-hours GP commented that emergency calls often resulted from a combination of carer plight and patient need: „we go back and listen to the calls and the majority of them [suggest] ... family are just not coping' [56].
- Where is limited time to organise a transfer, for example if someone is dying. Local ambulance services may want a four-hour booking in advance for urgent transfers from hospital to home, and at least 48 hours' notice of planned urgent transfer between care settings. Even then, delays may mean that the patient dies before they can get home or to a hospice.
 - „Those patients have got an extremely poor standard of care in terms of waiting. You go for them at five or six o'clock at night, they may have been 3 hours waiting already, and then we stand ... in traffic for the best part of another 2 hours. It's really, really quite poor.' (Ambulance clinician [56])

Transport delays are exacerbated by distance, poor roads and remote rural homes.

- Sometimes planned urgent transfers do not have the crews with the right training, placing patients at more risk.
- Ambulance clinicians are trained to resuscitate, and need clarity on the resuscitation status of patients. Presence or absence of an advance decision can be problematic:
 - if needed, it affects the type of transport required
 - timing of the implementation of a DNACPR (do not attempt cardiopulmonary resuscitation) order is an issue
 - the family may be uncertain if this hasn't been adequately discussed
 - resuscitation may be inappropriately applied by crews, sometimes causing injury to patients.

The SCIE Project Advisory Group said that DNACPR orders are often signed by hospital consultants, with patient and carer agreement, or by a GP if the person is at home. A copy of the DNACPR order should be kept with the patient, and emergency services and ambulance crews should accept it as valid. Occasions arise when this has not been discussed with the family, and it may fall to the out-of-hours GP to implement the person's wishes, which can be unfair as they don't know the person or their history. Prediction of death or approach of death is also notoriously difficult in a crisis situation.

Social workers

The role of social workers in palliative care is barely described in the literature. Statutory social workers (employed by state services) are most likely to be involved with people nearing the end of life in a hospital setting, to discuss discharge issues, especially if they are being discharged to a care home. They will then withdraw once the person is settled. However, multidisciplinary teams providing hospice care within a hospice may include a social worker, and there is evidence from the United States that they are an integral part of hospice services, including those delivered in the home or care home [22]. People who are dying and their carers may well need practical advice and support to access benefits, to advise on outstanding socio-legal issues (such as establishing care for the child of a dying parent) and – as in the United States context – to assist in advance care planning.

Advance care planning is described in the United States literature as within the expected remit of social workers, who have both the practical and communication skills to deal with sensitive issues. This is very different from the UK context, where social workers have specifically narrow roles, and no particular remit within end of life care. UK policy has been to train and educate health and social care staff at all levels – from GPs to housing workers – to have these „difficult conversations’. It is not clear whether this is cost-effective, or necessarily the best way to find out people’s wishes. Social workers in hospice teams in the United States are also described in the literature as a potential resource in resolving family conflict.

A rare paper on social work in this context [10] considered the potential role of social workers in palliative care for people with Parkinson’s disease in Northern Ireland, using focus groups. Although Northern Ireland has integrated health and social care trusts, only social workers from voluntary sector hospice services had an active role in palliative care, coordinating discharges, providing care pre- and post-bereavement, and giving support with practical, legal and financial issues to patients and their families. Running carer groups was seen as important to carers. All worked in multidisciplinary teams, and saw their role as providing „holistic’ care. Within hospice caseloads, Parkinson’s disease was often not the main reason for referral to palliative or hospice care.

The lack of social work support to people who are dying in the community is unfortunate. Many health and social care staff have limited time, training and competence to take on the challenging issues of ascertaining death preferences. The routine availability of a palliative social worker in community settings could also do much to improve „holistic’ care: for some people, there may well be outstanding practical and socio-legal issues that will disturb peace of mind. Otherwise, this falls again on family carers, who are unlikely to be able to visit community advice services (such as Citizens Advice) to resolve practical issues. Social work support could also help service users and carers to access benefits they are entitled to.

Extra care housing workers

Extra care housing is one option for frail older people, and there is excellent material on the role it might play in supporting people at the end of life to die in their own homes. Extra care housing offers access to 24-hour support from housing workers. Increasingly, tenants and owners (they could be either) have disability or health issues, and may have been assessed for health and social care needs (if state funded) at the point they became residents. „Extra care’ can just mean some shared amenities, but some schemes have been developed for residents with dementia.

A Housing 21 pilot programme in three settings aimed to equip staff to support people at the end of life [51]. Behind this scheme is the explicit understanding that extra care housing is a person’s home, but staff reported in this study that health and social care staff did not understand that it should be treated as the person’s home, and had on occasions discharged people from hospital into nursing home care without consulting extra care housing staff.

The project aimed to educate staff to understand the practical and emotional issues around end of life care, and to engage local health and social care staff in discussing how they could work in partnership with housing support staff to plan and deliver care at the end of a resident’s life. By the end of the training pilot:

- discussing death was more „normal’
- staff knew what to look for and how to respond
- local health and social care staff and housing professionals wanted to talk and plan more about how extra care housing could support end of life care
- local health services began to volunteer additional support, such as overnight Marie Curie nursing
- extra care housing staff knew more about local services, for example that the district nurse was the „gateway’ to getting equipment.

