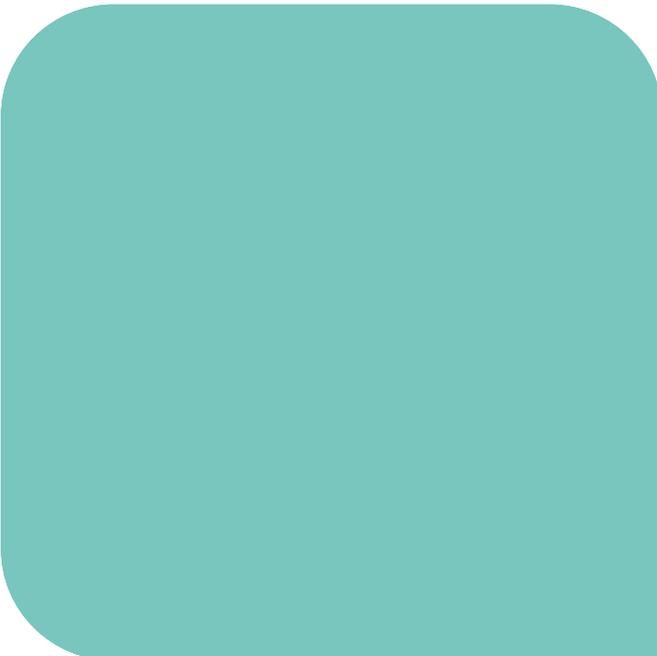


Dying well at home: the case for integrated working



The Social Care Institute for Excellence (SCIE) was established by Government in 2001 to improve social care services for adults and children in the United Kingdom.

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- enhance the skills and professionalism of social care workers through our tailored, targeted and user-friendly resources.

First published in Great Britain in May 2013
by the Social Care Institute for Excellence

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About this guide

This guide is based on evidence about what is needed to offer good care to people who are approaching the end of life and wish to be cared for and die in their own homes. It does not cover residents who live in care homes.

The guide is based on:

- a review of available quantitative and qualitative published research evidence, including studies that systematically collect qualitative material on what people think and say about services, and which services they value
- guidance on end of life care produced by authoritative sources, such as Marie Curie Cancer Care, the National End of Life Care Programme, and Skills for Care
- a workshop held at SCIE in 2013 with carers of people who have died
- practice examples
- a SCIE Project Advisory Group (of commissioners, providers, carers and service users), whose role was to review the way the guide was written and produced to ensure that it reflected real-life experiences and practice.

Research methodology

Evidence was drawn from over 70 papers, most of which were research, guidance and policy papers (see reference list). We included papers that were about:

- factors that influenced whether or not an adult (aged 18+) who wished to was able to die at home
- people who were considered to be at the end of life, that is, people who were expected to die within 12 months
- research indicating preferences and estimates of the number of people who want to die at home
- factors that support people to die at home or prevent it
- costs associated with dying at home (compared with costs of dying elsewhere – in a hospice or hospital)
- carers' needs while caring. Interventions to support carers after the death of their loved ones, for example bereavement counselling, were not included.

Most of the material included was from the UK, and most was published in the period from 2008 to 2012.

Acknowledgements

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- Sandra Vargeson, End of Life Care Coordinator, Sussex Community NHS Trust

We would also like to thank the people who attended the SCIE workshop in January 2013. Their experience, views and observations have helped to shape this guide.

With thanks to the [National End of Life Care Programme](#), which joint funded this project with SCIE.

Parts of the National End of Life Care Programme's work came to a close on 31 March 2013, while some elements continue from 1 April 2013 as part of [NHS Improving Quality](#), a new organisation set up to bring together the wealth of knowledge, expertise and experience of a number of previous NHS improvement organisations. You can find out more about continuing work on the [National End of Life Care Programme](#) website.

Introduction

This guide is about enabling people who want to die at home to do so and improving the quality of care they receive. In the context of this guide, „home’ means the place where a person usually lives. This includes „extra care’, sheltered housing accommodation and tenancy-based accommodation such as supported living, but not care homes. The guide is aimed at practitioners and managers supporting people with end of life care needs across the health, social care and housing sectors.

While „a good death’ at home may not be a feasible or desirable death for everyone, it could be a reality for many more people if there are 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.

Recommendations

Choosing to die at home

Professionals and providers should:

- Identify people who may be in their last year of life to ensure that they can access palliative care services when they need it.
- Liaise with all those involved in the care of the person.
- Support people at the end of life to choose their place of care and/or death
- Provide information and support to carers.

Commissioners should:

- Encourage providers to have a protocol for identifying and meeting the need for end of life care at home.
- Ensure, wherever possible, that people are enabled to die at home if they wish. Characteristics such as age or condition should not automatically exclude people.
- Ensure that providers have protocols in place for liaison between disease specialists (often in hospital settings) and primary/community staff.
- Ensure that support and services for carers are a priority.

Dying a good death

Professionals and providers should:

- Personalise end of life care and treat patients/service users and carers as experts in their needs and preferences.
- Involve people approaching the end of life in how care is delivered so they can continue to take part in valued activities and relationships and to determine their own routine activities and priorities.
- Treat patients/service users who are dying with dignity and respect, not talking down to or over them, even if they appear to be unconscious.
- Involve same-sex partners and be sensitive to cultural preferences and priorities
- Identify and respond to the spiritual and cultural needs that are important to the person and their carers
- Give people at the end of life and carers as much information as they want about the dying process and the services available
- Ensure that staff have had adequate training so that they can initiate conversations with people about their wishes and choices at the end of life.

- Support those wishing to die at home to draw up an advance care plan, which specifies their wishes as the end of their life approaches. This should contain both advance statements of wishes (such as preferred place of care and of death) and any advance decisions to refuse treatment (such as instructions about resuscitation). A copy should stay with the person.

Meeting carers' needs

Professionals and providers should:

- „Think family' and consider how support for carers can impact on care for the patient.
- Regard carers as central partners in care who need:
 - to be informed about the patient's medical condition and how it is likely to develop
 - to be trained to carry out basic nursing tasks
 - to know how they can get help at any time.
- Ensure that carers have a named professional who can assist them in accessing health and social care services, equipment and support.
- Ensure that carers have direct access to advice on financial planning, available benefits and how to maximise household income.
- Alert carers to their statutory right to an assessment and ensure that the assessment is followed by a written care plan that is implemented.
- Provide bereavement support to carers after the death of a loved one.

Coordinated care: health and social care and housing

Professionals and providers should:

- Ensure that networks and coordination arrangements are in place to enable health and social care professionals (including those responsible for arranging and delivering the care) to work together and share their knowledge.
- Ensure that patients/service users and carers see the same familiar staff where possible, and have a single nominated person to contact for advice who has influence across health and social care.
- Ensure that professionals are able to work flexibly and are responsive to the needs of patients/service users and carers.
- Ensure that GPs identify people approaching the end of life, and discuss and record end of life issues with patients/service users and their families. Ensure that the new electronic primary care registers are used to coordinate care and take account of people's wishes.

- Recognise the vital contribution that district and community nurses make to end of life care. Invest in the recruitment, training and supervision of health and personal care assistants as well as domiciliary care staff.
- Ensure that patients/service users and carers can access specialist advice and support „out of hours’, including essential medication and drugs for pain control.
- Ensure that advance care planning documents are accessible to out-of-hours and ambulance staff.
- Ensure that home care (or domiciliary) workers, healthcare assistants and extra care housing workers are trained and supported to work with people dying at home and their carers.
- Consider the role that social workers can play in supporting people at the end of life.

