Evidence for transforming community services

Services for end of life care
Transforming community services is important for everyone, no matter how young or old. As our population continues to age, it becomes increasingly important to provide high quality, accessible and appropriate end of life care.

We reviewed about 900 studies on innovative end of life care in the community to distil the key transformations required for services, staff and systems.

Information in this document is drawn from a rapid evidence review. We searched 10 reference databases for systematic reviews, randomised trials and observational studies available as of January 2009. Studies were screened for relevance and validity and key themes were identified. This document provides a summary of only those interventions which are not widespread in the NHS and which have the potential to transform community services. It is not an exhaustive overview of all literature identified.
Ten important issues identified by the research evidence that may improve end of life care in the community are:

- expanding palliative care to cover more than cancer
- using formal care pathways
- using automated systems to provide practical reminders
- focusing on supporting carers and family members
- using question lists and checklists can help families
- training peers and family members to provide support
- educating nursing homes to improve care
- addressing gaps in spiritual care
- providing GP home visits where needed
- considering complementary therapies for some
England has a strong focus on end of life care. The national Gold Standards Framework has a primary care component and the national End of Life Care Strategy, released in 2008, emphasises caring for people in the place of their choosing, including the community.

Many examples of good practice are already being implemented widely in England, and we do not repeat them here. Instead the focus is on initiatives with the potential to transform community services and which are not already widely known. Similar to previous systematic reviews,¹ we identified a paucity of literature about innovative community initiatives at the end of life. The brevity of this review reflects that.

We have used the terms end of life and palliative care interchangeably throughout the text to mirror the international literature, though we acknowledge that the terms have specific meanings in some contexts.

### Who: targeting care

**End of life care is about more than cancer**

Until recently, the focus of palliative care services has been on cancer and malignant disease. However, there is an increasing recognition that everyone nearing the end of their life can benefit from supportive care.

One study in the UK established a model of care for people with heart failure near the end of life. Specialist palliative care services collaborated with community based heart failure nurses. The heart failure nurses provided regular visits, support groups for patients and carers in hospice day therapy units, and referred patients for other palliative care as needed. The evaluators believe that joint work between community services and specialist hospital care has potential for sustainable, high quality care for people with advanced heart failure.²
Family members are often at the centre of providing care for people at the end of life, sustaining care when professionals are not available and supporting the service user both physically and financially.\(^3\) Research suggests that community services could significantly improve the quality of care available by supporting caregivers.\(^4\)

Caregivers generally face five burdens: time and logistics, physical tasks, financial costs, physical health risks and emotional burdens and mental health risks.\(^5\) To support family members, community services could focus on ensuring excellent communication with the family, encouraging appropriate advance care planning and decision making, supporting home care, showing empathy for family emotions and relationships, and signposting families to counselling for grief and bereavement.\(^6,7\)

Another option is providing practical toolkits and checklists to support carers and service users. A randomised trial in Australia found that providing a list of question prompts helped terminally ill people with cancer and their caregivers to ask questions of doctors and care teams. The list promoted discussion about prognosis and end of life issues without creating anxiety or impairing satisfaction.\(^8\)

Training in coping skills for family members has also been offered in hospices to good effect. One trial with more than 300 people compared a control group who received standard hospice care, a group who received standard hospice care plus three supportive visits to the family, and a group who received standard care plus three visits to teach coping skills. Compared with hospice care alone or hospice plus emotional support, the coping skills training was effective in improving caregiver quality of life and reducing burden related to patients' symptoms and caregiving tasks.\(^9\) Similar training, offered either in small groups or one to one, could be rolled out by NHS community services teams. This would require staff training, regular review and debriefing and additional capacity.
Community teams have identified that it is difficult to know when to stop offering curative care and move towards end of life care. But research suggests that the dichotomy of palliative and curative care doesn’t have to be. Transformational care is a blended model of care in the early stages of investigation.

Research suggests that presenting dying patients and their families with a transformational model of care instead of the traditional palliative or curative treatments may enhance the patients’ quality of life and benefit psychosocial aspects during the last few weeks of life. This model involves a combination of curative and palliative services provided by a care coordination team of nurses and social workers. It has been found to be particularly worthwhile in caring for people with AIDs.\textsuperscript{10}

An important part of new models of end of life care is offering spiritual support. A systematic review found that spiritual care was under-researched and underprovided. The review concluded that spirituality at the end of life is fundamentally important because it allows people to consider their lives, seek peace and forgiveness and have better quality of life in their final weeks. No guidance was provided about how community services could redress current gaps, but this was highlighted as an area in need of further exploration.\textsuperscript{11}
Other models of care use complementary therapies to address pain at the end of life. A systematic review of 21 studies found that acupuncture, transcutaneous electrical nerve stimulation, supportive group therapy, self hypnosis, and massage therapy may provide general pain relief and that relaxation / imagery can improve oral mucositis pain. People with severe chronic obstructive pulmonary disease may benefit from the use of acupuncture, acupressure, and muscle relaxation with breathing retraining to relieve dyspnea.