The Housing Learning and Improvement Network and the National End of Life Care Programme have produced a resource pack for housing, care and support staff [35]. Their recommendations are summarised in Box 2 below.

The same authors produced an earlier guidance pack [57] addressed directly to housing support workers involved with people at the end of life. This is full of useful tips about what to expect and what to do in various situations, and provides an outline directory of key local contacts (for the worker to fill in) and information about the roles of various health and social care staff. This publication, written for readers who may know little about health and social care services, would also be useful to staff of supported housing schemes, and to social care and healthcare assistants and domiciliary care workers.

Box 2: End of life care for extra care housing staff [35]

This joint publication reflects shared values of independence and choice for older people, extending into the end of life. Core steps and training needs for preparing and delivering end of life care are described here, reflecting the journey of a resident living in extra care housing:

- Building relationships to plan care and make conversations about end of life easier. Not making assumptions about relationships; focusing on what people like to do; offering choice and control: formats for support planning are supplied (not necessarily about end of life care).
- Enabling residents to enjoy life and achieve (minor and major) life goals.
- Approaching conversations about end of life – for example when another resident, friend or pet dies. Not closing down the topic because you feel uncomfortable with it.
- Supporting residents to have choice and control, advance care planning, identifying residents' wishes for care after death (e.g. funeral arrangements, organ donation, who can clear their possessions). The guide includes a useful table of different decisions and their legal authority.
- Diversity in dying: culture, spirituality and religion at the end of life. A useful guide from Merseyside & Cheshire Cancer Network offers an overview of religious practice: <http://queenscourt.org.uk/spirit/>
- Decision making and the Mental Capacity Act 2005.
- Knowing the people and services who can help in the delivery of end of life care (including keeping a local directory).
- Identifying when to initiate end of life care.
- Considering funding options for end of life care. People who are certified by a doctor as having less than six months to live may qualify for Attendance Allowance, and their main carer may qualify for Carer's Allowance. A funding for social services link is supplied (page 44) and continuing healthcare funding (free and not means-tested) can be assessed by a GP or nurse).
- Unforeseen events such as admission to hospital. Getting to know the hospital discharge team.
- Supporting family, friends and informal carers (includes a useful note on next of kin).
- Assessment, support planning and review. This section is about people moving in late in life and how their end of life care can be facilitated.
- Delivery of care and support, including medication. Facts on morphine use. Assistive equipment, etc.
- Care and support in the last days of life, including symptoms, what to expect, being flexible in smoking and drinking alcohol.
- Dying – a lot of realistic tips about rigor mortis, the need to defecate etc.
- Care and support after death, including telling other residents.
- Ongoing learning, development and reflection. There should be policies, for example, on the home's involvement in arranging and attending funerals.

Electronic palliative care coordination systems (EPaCCS), also known as locality registers

A crucial tool for supporting end of life care in the community is the EPaCCS register. This is a locality register held on a computer database, which holds key information, a core dataset, for people who have been identified as approaching the end of life (ordinarily those expected to die within 12 months). It enables coordination of care for these people, and their families and carers. Some primary care services have already introduced registers, and it is government policy in England to introduce end of life registers in all primary care settings. The related core information standard [27] includes the patient's choices around end of life care and place of death. Additional information can be included on the register, such as details about drug regimes and wishes around organ donation. Access and edit responsibilities should be clear, and the implementation guidance suggests a mapping exercise to determine who is involved in end of life care.

In Northern Ireland, palliative care registers are in place within most primary care practices, but may not include people with a diagnosis other than cancer. Primary care information systems are not always compatible with trust and other information and communication technology systems. The information held on a palliative care register should be accessible to care providers and should also be available to all out-of-hours and ambulance services to improve communication outside normal hours [65].

Shared electronic information systems are seen as vital to ensure proper coordination across services [66]. However, information should be shared not only across health and social care, but also between different health sectors. Past initiatives have found that registers can provide better data access and coordination in the primary and community healthcare sectors, but do not link with systems in the acute setting. Hospital and ambulance staff may then have no information on patients admitted through Accident & Emergency.

The implementation guidance [27] includes the proposed dataset, which was piloted in eight localities. It is detailed, but primarily health focused, with only a single reference to „formal carers involved in care (HSC [health and social care] agencies and staff by professional group)'. Healthcare staff can access the register, but social care staff may not be given access (even though some of the documents referred to, such as advance care plans made in residential settings, may be stored in social care settings). The guidance says that „[t]he clinician looking after you' can make changes if you wish to – not very immediate or possibly trustworthy if this is a hard-pressed GP. Service users are free to withhold consent for their details to be shared through the register, and the pilots used an opt-in approach. Clinicians and patients may be concerned that the information will not be current or even accurate.