Accessing equipment and services

Commissioners should:

- Ensure that there are protocols in place to deal with the key issues in rolling out electronic palliative care coordination systems (EPaCCS) or their equivalent, including what information should be recorded, how it is collected, updated and quality assured, and who should have access to the data.
- Assess the support available to people dying at home and their carers „around the clock’, and take steps to address the large gaps in service provision.
- Ensure that there are agreed protocols (e.g. prescription of opiates) between out-of-hours locum GP services and with regular primary care.
- Ensure that hospital discharge planning and case conferences include community staff, for example a district nurse.
- Ensure that there is a single point of contact for carers through which they can arrange a home-based assessment for home-based equipment by a qualified professional, such as an occupational therapist, and be trained to use it as necessary.
- Consider commissioning services that provide for blood transfusions and other intravenous procedures, which are available to people in their homes in order to avoid emergency hospital appointments and admissions.
- Commission services that address the need for patients to have analgesia at all times, as poor pain relief is often responsible for emergency admissions. Ensure that equipment such as syringe drivers and palliative care kits are available.
- Consider the provision of personal alarms for frail patients and carers and telecare.

Costs of dying at home

- The NHS should have a better evidence-based understanding of the relative costs of specialist and generalist care at the end of life, analysed according to place of care delivery.
- Time spent in hospital in the last year of life is the most expensive factor in end of life care. Policy makers and commissioners should concentrate on interventions to keep people out of hospital if they do not need to be there, and to discharge them as early as possible.
- Economic analyses should reflect the „cost’ to family members of caring, and should consider how savings to the state can be harnessed to support carers to continue to care at home.

Commissioning

Commissioners should:

- Review palliative and end of life care services available in the locality to confirm that they are able to support people of different ages, ethnicity and social background to die well at home.
- Ensure that training is available for „generalist’ carers in the community who provide most end of life care for those who die at home. Training needs to include communication and care planning with patients and carers, and improving their own understanding of good-quality palliative care (including the use of analgesia). Less well-qualified staff can provide good responsive care if they are trained and well supervised.
- Commission specialist palliative rapid response teams and rapid discharge facilitation teams and model possible cost savings.
- Encourage general practice surgeries to use the electronic palliative care coordination systems (EPaCCS) register to promote patient choice, to improve coordination and to monitor outcomes of improved services.
- Consider how expertise on specific disease pathways can be made available to community health workers.
- Ensure that commissioned service practitioners are trained in, and compliant with, the provisions of the Mental Capacity Act 2005.
- Ensure that commissioned service practitioners are trained in the core competencies developed by the National End of Life Care Programme, Skills for Health, Skills for Care and Department of Health.

Professionals and providers should:

- Develop local protocols and processes of communication and coordination as these can improve patient and carer experience.
- Ensure that contracts provide 24-hour access to advice and support, for example a telephone helpline staffed by a palliative specialist to improve patient care and reduce expensive and unnecessary out-of-hours emergency admissions.
- Ensure that patients, families and the public have access to information about what dying at home may involve and that there are local services that can meet their needs.

Choosing to die at home

Making sure people have a choice about where they die.

„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 ... saying: “Yeah, you can come home.” And, as it turned out, it was a wonderful development.’ Carer [1]

Recommendations

Professionals and providers should:

- Identify people who may be in their last year of life to ensure that they can access palliative care services when they need it.
- Liaise with all those involved in the care of the person.
- Support people at the end of life to choose their place of care and/or death.
- Provide information and support to carers.

Commissioners should:

- Encourage providers to have a protocol for identifying and meeting the need for end of life care at home.
- Ensure, wherever possible, that people are enabled to die at home if they wish. Characteristics such as age or condition should not automatically exclude people.
- Ensure that providers have protocols in place for liaison between disease specialists (often in hospital settings) and primary/community staff.
- Ensure that support and services for carers are a priority.

Key points from research and policy

Who dies at home

- Between 50 and 74 per cent of people express a preference to die at home. This proportion may decline as death approaches and people feel they want more support and full-time care [2, 3].
- Fifty-nine per cent of all deaths are in hospitals while 17 per cent are in care homes and 18 per cent are in the person’s own home [3, 4].
- The single most important factor that enables people to die at home is the presence of a carer [4].

Factors that influence who dies at home

- Factors that increase the likelihood of dying at home are:
 - cancer diagnosis

- absence of complex conditions
- symptoms that can be managed in the home setting
- higher socio-economic status
- ethnic background (people from minority ethnic groups are less likely to die at home)
- not being in older age groups
- being married or not living alone
- gender (more men than women die at home)
- availability of local services.
- Services can respond to people's wishes to die at home by:
 - providing rapid access to palliative care and support at all times of the day and night
 - recognising people as being in the last year of life, or the end stage of their disease or condition, and referring them as early as possible to palliative care services [5, 6, 7]
 - providing support to avoid emergency hospital admissions
 - ensuring timely hospital discharge and provision of community services without delay.

Specific health conditions

- Palliative care services exclude many conditions such as chronic obstructive pulmonary disease [8], Parkinson's disease [9, 10], stroke [11] and dementia [12, 13].
- People and their carers should have access to specialist clinicians who can advise on their symptoms that are specific to their conditions.

Practice example

- **Practice example 4** outlines a scheme to provide bungalows, a homely environment with health services nearby, to people who cannot be cared for in their own home, because either they have no full-time carer at home or their home environment is unsuitable or overcrowded. Having end of life bungalows close together helps service providers.

Dying a good death

Improving the experience of people dying at home

„They talk to you like you’re an imbecile ... I have all my faculties, I just can’t walk.’ Person being cared for at home [17]

Recommendations

Professionals and providers should:

- Personalise end of life care and treat patients/service users and carers as experts in their needs and preferences.
- Involve people approaching the end of life in how care is delivered so they can continue to take part in valued activities and relationships and to determine their own routine activities and priorities.
- Treat patients/service users who are dying with dignity and respect, not talking down to or over them, even if they appear to be unconscious.
- Involve same-sex partners and be sensitive to cultural preferences and priorities.
- Identify and respond to the spiritual and cultural needs that are important to the person and their carers.
- Give people at the end of life and carers as much information as they want about the dying process and the services available.
- Ensure that staff have had adequate training so that they can initiate conversations with people about their wishes and choices at the end of life.
- Support those wishing to die at home to draw up an advance care plan, which specifies their wishes as the end of their life approaches. This should contain both advance statements of wishes (such as preferred place of care and of death) and any advance decisions to refuse treatment (such as instructions about resuscitation). A copy should stay with the person.

Key points from research and policy

Being person-centred

- The national End of Life Care Strategy for England [18] 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.

- Little research explores the views and experiences of people dying at home. Carers are powerful advocates and their views are often the only guide to service user experience.
- Being treated with dignity and respect is important to people at the end of life.
- Service users and carers are often reluctant to complain about services, fearing they will be regarded as troublesome and their care jeopardised [17].
- People at the end of life should have the choice to continue taking part in valued activities and relationships and to remain in control of their lives [19].
- People who are dying and their carers are at risk of social isolation, especially as some friends and family may be uncomfortable with the thought of death ([16], SCIE Project Advisory Group).
- Health and social care professionals should not assume that everyone is heterosexual [20], and should recognise and support minority lifestyles, identities and cultural preferences.
- While there is no agreed definition of spirituality, health and social care professionals should be alert to the need for spiritual care, which is not necessarily underpinned by specific systems of faith or religion [21].
- Carers can offer spiritual care by having the time to listen to their loved ones [21].
- People may need practical, legal or emotional support to deal with „unfinished business’: „A good death is where the patient has come to terms with the fact they are dying, they are at peace with themselves’ [17].