Regardless of the exact type of care provided in these models, a common theme emerges. High quality end of life care is based close to home, requires a mix of generalist and specialist care, needs to involve and support families fully and should seek to combine elements of palliation with other care to meet the patient’s underlying needs. This has significant implications for the NHS because community services still tend to focus on a medical model of care, aiming to cure people rather than support them to die well. There is a need for enhanced training in how to support family members as well as service users and a need to understand the range of other therapies available to people. Most of all, there is a need to build in capacity to provide this mixture of care because holistic care takes time and skill.

**Integrated care pathways improve outcomes**

Integrated care pathways are widely accepted to improve standardisation, continuity and collaboration among multidisciplinary teams. In end of life care the majority of studies of integrated care pathways are descriptive rather than outcomes focused. However there is an evidence base demonstrating improvements in symptom assessment, documentation of care goals, compliance with guidelines and pain control. In England, the Liverpool Care Pathway, the Gold Standards Framework and other approaches are all well known in primary care and take up rates are increasing. Other countries have similar initiatives.

As this review focuses on initiatives that are not widely known about or implemented, we have not documented the extensive literature about care pathways here because this is already a national priority in England and included in the National Strategy for End of Life Care.
More people are now choosing to spend their final days in a residential care setting. But nursing homes often send people to hospital regularly at the end of life, perhaps because they feel that they cannot cope or because they feel this is what the patient or their family wants. There is a need to upskill nursing homes on appropriate end of life care to avoid unnecessary admissions near the end of life. One study found that community based palliative care nurse specialists could offer advice on pain and symptom management to nursing homes and other communal residential facilities by telephone. This is a relatively cost effective use of nurses' time and can lead to substantial improvements in adherence to guidelines and quality of care.

Hospice teams have also offered training to nursing homes. In one programme, hospices visited nursing homes to provide six educational sessions to all staff. The education programme resulted in measureable improvements in care and increased referral to hospices.

Where: location of care

Numerous studies suggest that many people want to receive care at home or close to home in their final weeks and days. Some suggest people prefer the psychosocial climate in hospices compared to hospitals and that many want to die at home. However, reviews suggest that high quality, comprehensive information about people's preferences and satisfaction with care in different community locations is not readily available and more research is necessary.

One randomised trial in the US compared usual care versus an in-home palliative care intervention for people with less than one year to live. The group receiving home based care also benefitted from an interdisciplinary team providing pain and symptom relief, patient and family education, and an array of medical and social support services. People receiving care at home were more satisfied, more likely to die at home, and less likely to visit A&E or be admitted to hospital. This resulted in significantly lower costs of care. The authors concluded that this provides evidence for reforming end of life care.
Such intensive home care may be difficult to roll out in the NHS without building further skills and capacity. Home care may take more time than usual care and require more travel by nurses and specialists. Another US study found that home visits from GPs near the end of life improved outcomes compared to usual care\textsuperscript{19} and this may be more feasible in the NHS. In this study GPs did not have to visit extensively to notice gains in patient and family satisfaction, knowledge and quality of life.

Supporting people to die in a place of their choosing is a national priority and community services need to have the capacity and capability to support this. We identified numerous studies highlighting the value of patient choice but little high quality research demonstrating how community services could put this into practice. The evidence that did exist tended to be small scale or of low methodological rigour.
Multidisciplinary teams make a difference

Numerous descriptive studies outline the potential benefits of community and hospital teams working together, but few studies have examined the best people to involve in teams.

In New Zealand an integrated palliative care team has proven successful. A team of palliative care coordinators (augmented by specialist hospice clinicians), GPs, practice nurses and community district nurses worked together to improve the quality of palliative care. The team is funded to work together in the primary care environment. A mandatory induction course for each staff member is required along with other support courses. This is important because the team are not expected to be able to come together and work in an integrated way immediately; they are provided with clinical training in aspects of end of life care and, perhaps more importantly, training in how to work together effectively to provide patient centred care.