The pilot initiatives evaluated [67] identified a number of difficult issues around who could access, and who „owned', the record. Access by ambulance staff was identified as crucial, and access by hospice staff, often working outside the statutory sector, was considered desirable. The development of the minimum dataset led to some ambiguity: was this an outline register or a detailed care plan? In most pilots, only the GP could edit the register, but it was not clear that they had the opportunity or inclination to

explore the patient's wishes around place of end of life care, resuscitation preferences and so on. The key training element identified is to support clinicians – primarily GPs – in the development of communication and care planning skills. „Allowing healthcare professionals to feel comfortable having these conversations is vital in order to get them to engage with the project and in order to get a critical mass of patients consented to the register' [67]. In effect, this seems to be an extension of GP records, and the GP has to decide both whether the patient goes on the register and how the patient's choices will be ascertained. It is also not clear that the patient's record is widely available to other parties. These issues will need to be considered within local settings if EPaCCS are to be useful.

Well-coordinated and out-of-hours services in the community

Much of this guide has focused on services provided in the community and how they do or do not work together. A particular issue concerns support for patients and carers around the clock. Night nursing cover is rarely available through the public sector, and the Marie Curie night nursing service is only available in some areas, and then only to cancer patients. With support and signposting, families may be able to engage their own night cover. Volunteer sitters can help to give the main family carer occasional night-time cover.

Very often, carers in difficulty at night rely on the out-of-hours GP service for support, which may both be slow to respond and have little information about the patient; or they rely on the ambulance service. Both of these options may result in a patient being admitted to hospital. Although there must be exceptions, hospitals are generally not well equipped to serve the holistic needs of patients, cannot offer personalised care driven by individual choice by familiar and consistent staff, and can be a frightening place to die. It can also be difficult for frail patients to get out of hospital, which is why priority discharge services for people at the end of life have been trialled.

Some commentary describes admission to hospital as a failure of care to support dying at home, and poor community provision as a barrier to dying at home. One research paper [59] highlights the following „barriers', which may prevent death at home from being a reality:

- inability of the carer to cope
- poor symptom control and unmet nursing needs
- poor discharge planning and coordination, since many people will have episodes in hospital during their final year – lack of information provided to community teams at discharge may mean that palliative needs are only identified when a district nurse is called in for a minor procedure
- lack of understanding of community services by hospital staff, who make unrealistic promises of community support to patients and carers – „You get the feeling that they do it, and don't include you, so they can get the patient out' (district nurse [59]); case conferences prior to discharge may be conducted without community input

- difficulty in establishing additional equipment and services – district nurses, who are often the „gateway’ to community equipment, said that hospital staff notified them too late to get a bed, mattress for pressure relief and so on in time for the patient’s discharge
- difficulty delivering „care packages’ – care packages were unlikely to be adequate for someone who lives alone; patients may have agreed funds for purchasing, for example, seven days of night sitters, but lack of suitably trained staff to do the sitting is often more of a problem than funding it and relatives then feel very disappointed
- inadequate out-of-hours medical provision, including access to medication and medical records – locums will not prescribe morphine; out-of-hours doctors usually have no patient records and so they rely on carers to brief them.

Although these „difficulties’ concern a range of people and services, local commissioners and clinical commissioning groups need to assess the local configuration to consider what can be done to deliver a „round the clock’ support for people at the end of life and their carers. Even telephone helplines, if they are staffed by knowledgeable clinical staff, can help people to cope with uncertainty when daytime services are not available.

General needs for home equipment

A descriptive evaluation of a fast-track discharge scheme [49] includes a protocol and checklist for ensuring that the environmental needs of the household have been assessed. To support dying at home, a home will need:

- the patient’s DNACPR (do not attempt cardiopulmonary resuscitation) status identified and notified to ambulance services
- discharge summaries faxed to the GP and the out-of-hours GP service [48]
- bed space with electric sockets nearby
- prescription of oral and subcutaneous opiates
- a „lock box’ provided for drugs
- a copy of a leaflet with the title „The Last Few Days or Weeks at Home’
- a list of useful telephone numbers for carers
- equipment for caring for people at the end of life in the home setting, which may include oxygen supplies, hoists, commodes, bath chairs and beds with pressure relief mattresses.

The equipment needs of terminally ill patients may be quite complex, and there is no reason why family carers should be expected to know what they are, nor how to access them. Carers who attended the SCIE workshop [16] had conflicting experiences of how

easy it was to find out about them, with the key variable being finding the right person to take the referral. This was often the district nurse, but not all the patients saw a district nurse. Carers need a single point of contact through which they can:

- arrange assessment (preferably in the home, possibly before the patient is discharged) by a qualified professional, such as an occupational therapist
- order equipment
- be trained to use it, if necessary.

Blood transfusion

A number of clinical interventions that people may need at the end of life, which are not normally delivered at home, could possibly be brought into and managed within the home environment. A pilot blood transfusion service administered in 11 patients' homes in Northern Ireland was evaluated [60]. Transfusions are commonly required in cancer patients for symptoms of anaemia, and can alleviate physical weakness and improve wellbeing during palliative care. The authors of the evaluation suggest that as much as 40 per cent of hospital admissions could be motivated by a need for transfusion. Having provided the appropriate training for Marie Curie nurses, they concluded that transfusion can be done at home, and unnecessary admissions can be avoided. All patients would recommend the service to others: „I have terminal cancer and am 75 years old. I got the treatment I needed and was comfortable ... it took a lot of pressure off the family' [60].