Advance care planning

- People who are dying should have the opportunity to make an advance care plan, which includes where they would like to die and whether they would prefer treatment and/or resuscitation as their condition deteriorates. Advance care planning may also include:
 - 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].

Difficult conversations

- GPs and primary care nurses say that people may change their minds about preferences for care, treatment and preferred place of death [23].

- Some GPs and nurses find it difficult to discuss death, regarding it as potentially unethical: „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]).
- If they cannot discuss death with a patient, professionals may make assumptions about what the person would prefer.
- Primary care staff need training and support to develop advance care plans. It is important to establish and record people’s preferences, both to see that they are respected and met, and to enable audit.

Practice examples

- **Practice example 1** illustrates a volunteer befriending service, which can combat social isolation and help users and carers carry on with some of the activities they enjoy.
- **Practice example 6** is about ensuring that the dying person’s wishes are recorded and kept with them, so that they are accessible especially to professionals who do not know them, out-of-hours locum GPs and ambulance crews.

Meeting carers' needs

The needs and experiences of carers supporting a person to die at home

„The main message is we all want the best for our loved one.’

Bereaved carer, SCIE workshop [16]

„It felt like I was on a treadmill and I had to find out everything as I went along.’ Carer [1]

Recommendations

Professionals and providers should:

- „Think family’ and consider how support for carers can impact on care for the patient.
- Regard carers as central partners in care who need:
 - to be informed about the patient’s medical condition and how it is likely to develop
 - to be trained to carry out basic nursing tasks
 - to know how they can get help at any time.
- Ensure that carers have a named professional who can assist them in accessing health and social care services, equipment and support.
- Ensure that carers have direct access to advice on financial planning, available benefits and how to maximise household income.
- Alert carers to their statutory right to an assessment and ensure that the assessment is followed by a written care plan that is implemented.
- Provide bereavement support to carers after the death of a loved one.

Key points from research and policy

Family carers

- The term ‚family carer’ is used to mean a person or people identified by the person dying (where possible) as important to them, and is intended to cover a spouse, partner, child, other relative, friend or supporter who cares for, and cares about, the person who is dying.
- Having a live-in carer to assist the person dying is probably the most important factor in enabling a person to die at home if they wish [4, 5].
- Around 500,000 carers provide support to people dying at home of a terminal illness [28]. It is estimated that the total value of support provided to frail and disabled people by family carers was worth £71 billion in 2007 to the health and social care economy (Carers UK, quoted in [3]).

- Carers act as advocates for the dying person, and they are often the most informative source for research and evaluation of end of life care services.

Practical support needs

- Carers of people dying at home have a range of practical support needs:
 - Information – How best to care for the dying person (diet, hydration, feeding, swallowing; incontinence care; access to specialist services or equipment; general patient comfort, including positioning and lifting, medication and symptom management). Carers say that the professionals who come into the home should work more closely with them, and offer on the job training including written material where available. Professionals are often too occupied with completing nursing tasks to offer advice, although they must be aware that the family carer has to provide most basic nursing care [29, 30].
 - Help to access equipment and navigate and engage with the complexities of health and social care services – A designated person with influence in the system is considered valuable: „Having one named person who will “walk the walk” with you’ [16].
 - Financial and benefits advice for both themselves and the person cared for – This is clearly crucial, as carers may give up their entire income in order to care. Households may be in serious financial difficulty [1, 16].
- Family carers need health and social care professionals to communicate well with them. They need:
 - acceptance by health and social care professionals that they are crucial members of the care team, and should be consulted and informed about all aspects of the dying person’s welfare
 - to know about how the person’s illness will progress, what to expect and how to recognise and respond to change and deterioration.
- Carers also identify shortcomings of services for end of life care in the community [16]:
 - There is a lack of continuity of staff, especially those of social care domiciliary agencies.
 - GPs and other healthcare staff may refuse to communicate on the grounds of „patient confidentiality’, which is unacceptable except where a patient has requested it. If the patient lacks capacity to endorse the carer’s request for information, it is clearly in the best interests (Mental Capacity Act 2005) of the person for health staff to communicate with the family carer.
 - Carers often said that they had to coordinate the input of health and social care professionals, as the services were not integrated and did not liaise with each other.

Psychological needs

- Carers also identify a range of psychological difficulties (including depression and anxiety, feelings of powerlessness and helplessness, low caregiver esteem), physical and emotional stress, and psychosocial difficulties [16, 31]. Intense, negative, conflicting and difficult emotions (fear, guilt, hopelessness, etc.) combined with feelings of inadequacy, insufficiency and uncertainty about their abilities, can accelerate stress and burnout [32]. Carers are also often extremely socially isolated, and may have little opportunity to engage with „normal’ life.
- Many carers are themselves elderly and frail and the caring role is often associated with sleep disturbance and fatigue. Physical frailty can lead to the breakdown of ability to care.
- Carers should be assessed for social care support, at the very least for respite and help with household tasks.
- Research suggests that caregivers are ambivalent about expressing their own needs, against a background of lack of information about rights, lack of time and discomfort in confiding in strangers [32].
- Caregiving may be perceived as a loving or conscious choice, or as an obligation.
- A number of factors can help caregivers:
 - Commitment to the dying person, and satisfaction with one’s caring, can provide greater resilience to stress and burnout: professionals can encourage family carers to recognise their own expertise and ability and confirm that they are doing a good job in difficult circumstances.
 - Trusting relationships, support networks and the sharing of tasks and concerns contribute to security, reassurance, comfort and manageability, and mitigate anxiety, stress, uncertainty and feelings of abandonment [16, 32].
- There is research on psychosocial and support interventions for carers [33]; but this showed that finding time for attendance at group or one-to-one sessions – or even for telephone support – was problematic for carers. The focus of carer interventions is repair (when carers cannot cope), 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]).

Assessment

- Carers are entitled to an assessment of their needs. It is not clear how commonly this is offered or whether it results in a support plan [28].
- Carers have suggested that „what helps’ them is primarily being part of a good care team, ensuring that the person cared for has the best possible support. Research suggests that good „quality of death’, and the satisfaction of knowing they fulfilled the person’s wish to die at home, may help family carers to cope with the loss of a loved one [31].
- Other factors that have helped carers are:
 - trusting relationships and honest communication with providers, who listen to and support them
 - befriending schemes, and support from friends and neighbours: people who spend time with them and the dying person, and reduce their sense of isolation
 - having a personal budget so that the carer can engage someone who they can train and supervise. This option is not well publicised.
- Our exploration of research was unable to consider post-bereavement support for carers. This may be valuable: it may only be after the death of a loved one that carers can afford to admit the impact on themselves. After a long period of caring, people may be extremely isolated; even the visits of health and social care staff will cease [1]. The impact of caring for a dying loved one is complex and long term.

Practice examples

- **Practice example 1** outlines a befriending scheme that trains and coordinates volunteers to support people dying and their carers, developed by a hospice.
- **Practice example 11** describes an initiative to provide practical and emotional support to frail older carers specifically.

Coordinated care: health and social care and housing

Working together to support people dying at home

„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.’
GP [38]

„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.
Community nurse [39]

Recommendations

Professionals and providers should:

- Ensure that networks and coordination arrangements are in place to enable health and social care professionals (including those responsible for arranging and delivering the care) to work together and share their knowledge.
- Ensure that patients/service users and carers see the same familiar staff where possible, and have a single nominated person to contact for advice who has influence across health and social care.
- Ensure that professionals are able to work flexibly and are responsive to the needs of patients/service users and carers.
- Ensure that GPs identify people approaching the end of life, and discuss and record end of life issues with patients/service users and their families. Ensure that the new electronic primary care registers are used to coordinate care and take account of people’s wishes.
- Recognise the vital contribution that district and community nurses make to end of life care. Invest in the recruitment, training and supervision of health and personal care assistants as well as domiciliary care staff.
- Ensure that patients/service users and carers can access specialist advice and support „out of hours’, including essential medication and drugs for pain control.
- Ensure that advance care planning documents are accessible to out-of-hours and ambulance staff.
- Ensure that home care (or domiciliary) workers, healthcare assistants and extra care housing workers are trained and supported to work with people dying at home and their carers.

- Consider the role that social workers can play in supporting people at the end of life.

Commissioners should:

- Develop joint protocols between ambulance services, secondary care staff and primary care staff in relation to resuscitation – do not attempt cardiopulmonary resuscitation (DNACPR) – orders, and other relevant documents on patient choices for care.
- Work to speed up hospital discharge so that people do not die in hospital while waiting for community nursing cover, equipment or transport.

Key points from research and policy

Specialist palliative care

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]

- Specialist palliative care teams are not universally available. Therefore, most of the health and social care services provided in the home are provided by „generalist’ workers, such as GPs, district nurses and domiciliary home care workers, who do not necessarily have training in palliative care.
- Multidisciplinary palliative care teams, sometimes called „hospice at home’ or „rapid response’ teams, may be available in the local setting. If so, face-to-face care is usually provided by a single nurse or healthcare assistant with specialist training, supervised by a senior clinician.
- Currently, about 355,000 people across England need palliative care, but fewer than half receive it [40].

Generalist palliative care

- There is local variation with regard to the provision of palliative care. The third or voluntary sector is active in providing palliative care.
- End of life care in the home is often led and provided by GPs and district nurses, as there is a shortage of specialist care services.
- GPs (and patients and carers) may have difficulty in identifying the point when a person is approaching death [38]. There may then be delays in referring patients to palliative or nursing care. GPs say they often do not know the patient’s wishes [41]. GPs may be reluctant to discuss the person’s impending death and therefore do not clarify what the person’s wishes are [1, 23].

- Community nurses suggest that GPs, and in particular locum GPs working at night, can be „risk averse‘.
- The Gold Standards Framework (GSF) for primary care has been said by nurses to have improved communication and teamwork between GPs and community nurses [43]. The framework has been shown to improve the chances of people wishing to die at home to do so.

Care providers working together

- Hospice at home and palliative care teams tend to work best if there is good communication between frontline and „managing‘ staff. Care planning, care coordination and liaison are important activities of the team. Hospice-type services delivered at home have been shown to prevent hospital admissions, but are more likely to be effective if:
 - they can offer rapid response at all hours
 - they do not rely on agency nurses
 - they can provide overnight nurses
 - they include provision for prescribing medication [44, 45, 46, 47].
- As most people in the last year of life spend time in hospital, rapid discharge teams can increase the number of people who are able to die at home [45, 48, 49]. Arrangements for discharge include:
 - liaison with community services
 - procurement of equipment and drugs
 - prioritisation of people at the end of life for hospital transport.
- Domiciliary home care workers [50] and extra care housing officers [51] are well placed to provide practical advice, personal care and emotional support to people dying at home.
- Social workers are rarely available to people dying at home but may well have the skills to support advance care planning and to assist with practical and financial problems [10].

Practice examples

- **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.
- **Practice example 3** shows some of the outcomes for patients when primary care staff adopt the Gold Standards Framework for supporting people to die 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.
- **Practice example 10** describes the Amber Care Bundle for specific use with people who have had a stroke.

Accessing equipment and services

Equipment and community services needed in the home to enable people to be cared for until death

„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.’ Community nurse [25]

Recommendations

Commissioners should:

- Ensure that there are protocols in place to deal with the key issues in rolling out electronic palliative care coordination systems (EPaCCS) or their equivalent, including what information should be recorded, how it is collected, updated and quality assured, and who should have access to the data.
- Assess the support available to people dying at home and their carers ‘around the clock’, and take steps to address the large gaps in service provision.
- Ensure that there are agreed protocols (e.g. prescription of opiates) between out-of-hours locum GP services and with regular primary care.
- Ensure that hospital discharge planning and case conferences include community staff, for example a district nurse.
- Ensure that there is a single point of contact for carers through which they can arrange a home-based assessment for home-based equipment by a qualified professional, such as an occupational therapist, and be trained to use it as necessary.
- Consider commissioning services that provide for blood transfusions and other intravenous procedures, which are available to people in their homes in order to avoid emergency hospital appointments and admissions.
- Commission services that address the need for patients to have analgesia at all times, as poor pain relief is often responsible for emergency admissions. Ensure that equipment such as syringe drivers and palliative care kits are available.
- Consider the provision of personal alarms for frail patients and carers and telecare.

Key points from research and policy

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

- The EPaCCS register is a locality register held on a primary care computer database, which holds key information for people who have been identified as approaching the end of life. Local decision makers must adopt the related core information standard (ISB 1580) [27], which will include the patient's choices around end of life care and place of death. Local decision makers will also decide who can access and edit the electronic system.
- Information should be shared across health and social care and between different health sectors, for example primary and acute care. Hospital and ambulance staff may have no information on patients admitted through Accident & Emergency [58].
- Although, in principle, EPaCCS are likely to improve coordination, the pilot initiatives have identified a number of issues. These include [27]:
 - whether these are outline registers or care plans
 - who should – and who has time to – update them, and how useful they are if not updated
 - how omissions, such as failure to record preferred place of death, will be dealt with
 - who needs to have this information (e.g. ambulance crews are thought to be an essential user; social care staff may not have access)
 - the role of patient consent in recording information and deciding who can see it.
- Registers may need to include people who have a long-term deteriorating condition, which could progress to a terminal phase at any time. People with Parkinson's disease, stroke and chronic obstructive pulmonary disease are likely candidates.

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

- 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. Another common alternative is to call the ambulance service. Both of these options may result in a patient being admitted to hospital, unnecessarily and/or against their expressed wishes.
- Out-of-hours medical provision, including access to analgesic medication and medical records, is often poor. Locums do not know the patient and may be unwilling to prescribe morphine [59]. Out-of-hours doctors usually have no patient records and so they rely on carers to brief them.

- Coordination of care among community-based staff, and between day and night staff, is a problem [59]. Coordination between hospital and community, when a person who is in a terminal phase is discharged home, is also often inadequate. Community staff should be formally included in hospital discharge planning.
- A night nursing service (e.g. from the Marie Curie Cancer Research charity) may be available to give carers support overnight, although in some places this service is restricted to cancer patients. Carers may wish to purchase (with or without direct payments) their own night care, although some have found it difficult to identify suitable people [16]. Friends and relatives may also take on this role.