Pain-relieving drugs and syringe drivers

A review of the evidence base for hospice at home services [5] identified some reported problems with medication compliance (60 per cent) in patients receiving care at home, especially with medication prescribed four times a day. Ninety per cent of patients had two or more prescribers (hospital and GP), which may lead to contradictory advice, and side-effects from combining different drugs. This is also a problem in care homes and it is very likely that lay carers have similar difficulty in delivering complex drug combinations. However, syringe drivers can be highly effective in administering appropriate levels of palliative and pain-relieving drugs: one study found that those receiving medications by syringe driver were four times more likely to die at home.

The use of syringe drivers is relatively routine in palliative care settings, but less so in patients' homes. A study [15] of their use by community nurses in rural settings found that nurses were not necessarily familiar with their use, and were also found to need greater knowledge of palliative drugs, alongside the physiological changes that end of life might entail. Nurses said that they might have to bring a colleague along (with time implications) to set up the driver and dosage. Monitoring drug administration was seen as involving more nurse support: „We usually see them 3 times a day, ourselves twice and evening nurses once, because it's important to know that the mix of drugs is working and if it isn't ... the regime can be adjusted' [15]. However, patients and carers found that they offered consistent impact and were less likely to cause nausea: „I felt quite good about it ... because (previously) they were coming out and giving us

injections every night ... it's over 24 hours, it's bound to help rather than taking tablets and still being sick' (patient [15]).

A review [61] of the clinical literature was conducted to consider whether palliative sedation is effective treatment for people suffering from advanced cancer who are thought to be near the end of life. The focus of the review was on challenges of providing this in a home setting (as sedation is more common in hospitals and hospices). Palliative sedation is often given in steps, possibly of one drug at different strengths, or moving onto different drugs. None of the six studies included was of good methodological quality, and they came from non-UK settings (mostly European). Agitated delirium, breathlessness and pain were the most common problems treated with palliative sedation, for an average of one to three-and-a-half days, but there was no statistically significant association with a hastened death. Benzodiazepines, specifically midazolam, have been most frequently used, alone or in combination with neuroleptics and opioids. Findings suggest that palliative sedation does not artificially speed up death, but it is much less likely to be given at home than in hospital settings.

Discussion includes:

- the need for continuous bedside presence after sedation
- whether the drugs are available at home
- whether the preferences of the person are known
- awareness of the person and their family of this option – palliative sedation is one option that could be discussed with patients and included in an advance care plan.

We looked for material on the use of palliative medication kits, which are kept in the homes of people approaching death. The one study found is from Canada [62] but is briefly described here because we did not find much on this elsewhere.

The population in the study were patients receiving care in the community, anticipated to die within the next two weeks and wishing to be cared for at home as long as possible. The intervention was a drug kit to be used when patients were experiencing symptom escalation or crisis; the drugs to manage these were otherwise not available. Community palliative care nurses recommended when to open the kit and received verbal orders from the supervising palliative care physician for the medications to be administered. Kits included oral and injectable morphine, low-potency neuroleptic, lorazepam (anxiolytic and sedative properties) and transdermal scopolamine gel to manage oral and respiratory secretions. This was a clever controlled study as no one was denied the kit – however, it is not clear why some kits were opened and some not, and who made those decisions.

The main outcome measures were: the number of kits placed and opened and the prevalence of home death in those instances; and the number of kits placed and not opened and the prevalence of home death in those instances. The study showed that using the medication kit achieved a significant increase in rates of home death, and concluded that palliative medication kits are a simple and effective way of anticipating and addressing comfort and symptom control for dying patients being cared for in the

community. These kits can avert admissions to hospital, improve the patient's comfort, extend the period of time that patients can be cared for in their homes and increase the likelihood of a home death.

Having medication ready for use within the home may overcome the reluctance of GPs and locums to prescribe or to carry opiates and similar drugs, provided that they have an agreed protocol for their use. By definition, people needing these drugs are likely to be in pain: an ambulance journey to hospital because this is the only source of palliative drugs throughout the day and night is probably the last option they might wish for.

Telecare and personal alarms

In remote areas, people may have little access to services, and may in effect (with family carers) have to monitor their own symptoms and decide whether they are in need of further support. In rural Scotland, a feasibility study of a handheld mobile phone application to monitor the symptoms of people with advanced cancer at home was carried out [68]. This allows subjective assessment of the incidence, severity and distress of six of the common palliative symptoms:

- nausea
- vomiting
- fatigue
- constipation/diarrhoea
- pain
- distress.

Self-care advice relevant to the severity of symptoms was available on the handheld mobile phone, and patients and professionals could access symptom graphs to monitor changes and trends. The study was funded by Highland/Orkney/Islands NHS and hospices.

Most users found the device easy to use, although there was some dissatisfaction with the multiple choice approach and rating, especially in relation to pain – for example there was no way of saying where the pain was, or of recording the analgesics that explained the different levels day to day. Patients (some at a distance from local health centres) felt that they were in touch with professionals – there was telephone access and staff could provide daily monitoring and reassurance. The knowledge that symptoms were being actively monitored daily by staff was reassuring to patients. The system could also be adapted to allow carers to record their concerns and observations as well.