General needs for home equipment

- To support dying at home, research suggests that 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 [49]
 - 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.
- Carers should not be expected to know what will be needed, and should be offered a home-based assessment by a qualified professional (e.g. an occupational therapist), and a person to contact when the person's needs change and different equipment is required.

Blood transfusion

- Some clinical interventions that people may need at the end of life could easily be delivered at home. An example is blood transfusion, which is commonly required in end of life care for cancer to address anaemia and improve wellbeing [60].

Pain-relieving drugs and syringe drivers

- Managing complex medication at home can be a problem. One review on hospice care at home [5] reported problems with medication compliance in 60 per cent of patients receiving care at home, and most patients had two or more prescribers (hospital and GP).

- Syringe drivers can be highly effective in administering appropriate levels of palliative and pain-relieving drugs in the home setting. A study [15] of their use by community nurses in rural settings found that nurses needed training in their use.
- Palliative sedation is often used in the last days of life to control symptoms such as agitation, breathlessness and pain. A review [61] of the clinical literature found that this could be provided safely in the home setting, although it is more common in hospitals and hospices.
- Not having drugs in the home ready for use when pain escalates is a common reason for hospital admission of people during terminal illness. One rural Canadian study [62] showed that palliative medication kits, which are kept in the homes of people approaching death, can enable people to remain and die at home. In the UK context, having drugs in the home may overcome the reluctance of locums to administer opiates and other analgesia.

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, patients found that a handheld mobile phone application to share symptoms and queries with remote health professionals was reassuring [63].
- The most common telecare applications in rural Scotland [63] are dedicated out-of-hours specialist advice through telephone lines, with enquiries about symptom control and medication advice uppermost in the concerns of callers.
- Personal alarms, designed to be worn as pendants around the neck, were made available to patients at home in an Australian study [64]. The alarm would trigger an alert to a hospice service. Patients reported the benefits of having a greater sense of security, especially if they fell, and increased confidence in carrying out daily tasks. However, patients tended to remove the alarm in the shower, and while sleeping. Personal alarms could be relevant and useful for homes where both the person with the terminal illness and their carer may be frail.

Practice examples

- **Practice example 5.** The Partnership for Excellence in Palliative Support (PEPS) service in Bedfordshire illustrates a single access point, which aims to deliver expert advice and services „round the clock’.
- **Practice example 7** describes a London-wide initiative to build on the EPaCCS record and make it available to local authorities, hospital, primary and community care staff and the ambulance service.

- **Practice example 8.** The Midhurst Macmillan Specialist Palliative Care Service offers a range of services in the home setting, including blood transfusions, intravenous antibiotics and analgesia. The service works collaboratively with generalist services.
- **Practice example 12** describes an intravenous therapy team, working in home settings.

Costs of dying at home

The economic impact of people dying at home

Reducing reliance on acute care could release resources and better meet people's preferences. Health economist [3]

Recommendations

- The NHS should have a better evidence-based understanding of the relative costs of specialist and generalist care at the end of life, analysed according to place of care delivery.
- Time spent in hospital in the last year of life is the most expensive factor in end of life care. Policy makers and commissioners should concentrate on interventions to keep people out of hospital if they do not need to be there, and to discharge them as early as possible.
- Economic analyses should reflect the „cost' to family members of caring, and should consider how savings to the state can be harnessed to support carers to continue to care at home.

Key points from research and policy

Difficulties with costing

- 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. The limited evidence on costs suggests that dying at home is less expensive than dying in a hospice or hospital, with hospital care the most expensive option.
- Available evidence on the relative costs of delivering end of life care at home, versus in hospices or hospitals, is flawed, because, for example, it tends to take account of the cost to the taxpayer [3]. The analysis model used in most cost comparisons is based on patients physically spending time in different locations: therefore it does not take account of the cost of new models of hospice care that are delivered in people's homes.
- A major omission of economic modelling in end of life care 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 value of unpaid care by families, friends and relatives (although this is not limited to care given to people in the last year of life). If the value of this input were made more transparent, it could justify the cost of better support to carers to help them to continue to provide care at home.

- 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 [3]. This figure does not include the costs of „generalist’ health and social care staff (people who do not have specialist palliative care training). The overall cost of end of life care to the public sector is likely to amount to billions, and is unknown.

Potential for cost savings

- Most cancer patients experience admission in the last year of life. The National Audit Office [3] modelled the cost of caring for cancer patients in the last year of life, and found that the highest costs arise from hospital admissions and length of stay in hospital. A small fall in hospital admissions (e.g. 10 per cent), and reduction of the average length of stay (e.g. by approximately one-third), would deliver cost savings of around £151 million a year.
- Other reviews (of non-cancer patients [45] and European and United States studies [69]) show consistently that people in the last year of life often do not need to be in hospital, and that care delivered at home is likely to be cheaper than that delivered in hospitals and hospices.
- A further review of international literature [70] suggested that even in hospital settings, palliative care delivered by trained palliative care staff was cheaper than the care delivered by generalist or other specialist hospital staff. This suggests that investment in palliative care in both hospital and community settings may save money.
- A National Audit Office survey [2] concluded that primary care trusts’ expenditure on specialist palliative care services does not reflect the pattern of need.

Practice example

- **Practice example 8.** An economic and qualitative evaluation of the Midhurst Macmillan Specialist Palliative Care Service suggests that the service is cost-effective as well as offering maximum choice to people at the end of life.

Commissioning

Systemic and organisational issues

„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.’ Carer [16]

Recommendations

Commissioners should:

- Review palliative and end of life care services available in the locality to confirm that they are able to support people of different ages, ethnicity and social background to die well at home.
- Ensure that training is available for „generalist’ carers in the community who provide most end of life care for those who die at home. Training needs to include communication and care planning with patients and carers, and improving their own understanding of good-quality palliative care (including the use of analgesia). Less well-qualified staff can provide good responsive care if they are trained and well supervised.
- Commission specialist palliative rapid response teams and rapid discharge facilitation teams and model possible cost savings.
- Encourage general practice surgeries to use the electronic palliative care coordination systems (EPaCCS) register to promote patient choice, to improve coordination and to monitor outcomes of improved services.
- Consider how expertise on specific disease pathways can be made available to community health workers.
- Ensure that commissioned service practitioners are trained in, and compliant with, the provisions of the Mental Capacity Act 2005.
- Ensure that commissioned service practitioners are trained in the core competencies developed by the National End of Life Care Programme, Skills for Health, Skills for Care and Department of Health.

Professionals and providers should:

- Develop local protocols and processes of communication and coordination as these can improve patient and carer experience.
- Ensure that contracts provide 24-hour access to advice and support, for example a telephone helpline staffed by a palliative specialist to improve patient care and reduce expensive and unnecessary out-of-hours emergency admissions.

- Ensure that patients, families and the public have access to information about what dying at home may involve and that there are local services that can meet their needs.