The range of use of telecare in Scotland was explored as part of this programme [63]. The most common application was dedicated out-of-hours specialist advice through telephone lines, with enquiries about symptom control and medication advice uppermost in the concerns of callers. Patients and carers in focus groups and interviews said that the service was welcomed, but should be an adjunct to, not replace, personal

contacts. There was more evidence of use in remote and rural areas, where it may have higher priority. In the Orkneys, „televisiting’ may be carried out, especially if it is supported by a webcam. However, broadband access is not universally available.

Personal alarms

In Australia, a small study of personal alarms was conducted [64], largely to see whether a randomised controlled trial methodology could be adapted for people living alone at home who had a terminal illness. People consenting to join the study were offered a small benefit: either the use of a personal alarm (which had to be purchased by the patient) or additional care assistant support hours. The alarms, which were designed to be worn as pendants around the neck, would trigger an alert to a hospice service if they were set off (by depressing a button). Patients reported the benefits of having a greater sense of security, especially if they fell, and increased confidence in carrying out daily tasks. However, only half the patients wore the alarm in the shower, and 57 per cent did not wear it in bed for fear of choking or setting off the alarm while asleep. Personal alarms could also be relevant and useful for homes where both the person with the terminal illness and their carer may be frail. It is not clear whether they are readily available to people and their carers in the home setting: again, a home-based assessment for equipment should include this possibility.

Costs of dying at home

Providing good-quality care to people at the end of life is not primarily a matter of cost but one of social and societal values. However, in present circumstances, the relative cost of dying in different settings is important. Although there is limited evidence on costs, that which does exist suggests that dying at home is less expensive than dying in a hospice or hospital.

However, material on comparative costs should carry a caution: much of it concerns only the cost to the taxpayer, but hospice costs are adjusted upwards to reflect the fact that the state pays only around 31 per cent of charitable hospice care, and 88 per cent of NHS-funded hospices [3]. The analysis model used in most cost comparisons is also based on patients physically spending time in different locations: therefore it does not take account of new models of hospice care that are delivered in people's homes. But the major omission of this type of economic modelling is the value of the huge input made by family carers, which may involve lost earnings, 24-hour care and sometimes physical and mental health consequences from which they may never fully recover. A National Audit Office study [3] quotes an estimate of £71 billion in 2007 for the cost of unpaid care by families, friends and relatives (probably based on nominal earnings for the time spent caring).

The National Audit Office study [3] considered the total cost of end of life care, and explored (using models) the comparative costs for people dying of cancer, or organ (heart and lung) failure, who die in acute hospitals or in the community. The exact costs of end of life and palliative care are unknown, but in 2006–07, primary care trusts spent an estimated £245 million on specialist palliative care services (defined as „an aspect of EOLC [end of life care] delivered by health and social care staff with training in the management of pain and other symptoms and in the provision of psychological, social and spiritual support' [3]. This figure does not include the costs of „generalist' health and social care staff (staff who do not have specialist training), such as GPs, nor of unpaid carers, so the overall cost of end of life care is likely to amount to billions, and is unknown. This study reviewed other sources of data, agreeing with others [70] that evidence on the cost of care for terminal patients is sparse.

The National Audit Office model [3] applied a „decision analysis' approach, looking at the average costs of services likely to be required by people dying in different settings. It built on available data from the Hospital Episode Statistics database (held by the NHS Information Centre) on emergency admissions to hospital and length of stay. Similar data on hospice admission are held by the National Council for Palliative Care. The analysts also had access to data on where patients were discharged to (home or hospice).

Economic models ordinarily consider the costs of admission to hospital and length of time spent in hospital in the last year of life. It is not unusual for people in the last year of life to have several admissions, possibly for relatively straightforward procedures, such as blood transfusions, adjustment of palliative drugs and other needs, which could be provided to the person at home.

The analysts in the study [3] estimated that the cost to the taxpayer of care in the last year of life for the 127,000 patients who died of cancer in 2006 was approximately £1.8

billion or £14,236 per patient. (With 10 per cent variation in either direction, since these figures were estimates, this would be £1.64 to £1.98 billion.) Daily cost of home/community care was £25.22 to £30.82, and of hospital care was £199.82 to £244.22. Daily cost of hospice care was £119.23 to £145.72, less than hospital care but far more than home care. For cancer patients in 2006, there were averages of 1.2 emergency admissions, 17 days in hospital and 3.5 days in a hospice in the last year of life. This model shows that for cancer patients alone, considerable savings can be made if the number of hospital admissions and the length of stay can be reduced: if hospital admissions fall by 10 per cent, and the average length of stay is reduced from 17 to 12 days, £151 million a year could be saved.

Data from the study on the cost of community services for organ failure patients were less certain, and these patients may require more expensive acute care, which may be difficult to provide at home. However, research has also consistently highlighted the fact that many patients – up to 40 per cent in one study [3] - who died in hospital had no medical reason to be there at all. This point reminds us of the plight of people held in hospital because community services and equipment are not in place, or ambulance services do not consider discharge arrangements a priority [49, 56]. The model may, however, also show savings because people wanting to die in the community opt out of more hi-tech (by definition, expensive) interventions [3].

The National Audit Office report [2] concluded that the community (home or hospice) is the preferred place of death for 50 to 70 per cent of people, and it is also likely to be the cheapest place to provide services. Although the analysis did not include costs to carers or the dying person (through paid social care costs), nor the cost of training staff and setting up community teams for supporting people to die at home, it remains very likely that delivering choice in people's preferred place of death would also deliver savings to the public purse.

An earlier review of studies modelling comparative costs of dying in hospital versus at home included European and United States literature [69]. The authors found that economic studies consistently report cost savings if care in the last year of life is delivered at home. However, the flexibilities within the model make it difficult to assess exactly how much is saved, as this can depend on factors such as the cause of impending death (e.g. whether the patient has cancer or organ failure), the number of unplanned admissions and length of admission. The authors concluded that England and Wales lag behind Holland, Italy and other European countries in terms of the percentage of people enabled to die at home. However, it is not clear whether such differences arise because there are more community-based palliative care services, better-equipped primary care services or different cultural expectations in these other countries.

Other systematic review papers [4, 71] concluded that rates of dying at home were influenced by (inversely related to) the availability of hospital beds, which tells us nothing about the adequacy and quality of care received at home. It may, however, suggest that NHS beds are perversely rationed: a GP may be more likely to recommend admitting a patient, regardless of need, if there is no bed shortage.

A review of international literature [70] published between 2000 and 2009 sought data on the costs of treatment for terminal patients (a) in different settings and (b) comparing

palliative care with alternative therapeutic approaches. Only two studies based on UK services were found, studies could not be synthesised due to different methodology and the descriptions of services provided in different country settings were poor.

The few studies that focused on treatment of terminal patients across health care settings showed that hospitalisation costs represent the main component of palliative care costs. In the hospital setting, palliative care tends to be cheaper if it is delivered in a specialist palliative care unit. This is also probably true of palliative care delivered at home by specialist staff: it is suggested that specialists are less likely to admit patients to hospital, thereby making savings [70]. Palliative care costs also depend on patient characteristics, such as diagnosis, stage of disease and age: different approaches to delivering palliative care are not substitutes of each other and, thus, have different costs.

Costs to patients and carers were not included in any of the studies described in this section. The scope of included costs also tended to leave out administration, laundry, buildings etc. (hospital costs) and home adaptations etc., so we are not comparing like with like.

The National Audit Office survey [2] concluded that primary care trusts' expenditure on specialist palliative care services does not reflect the pattern of need. Coordination between health and social care services in relation to the planning, delivery and monitoring of end of life care is generally poor and is hampered by different funding streams. A detailed examination of patient records in one primary care trust found that 40 per cent of patients who died in hospital in October 2007 did not have medical needs that required them to be treated in hospital, and nearly a quarter of these had been in hospital for over a month. Reducing the amount of time that people approaching the end of their life spend in hospital could make resources available, which could be used to better support people in their preferred place of care. There is also some evidence pointing to cost advantages of specialist palliative care at home as compared with alternative, including generalist or primary care, models [70], although this needs to be corroborated by further research.

The lack of reliable research into the comparative costs of high-quality, generalist and specialised palliative and end of life care in home settings is unfortunate. Potential cost savings could reinforce the demand for further investment in home delivery of services by people dying at home and their carers.

Commissioning

Much of the information within this guide concerns commissioning. Most end of life care for people living in the community has been provided by „generalists’ (GPs, district and community nurses and health and social care assistants). Access to voluntary sector palliative specialists is largely dependent on where people live and whether their primary diagnosis is cancer. This suggests that there is great unmet need, a huge burden on carers who are often frail themselves, and many unnecessary and unwanted admissions to hospital when crises arise.

A national consultation with practitioners, commissioners, academics and service user groups on improving generalist end of life care [72] aimed to identify, using nominal group techniques, major concerns of national and local importance in the provision, commissioning, research and use of generalist end of life care. Of the 285 healthcare practitioners (primary, secondary, specialist and palliative), commissioners, academics and representatives of user and voluntary groups who were contacted, 210 took part (so a high response rate of 74 per cent). The consultation defined „generalist’ as care provided by health and social care professionals other than by those with a specialist palliative care remit. End of life care was defined as care provided in the last year of life to someone with an advanced progressive disease likely to shorten their life. Interviews and email questionnaires invited challenge to the definition and aimed to flush out:

- what was deemed generalist care
- what was deemed specialist palliative care
- how available these were to individuals
- what training or research was needed.

Key themes were extracted and fed back to consultation meetings for discussion and clarification. The following five themes are among those that emerged.

Lack of expertise and training needs

- There is a lack of expertise in end of life care among a hard-pressed health and social care workforce. Generalists only have a few patients at the end of life at any one time and find it challenging to maintain expertise.
- It is difficult to engage busy practitioners in education.
- There is a high turnover of social care staff, which diminishes the value of training.
- There is a lack of funding for training.
- Education and training budgets for end of life care support need to be ringfenced.
- The Royal Colleges have not paid enough attention to end of life care.

- „The Liverpool Care Pathway can work well but a big challenge is keeping it going with staff turnover’ (policy maker).
- „I don’t think it improves care very much without an education programme that goes with it ... Very labour and resource intensive’ (specialist in palliative care).