Key points from research and policy

Deficiencies in generalist care

- Much of the information within this guide concerns commissioning. Most end of life care for people living in the community is 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 consultation on „generalist’ end of life care [72] found:
 - There was a lack of expertise in and a need for funding of training for end of life care. Funding for end of life care training is not ringfenced, but implementation of initiatives such as Liverpool Care Pathway requires training. Training of the health and social care workforce is challenging because staff are overstretched, and there is a high turnover of social care staff.
 - There were gaps in primary care provision, including:
 - the low number of senior community nurses
 - lack of investment in end of life care in general practice
 - poor provision of out-of-hours services with no night-time nursing cover
 - poor communication between GPs and out-of-hours locums.
 - There was poor integration between health professionals and social care assistants, and poor continuity of care between hospitals and community staff, including the referring GP. Roles were not clearly defined, and little of the condition-specific expertise of consultants filtered through into end of life care in the community.
 - End of life care initiatives that were supposed to support better generalist care were often not evidence based and/or rigorously evaluated for cost-effectiveness. Evaluation of advance care planning is an example. A poor evidence base may discourage adoption of policy.
 - There was no equality of access for different types of people, for example frail older people. Those without cancer may not get palliative services, especially if they have learning difficulties, mental health needs, or cultural

or language issues. Voluntary sector services and hospices cannot be presumed to fill the gap.

- Commissioners should consider who should be providing end of life care in the community, whether their current roles, skills and capacity equip them for it, and whether specialist palliative staff could provide better value [70].
- The National End of Life Care Programme has produced a toolkit for health and social care commissioning [73]. It identifies the main elements involved in commissioning end of life care services, explains the commissioning cycle in practical terms and offers a four-stage approach across all sectors.

Integrated commissioning

- The National End of Life Care Programme [66] has also produced guidance based on contributions from end of life care commissioners and providers of services within seven primary care trust areas. Although the report covers death in all contexts, the following essentials were highlighted:
 - strong commissioning and clinical leadership
 - use of nationally recognised drivers that attract payment for providers, especially GPs, and especially to improve out-of-hours cover
 - flexible budgets and care packages
 - use of nationally recognised tools or their local equivalent – advance care planning, preferred place of care etc.
 - shared electronic information systems, linked to acute settings – important in order to ensure proper coordination across services and recording and abiding by the individual's preferences
 - clearly defined access to 24-hour cover – a single point of access was raised as beneficial to patient and carers, as was the use of anticipatory drug boxes in the home to allow 24-hour access to medication
 - use of facilitator roles and coordination of care across boundaries – coordination of care, and working together, is everybody's business, but the introduction of facilitator roles with a single point of access appears to have a positive impact on services
 - training to support staff delivering end of life care – training is seen as an investment priority, and applies at virtually all staff levels; GPs, out-of-hours GPs, district and community nurses, and community providers of social care are insufficiently trained in end of life care; staff also need training in the use of the electronic information sharing systems.
- 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 core

competencies for staff working with people at the end of life [74]. A companion guide to workforce development has also been published [75].

The future

- There is remarkable agreement from commentators on the core areas that commissioners should address in order to improve quality and equality of access to end of life care for people dying at home. Despite the costs involved, there are likely to be significant resource savings if more people are kept out of hospital and are cared for at home.
- Carers may lack clarity about how money is allocated and how services are arranged. They are concerned about the effect of new commissioning arrangements on end of life care services.

Practice examples

Practice example 1: St. Catherine's Hospice: Carers' Befriending Service, Central Lancashire Cancer Partnership Group

The Carers' Befriending Service is a free service developed by hospice social workers and provided by trained volunteers who sit with a cared-for person in the carer's absence. The cared-for person must have a palliative diagnosis, be mainly housebound and socially isolated. The volunteer can sit with the cared-for person in their own home for up to four hours a week.

The service aims to:

- promote social, leisure and learning opportunities for carers, enhancing the health and wellbeing of carers
- promote improved quality of life for the carer, thereby preventing breakdown
- provide reassurance to the carer in the knowledge that a trained volunteer is with the service user.

Implementation of the service included:

- development of criteria, a referral form and risk assessment tool
- an „interest' checklist to match potential befrienders with a cared-for person
- advertising for potential befriending volunteers who completed application forms and Criminal Records Bureau checks
- a three-day training programme for six potential befrienders.

The service started in September 2011.

Carers have taken breaks to attend medical appointments, relax or shop. Befrienders have provided psychological support to the cared-for person and their carer. The scheme links the cared-for person, their carer and the Family Support Team at the hospice. Befrienders have sat with the cared-for person in the final days of life and at death. Others have supported cared-for people when admitted as inpatients.

Cheryl Scott, Family Support Manager, St Catherine's Hospital.

Practice example 2: Training domiciliary care workers

Recognising that domiciliary care workers play a vital role in enabling patients to be cared for in their own home, the North West Strategic Health Authority end of life care group supported initiatives across the region to support workforce development in domiciliary care. One initiative through the Pan Merseyside Network of local authorities focused on training domiciliary care staff in Wirral. A local end of life training partnership was established for this purpose. Wirral Metropolitan College Health and Social Care Team then produced a two-day course – „Introduction to the principles of end of life care' – with support, help and advice from the Wirral End of Life Care Team facilitators

and Cheshire & Merseyside Cancer Network. The course drew on the experience of Bradford & Airedale End of Life Care training programme for health and social care staff, delivered since 2004, and the Skills for Care framework of National Occupational Standards.

Eight two-day programmes have been delivered by Wirral Metropolitan College tutors to a total of 130 staff. Feedback from both the attendees and the managers has been very positive and encouraging. In almost all cases, people attending the course feel that they have increased confidence, skills and knowledge and most feel that they will benefit from the training and apply it in practice. Impact on people receiving care, their families and others providing support is still to be evaluated.

Cathy Grant, Programme Team Manager, Health and Social Care, Wirral Metropolitan College.

Practice example 3: Gold Standards Framework

The **National Gold Standards Framework Centre in End of Life Care** runs quality improvement programmes and accreditation to enable a „gold standard’ of care for all people nearing the end of life. Gold Standards Framework (GSF) training in primary care, care homes, domiciliary care, acute hospitals, community hospitals and dementia care involves a three-step programme to empower health and social care workers to:

- better identify people in the final year of life and include them on a register
- assess their clinical and personal needs with recorded advance care planning discussions
- proactively plan well-coordinated care in alignment with their preferences to reduce avoidable hospitalisation and enable more to live and die in their preferred place of care.

All programmes recommend recording and reviewing an advance care plan as standard. Advance care planning is a way of clarifying, formalising and recording the wishes, needs and preferences of people as they approach the end of their life and ensures that this information is communicated to others involved in their care. For example, if a person expresses a wish to die at home, this can then be planned for and coordinated with carers and the family involved. It also increases the person’s sense of choice and control and has been shown to help reduce numbers dying in hospital significantly.

A key requirement for GSF accredited care homes is that every resident is offered an advance care plan discussion, including a resuscitation, „allow natural death’ and „best interests’ discussion with those with dementia. GP practices that have undergone the GSF „Going for Gold’ training and accreditation have seen their proportion of patients recording such discussions quadrupling from 15 per cent to 60 per cent. This leads to a doubling of people dying in their preferred place of care, and a halving of inappropriate crisis admissions and hospital deaths at the end of life. GSF programmes in acute and community hospitals have also demonstrated reduced length of stay and better communication with GPs. GSF accreditation is recognised as a marker of quality

assurance by the Care Quality Commission, the Department of Health, commissioners and others.

Practice example 4: Bungalow Beds, Sandwell

The aim of Bungalow Beds was to provide a „home from home’ setting where patients and their loved ones could spend quality time together and to meet both physical and emotional needs.

The bungalows provided six beds across six sites for Sandwell patients who needed end of life care. Care was provided by healthcare assistants who, over the course of the pilot, developed the skills and knowledge to care for end of life patients. Clinical interventions were carried out by general practitioners, district nurses and the community palliative care team (known as Hospice at Home).