Gaps in primary care provision

- There is little emphasis in primary care on the importance of palliative care – financial incentives (such as GPs get) might be helpful.
- Reorganisation of some district nursing teams, and transfer of some into community matron roles, has left gaps in provision and poor links with GP practices.
- There are too few community nurses at senior or „sister’ level.
- Almost half of respondents thought that out-of-hours primary care is deficient. Transfer of notes about patients between services (e.g. day and out-of-hours doctors) is not optimal. There is no district nursing service outside of daytime hours.

Lack of integration between hospital and community, and health and social care

- „The division between social services and health care is an absolute nightmare ...’ Care assistants needed to be involved in case discussions, but were often thought to be too low status.
- Continuity of care, especially between hospitals and community staff, is poor, as is the link to the referring GP. „There are huge delays in discharges ... the speed at which patient assessments are made is too slow, meaning that some patients who may have been able to stay at home end up having to be admitted because they didn’t receive care as quickly as they required’ (generalist).
- It is unclear who should take responsibility for end of life care.
- Specialists in other areas, such as respiratory and cardiac specialists, might hold greater expertise on end of life care for some conditions than do most generalists.
- Generalists should be able to liaise with specialists to plan end of life care.

Research on cost-effectiveness needed to guide commissioners

- End of life care initiatives intended to support better generalist care are often not evidence based and/or rigorously evaluated for cost-effectiveness.

- „We need more research on the benefits, harms and risks of encouraging ACP [advance care planning] prior to the national recommendation of implementation and any particular advance care planning tool’ (generalist).
- Cost-effectiveness studies are urgently needed to motivate more NHS spending.
- Research priorities include effective models for non-cancer patients, for out-of-hours care and for hospital care and rapid discharge (to facilitate care and death in preferred places).
- Perspectives and experience of patients and carers should be paramount, as well as including cost-effectiveness to motivate investment.

No equality of access to end of life care services

- Discrimination: „Frail older people and their families ... are regarded as a drain on hospital resources and are not treated in the same way as younger patients with cancer.’
- There were many references to the low priority accorded to end of life care: a reliance on voluntary sector hospice care was seen to reflect major weaknesses in the system.
- Difficulties in prognosis meant that many people just did not get a palliative service, especially if had learning difficulties, mental health needs, or cultural or language issues.
- The vital role of carers is not recognised or supported.

We now move on to other research.

Collaboration

Policy directives, including the output of the National End of Life Care Programme, emphasise the importance of collaborative working in end of life and palliative care. Collaborations develop from referrals. One study [76] explored the influences on referrals within general and specialist community palliative care services within three primary care trusts in North West England. In the UK, such professionals rarely work in formal multidisciplinary teams, so partnerships are informal networks around patients, and referrals may be formal or informal. Referrals into palliative services may be hindered by reluctance to accept that a patient is near death, and by ill-informed assumptions that good care is already being provided.

In the study, judgements about fellow professionals’ performance heavily influenced referral. GPs were highlighted as possibly unresponsive: „Some GPs don’t do the GSF [Gold Standards Framework], and won’t do the GSF, some won’t provide anticipatory medication for patients who are in the terminal phases, some won’t go out and visit patients’ (district nurse [76]). However, there was a range of experience, from poor to

good, of joint working between nurses and GPs in primary care. Commissioners should consider whether GPs and primary care nurses should be expected to provide most end of life care in home settings, as they clearly are not (according to much of the evidence described in this guide) resourced or trained to do so.

District nurses were criticised for working practices – but they suggested that they have too many diverse cases to see people through end of life care. In effect, they often only got to see the patient in a crisis situation (rather than being commissioned early by GPs). A culture of mutual blame was apparent. Specialist nurses said that the home visits often generated „cues’ about support needs, and what could improve the situation, but that district nurses might often ignore these, especially if they already had a lot of other visits to do. In some sites, district nurses reported good rapport with Macmillan and other specialists, as sources of advice. Some GPs said they didn’t see that Macmillan nurses or hospice at home could provide better services than their own „generalist’ care, although this view may be founded on a narrow definition of what good palliative care is.

Success factors in relation to supporting death at home

The National End of Life Care Programme has produced guidance – „Critical success factors that enable individuals to die in their preferred place of death’ – based on contributions from end of life care commissioners and providers of services within seven primary care trust areas [66]. However, the guidance is about supporting death in the preferred place, including care homes, hospices and hospitals, so not all factors are relevant to death at home. Success factors relevant to commissioning to support death at home, with our commentary, include the following:

- Strong commissioning and clinical leadership

Commissioners need to take a whole systems approach to identifying gaps in care. Local champions for the Good Standards Framework and Liverpool Care Pathway were cited as clinical leaders.

- Use of nationally recognised drivers that attract payment for providers, especially GPs

Can GPs be incentivised to provide better continuity between general and out-of-hours GP cover?

- Flexible budgets and care packages

These need to respond rapidly to a patient’s changed condition. Continuing care packages available as part of the continuing healthcare fast-track discharge processes have facilitated more people being able to move to their preferred place of care but may not take account of those who do not meet the criteria for funding.

- Use of nationally recognised tools or their local equivalent (advance care planning, preferred place of care etc.)