In total, 43 patients were admitted to the bungalows. The majority of referrals came from the community, palliative care, clinical nurse specialist team. Thirty-five went on to die in the bungalows, three were transferred to hospital, three patients returned home, one went to a nursing home and one went to an assisted living facility.

Of the admissions, 72 per cent were for end of life care, 23.2 per cent were for symptom control and 4.8 per cent were to support carers. The average length of stay for patients was 12.6 days although this figure was skewed as one patient remained for 101 days due to delays with social care assessment and placement. Excluding this patient gives an average length of stay of 10.4 days.

The pilot was evaluated from 1 May to 31 October 2012. The lack of a clear financial model made it difficult to assess costs although they were likely to be less than hospice care provision. Further work will need to be undertaken if this service is re-commissioned.

Diana Webb, Sandwell and West Birmingham Hospital NHS Trust.

Practice example 5: Bedfordshire Partnership for Excellence in Palliative Support (PEPS)

Partnership for Excellence in Palliative Support (PEPS) is a service that provides 24-hour support to patients in the last year of life and coordination of palliative care across Bedfordshire. A telephone number held at the PEPS centre offers a single point of contact to provide a seamless service for patients, their carers and care professionals when advice and support are needed.

The service was developed by Sue Ryder and NHS Bedfordshire in partnership with 15 other provider organisations in the county. Since its launch in December 2011, more than 1,000 local people have registered to use the service, which sees qualified nurses who are experienced and skilled in palliative care, screen calls to identify the most appropriate health or care professionals to respond to the caller’s needs.

The coordination centre, which is hosted by Sue Ryder at St John’s Hospice in the village of Moggerhanger in Bedford, also hosts an electronic register – the Information

System for PEPS (ISP) – which gives nurses up-to-date information about the patient's condition (with consent), provided in line with the patient's preferences and choices.

Prior to PEPS, palliative care services were disjointed and provision was not equitable across the county.

Alongside the introduction of the coordination centre, out-of-hours services, including face-to-face nurse assessment and a palliative care support worker service, have been established countywide to enable patients to be cared for at home.

Jo Marshall, Business Development Manager, Sue Ryder.

Practice example 6: Message in a Bottle, East Midlands

Originally devised by the Lions Club, Message in a Bottle is a simple idea designed to encourage people to keep their basic personal and medical details on a standard form and in a common location – the fridge.

It saves the emergency services valuable time if they need to enter a property in an emergency situation as they can identify quickly whether a person needs special medication or has allergies.

What's in the bottle? There is an information form with the person's name, medicines, allergies and relatives' contact details. In this project, it is suggested that the information in the bottle includes a signed living will, advanced statements or advanced decisions documentation, if that is applicable.

The person simply fills in the forms and puts them in the bottle in the fridge. To highlight that they are part of the scheme, one green sticker should be stuck on the fridge door and another on the inside of the house door.

Any bottle with a wide neck or a plastic container is suitable. Lions Clubs bottles are often available from GP surgeries, pharmacies and local Lions Clubs or can be ordered from the Lions Clubs' UK headquarters on 0845 833 9502. If only one bottle is ordered, it is free.

Jo Baggott, Strategic Communications Manager, NHS Midlands and East.

Practice example 7: Coordinate My Care: joining up London's end of life care services

Coordinate My Care (CMC) is a clinical service that coordinates care. It provides a care pathway that enables health professionals from primary, secondary and community care to put the patient at the centre of healthcare delivery. It is integrated with NHS 111 and designed to facilitate and strengthen communication across care settings. Modern technology is at the centre of the service, making information accessible 24/7 to professionals responsible for delivering coordinated care.

The service has been developed to encourage patient choice and to preserve dignity and autonomy at the end of life.

At the heart of CMC is a care plan that is developed by a patient with their nurse or doctor if and when both feel that it is appropriate. It contains information about the person and their diagnosis, key contact details of their regular carers and clinicians, and

their wishes and preferences in a range of possible circumstances. This care plan is uploaded to the CMC system to which only trained professionals involved in their care can have access. These include ambulance control staff, NHS 111 operators, GPs, out-of-hours GP services, hospitals, nursing and care homes, hospices and community nursing teams.

The delivery model comprises a comprehensive training programme underpinned by a central web-based service that allows visibility to care providers. Over 5,000 healthcare professionals have been trained to use the service.

Across London, there are 5,273 CMC patient records that contain patients' wishes and state their care plan. Over the past 23 months, 1,339 patients on CMC have died: 78 per cent in the community (34 per cent at home, 30 per cent in a care home and 14 per cent in a hospice), 21 per cent in hospital and one per cent in other locations. Twenty-seven per cent had no place of death recorded. By comparison, 2010 Office for National Statistics data for London reported that 59 per cent of patients died in hospital. Of those CMC patients who had a preferred place of death documented, 80 per cent died in their preferred place of death.

Julia Riley, Head of the Department of Palliative Medicine and Clinical Lead for Coordinate My Care.

Practice example 8: Midhurst Macmillan Specialist Palliative Care Service

This innovative, flexible and community-based care model is managed by the Sussex Community NHS Trust. It consists of a multidisciplinary team of specialist palliative care professionals, who link well with members of the primary healthcare team, community services, social services, care agencies and voluntary organisations in the locality, to provide proactive specialist palliative care and support following early referral from either the hospital or GP.

Care is undertaken either at home or in the community and may include blood/blood product transfusions, parenteral treatments, intravenous antibiotics, fluids and analgesia. The service accepts referrals for any person over 18 years of age who is living within a specified area with cancer or any life-limiting chronic progressive disease and who is experiencing complex problems.

The advantages of the model are that it extends choice at the end of life for people and their families, enables an early referral to active specialist palliative care and leads to good clinical outcomes such as less frequent Accident & Emergency attendances and decreased hospital stays. The majority of people cared for by this team will die in their preferred place, which is normally their own home.

An economic and qualitative evaluation of the service commissioned by Macmillan Cancer Support, which is still to be published, suggests that the service is cost-effective as well as offering maximum choice to people at the end of life. In the meantime, a summary is available from Macmillan Cancer Support on request.

Adrienne Betteley, Programme Manager, Palliative and End of Life Care, Macmillan Cancer Support.

Practice example 9: Majlish Homecare Services

Majlish Homecare Services (MHS) is a charity that has provided quality culturally appropriate homecare services for the past 12 years to vulnerable older people and others living in East London in their own homes.

MHS began its life as a pensioners' club based in Tower Hamlets in the 1980s focusing on the older Bengali community. It has developed into a homecare service by its founder, Rahman Jilani, providing personal care services to the older Bengali population living in the borough and covering the wider community in other London boroughs.

The MHS ethos is to encourage care for the community by the community and to place the service user at the heart of its approach. Care staff are directly employed by MHS and are appointed from the communities where they operate. All new staff receive extensive training provided by MHS before they start to visit people's homes to ensure that they attain high-level care standards. All staff are required to reach NVQ Level 2 and further training is provided by MHS in many other areas, including dementia care and end of life care. A number of staff have recently qualified as healthcare assistants and will be under the supervision of a qualified nurse to provide basic healthcare services to people in their own homes.

MHS is the UK arm of the Sir William Beveridge Foundation, an international non-governmental organisation established in 2006 that also provides homecare services to vulnerable older people living in Dhaka and Sylhet, Bangladesh.