National tools, or localised versions, were utilised to some degree by all and recognised as contributing to clear protocols and understanding of processes across boundaries.

- Shared electronic information systems

These are seen as vital to ensure proper coordination across services and recording the individual's preferences. Many in the primary and community care sectors work very well but do not link with systems in acute settings – this hampers patients admitted through Accident & Emergency and no information is available to the hospital or ambulance staff.

- Clearly defined access to 24-hour cover

A single point of access was raised as beneficial to the patient and carers. Many of the initiatives cited in the guide are led by voluntary sector partnerships, for example with the hospice sector. Use of „Just in case' boxes to hold medicines in the home for the last 24 hours of life were highlighted as a contributing factor for avoiding admissions.

- Use of facilitator roles and coordination of care across boundaries

Coordination of care was seen as about working together to an agreed plan to provide a seamless service and not about a particular role, but the introduction of facilitator roles would appear to be having a positive impact on services. Again, coordination services should have a single access point.

- Training to support staff delivering end of life care

Training is seen as an investment priority. Those providing out-of-hours services must be confident to deliver treatment in the home setting to avoid unnecessary admissions. Some of the evidence included in this guide [66] suggests that district and community nurses are insufficiently trained in end of life care. Although social care providers in the community are not explicitly considered, clearly training in basic palliative care and wider end of life care training for staff would benefit domiciliary workers. Staff training in the use of the electronic palliative care coordination systems (EPaCCS) is equally important if the register is to be a useful tool. Family carers also need training in basic healthcare, as this would reduce reliance on health services. It is also clear that all care professionals need training and support in the application of the Mental Capacity Act 2005 in order to implement advance care plans and best interests decisions in compliance with the law.

These issues are consistent with the national End of Life Care Strategy for England [18], which also highlights the need for:

- improved ambulance transport services for people near the end of life

- additional specialist palliative care outreach services to provide advice and care for non-cancer patients.

The carer's view

Carers who attended the SCIE workshop [16] had a number of additional observations to convey to commissioners, particularly as commissioning is about to become the responsibility of new clinical commissioning groups. Among these were:

- „It is not clear how money is allocated, for example to end of life care for older people’.
- „The local picture of services is very varied: they should be democratically controlled. GPs should be accountable for [end of life care] services. Patient participation is very important.’
- If GPs are to be commissioners, they should be made to declare their interests as many have investments in care delivery, for example in care homes.
- Services are becoming more fragmented in a competitive environment that doesn't put patients first. End of life care is not likely to be attractive to private providers: particular effort is needed to ensure that the quality of home support services does not deteriorate further.

Workforce training programmes

With the exception of specialist palliative care staff, our review of research identified training needs for all health and social care professionals working to support people to die at home. This is not surprising: they are „generalist’ staff, who may have had little or no training in this area.

The National End of Life Care Programme has combined with Skills for Health, Skills for Care and the Department of Health to produce a set of „Common core competences and principles for health and social care workers working with adults at the end of life’ [74]. This 30-page resource illustrates the seven principles or values that underpin all workforce development, activity and service delivery, and provides a very accessible outline of skills and knowledge that training should deliver, as well as a glossary of common terms, and a number of case studies from practice. It is deliberately aimed at a wide generalist audience.

The seven principles that underpin all workforce and service development, activity and delivery, irrespective of level and organisation, are as follows [74]:

- Choices and priorities of the individual are at the centre of planning and delivery.
- Effective, straightforward, sensitive and open communication between individuals, families, friends and workers underpins all planning and activity. Communication reflects an understanding of the significance of each individual's beliefs and needs.

- Delivery through close multidisciplinary and interagency working.
- Individuals, families and friends are well informed about the range of options and resources available to them to be involved with care planning.
- Care is delivered in a sensitive, person-centred way, taking account of circumstances, wishes and priorities of the individual, family and friends.
- Care and support are available to anyone affected by the end of life and death of an individual.
- Workers are supported to develop knowledge, skills and attitudes. Workers take responsibility for, and recognise the importance of, their continuing professional development.

A companion publication, „Developing end of life care practice: A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care’ [75] was published in the same year (2012). As well as updating the competences, this guide maps the competences against the common induction standards and Qualifications and Credit Framework (QCF), a new national framework that gives organisations, employers and trained staff a flexible means of validating the level and transferability of care qualifications and skills. It is possibly a less accessible guide, but aimed at trainers and managers.

In conclusion, there is good agreement on what high-quality end of life care in the home environment should look like. There is widespread agreement on the problematic issues that must be addressed in order to deliver it, and positive evidence of potential for cost savings at the systems level, which more end of life care at home may deliver. There are also shared aspirations, based on our common humanity, including those proposed in the national End of Life Care Strategy (2008) [18], which values:

- being treated as an individual, with dignity and respect
- being without pain and other symptoms
- being in familiar surroundings
- being in the company of close family and/or friends.

While „a good death’ at home may not be a feasible or desirable death for everyone, it undoubtedly could be a reality for many more people if we nurture the services to support it. There are likely to be significant resource savings if more people are kept out of hospital and are cared for at home. Successfully enabling people to die well in their own homes is a priceless achievement.

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