Rahman Jilani, Executive Director, Majlish Homecare Services.

Practice example 10: The Amber Care Bundle

The Amber Care Bundle is a staged process in which a person who has had a stroke is supported to make their wishes and preferences about end of life known. It is not about stopping treatment but about identifying and carrying out what the person wants in a timely and pre-planned manner. It also keeps the patient and their relatives or carers up to date with what is happening, ensuring that staff talk to patients and those close to them about treatment options and where they want to be cared for.

Taking the Amber Care Bundle approach, a number of key decisions have to be made, including whether or not the person wants cardiopulmonary resuscitation and what they want to happen if they become unwell. This approach emphasises the importance of involving patients in decision making, allowing time for consideration and in line with their assessed mental capacity on a daily basis.

The approach is being piloted at the Royal Bournemouth Hospital where patients in the end stages of life following stroke are referred to the palliative care team. The ward team of therapists and nurses work with the palliative care team, care agencies and families/carers to give education and condition-specific information and handling advice/equipment. Therapists give information on activities of daily living that the patient is able to participate in and how best family/carers can support them to do this.

The neuro-therapy team offers telephone support or home visits after discharge, usually in the first few weeks to aid transition to community teams.

Louise Clark, Senior Occupational Therapist, Royal Bournemouth Hospital.

Practice example 11: The needs of older carers

This project, a joint initiative between Age UK and the Department of Health, began in 2010 and focuses on the needs of older carers, rather than those being cared for. The idea is to empower older carers by focusing on their practical and emotional needs, helping them to be more effective in their support to their relative or friend.

The three-year project began with Age UK Leeds and Age UK South Tyneside. They were joined in April 2011 by Age Concern Kingston upon Thames and Age UK Leicester, Shire and Rutland. In 2012, the newly developed procedures and protocols were extended to Age UK Oxfordshire and Age UK Lancashire.

All the local bodies involved have to identify a project manager to run their pilot and recruit volunteers who can offer relevant services to carers and their relatives and friends. Volunteers can either provide support themselves or signpost the carers to Age UK or external practical services such as shopping, cleaning, gardening, food delivery and benefits advice.

There are examples of partnership with social services (for complex cases), local hospices and voluntary sector organisations.

Volunteers can also arrange or provide emotional support to older carers, such as advocacy services, counselling, befriending or spiritual assistance, to enable them to care for people at the end of their lives, in their own homes. Anecdotal evidence suggests that the service has benefited both carers and the relatives being cared for.

Linsey Reynolds, Programme Manager, Age UK.

Practice example 12: Community Intravenous Therapy Team

The Community Intravenous Therapy Team is a team of specialist nurses who have undergone additional training and development in the delivery of intravenous therapies. The aim of the team is to give people at the end of life the option of early hospital discharge and to reduce avoidable admissions. This extends the offer of care being provided either at home or in community health clinics. The team works closely with GPs to prevent admissions to secondary care. It offers clinical leadership, education, assessment and support within primary care in the management of patients requiring intravenous therapies. Through audit, education and research it aims to continually update the knowledge base and practice built on national evidence.

Therapies offered include intravenous antibiotics, iron, blood and platelet transfusions and the maintenance of intravenous access devices, including syringe drivers and cannulas.

The team works closely with local hospices, specialist palliative care teams, consultant haematologists, microbiologists, infection control physicians and secondary care consultants. It also links with the specialist practitioner of transfusion, infection control nurses and laboratory scientists.

The team includes founder members of the North West Merseyside and Cheshire Collaborative Intravenous Nursing Service group. It has developed guidelines that are now adopted across the region to standardise the care and maintenance of venous access devices across the region.

Christine McBride, Specialist Palliative Care Team Leader, Liverpool.

Resources

General practitioners

- [End of life care patient charter](#) (2011)

Housing

- [End of life care in extra care housing: Learning resource pack for housing, care and support staff](#) (2012). This resource pack, published by the National End of Life Care Programme and the Housing Learning and Improvement Network, and prepared by the International Longevity Centre, covers topics ranging from initial conversations and care planning through to the things that staff might be expected to do after a death.
- [Is it that time already? Extra care housing at the end of life: A policy-into-practice evaluation](#) (2008)

Integration

- [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](#) (2012)
- [Supporting people to live and die well: A framework for social care at the end of life](#) (2010)

Macmillan Cancer Support

[Macmillan Cancer Support](#) provides practical, medical and financial support for people with cancer and also campaigns for better cancer care. The 'Learn Zone' provides free and easy access to a wide variety of learning resources, online courses and professional development tools for health and social care practitioners and volunteers.

Marie Curie Cancer Care

[Marie Curie Cancer Care](#) provides information and advice for people with life-limiting illnesses and their families as well as contacts for nurses who can support terminally ill people who choose to die at home. There is information for commissioners on service design and innovative approaches to local care provision. Useful reports include:

- [Committed to carers: Supporting carers of people at the end of life](#) (2012)
- [Being cared for at home towards the end of life: What to expect when approaching death](#) (2010)

National Council for Palliative Care

The [National Council for Palliative Care](#) (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. It believes that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. It works with government, health and social care staff and people with personal experience to improve end of life care for all.

The charity produces practical guidance, training materials and a quarterly magazine – Inside Palliative Care – and runs conferences and workshops for people at the end of life and those who care for them. It also runs an extensive training programme and undertakes policy and campaigning work.

National End of Life Care Programme

The following publications are not referenced in the text, but may be useful:

- **Optimising the role and value of the interdisciplinary team: Providing person-centred end of life care** (2013)
- **Improving end of life care through early recognition of need: Exploring the potential for using predictive modelling in identifying end of life care needs** (2013)
- **Advance decisions to refuse treatment: A guide for health and social care professionals** (updated 2013)
- **Advance care planning: It all ADSE up** (2012)
- **Making the case for change: Electronic palliative care co-ordination systems** (2012)
- **Reviewing end of life care costing information to inform the QIPP End of Life Care Workstream** (2012)

National Institute for Health and Care Excellence (NICE)

- **Quality Standard for End of Life Care for Adults (QS 13)** (2011)
- **NHS Choices – End of life care guide**

Occupational therapy

- **The route to success in end of life care: Achieving quality for occupational therapy** (2011)

Specialist care

- **Commissioning guidance for specialist palliative care: Helping to deliver commissioning objectives** (2012). This was developed in collaboration with the Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care and Palliative Care Section of the Royal Society of Medicine.

Spirituality

- **Spirituality and ageing: Implications for the care and support of older people** (2013)
- **Merseyside & Cheshire Cancer Network** offers an overview of religious practice, which health and social care practitioners working with people from diverse cultures may find useful.

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Dying well at home: the case for integrated working

This guide is based on evidence about what is needed to offer good care to people who are approaching the end of life and wish to be cared for and die in their own homes. It does not cover residents who live in care homes.

The guide is based on:

- a review of available quantitative and qualitative published research evidence, including studies that systematically collect qualitative material on what people think and say about services, and which services they value
- guidance on end of life care produced by authoritative sources, such as Marie Curie Cancer Care, the National End of Life Care Programme, and Skills for Care
- a workshop held at SCIE in 2013 with carers of people who have died
- practice examples
- a SCIE Project Advisory Group (of commissioners, providers, carers and service users), whose role was to review the way the guide was written and produced to ensure that it reflected real-life experiences and practice.

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