Allied professionals may also have a role. One US study found that care co-ordination provided by allied health professionals helped people near the end of life develop advance care plans and improved satisfaction with care. The authors concluded that sometimes the best carers are those who have empathy and compassion, rather than just those who have specialist training.

In the US an approach to incorporating peers as part of the care team has been trialled. Dialysis patients were trained as peer mentors to help others think through end of life planning. The peer mentors focused on communicating information about advance care plans. A randomised trial with more than 200 people from 21 centres found that peer mentoring significantly influenced the completion of advance care plans compared to distributing standard printed information or no intervention. The influence was most prominent among minority ethnic groups. The authors concluded that this approach may be culturally appropriate. They argued that it is commonly assumed that printed materials are effective in educating people about healthcare and decision making, but that the relationship-centred peer mentoring approach may be more effective in some cultural groups because it focuses on oral traditions.

"Acknowledging cultural differences and tailoring our approach could be powerful in enhancing trust and participation and decreasing potential disparities in healthcare outcomes."
Similarly, partners of people with cancer have been taught how to provide supportive pain management. Partners involved in the programme felt more confident in their caregiving role and were able to better manage people’s pain at home. A nurse visited at home and taught the patient and their partner about pain management protocols, spread over three sessions. There were significant improvements in quality of life.23

Research about working with patients and carers as part of the care team is in its early stages and is a very sensitive issue. However seeing service users and their families as active participants in care right through to the end of life has the potential to transform community services and may be worth exploring further.

A first step may be to work with patient and carer representatives and voluntary sector organisations to explore whether involving service users and carers in this way might be acceptable in the UK context and if so, the types of training, infrastructure and support that may be needed. It might be assumed that asking someone who is dying to mentor or educate others about this might be very emotionally upsetting, but research from the US found that this was not the case and that supporting others had positive effects on the dying person’s wellbeing and sense of worth. Service users would need to be carefully assessed as appropriate and regularly supported to ensure no adverse effects or additional stress.
Automated systems give easy access to information

Information systems have been designed to provide automated data, guidelines and reminders to staff offering end of life care. These systems have the potential to reduce variation and human error. Artificial intelligence techniques such as data mining, neural networks and case-based reasoning have been built into some systems, particularly in the US. For example, palliative information systems are being used to provide reminders about guidelines to reduce variations in outcomes and to disseminate expert level ‘know how’ to frontline clinicians caring for people in the community. Such automated information systems have been found to work well in other clinical areas when used as part of a more comprehensive care package. The same may be true in end of life care, though research is in the early stages.

Example of using information to make change

The Department of Health’s draft quality markers for end of life care emphasise the importance of regularly auditing care to ensure it meets best practice guidelines. A small pilot ‘national audit of end of life care in primary care’ is underway and due to report at the end of 2009. Every GP practice in 15 PCTs has been invited to submit information about all patient deaths occurring in February and March 2009. The practices use an online audit tool known as ADA (After Death Analysis) to submit basic details about an individual’s death, the services they used in the last six months of life, the type of support provided to families and carers, use of care pathways, and whether the person died in their preferred place. The questions are based on best practice identified in the Gold Standards Framework. No patient-identifying information is provided.

The online tool takes 10-15 minutes per death to complete. It provides feedback to each individual practice and data can also be collated on a PCT, SHA-wide and national level. As soon as a practice submits information online the programme immediately provides a summary of the practice’s performance compared to regional and national averages. The aim of the audit is to generate a national benchmark to help monitor improvement over time, but the ability to provide immediate individual comparative feedback to practices has been positively received.
This overview has briefly outlined examples of good practice for improving end of life care in the community. We summarised common themes from about 900 studies, including a small number of illustrative examples of key points. We focused not on examining individual services or models of care, but rather potential high impact changes that are not currently well embedded in the NHS. The priorities for further consideration are as follows:

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Evidence quality</th>
<th>Effect</th>
<th>Priority</th>
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<tbody>
<tr>
<td>Formal care pathways</td>
<td>High</td>
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<tr>
<td>Expand palliative care to cover everyone</td>
<td>Medium</td>
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<tr>
<td>Automated audit and feedback systems</td>
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<td>Address gaps in spiritual care</td>
<td>Medium</td>
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<td>M</td>
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<tr>
<td>Palliative care at home</td>
<td>Medium</td>
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<td>Training for family members</td>
<td>Low</td>
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<td>Question lists for families</td>
<td>Low</td>
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<tr>
<td>Training for nursing homes</td>
<td>Low</td>
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<tr>
<td>Peer support for people at the end of life</td>
<td>Low</td>
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<td>GP home visits</td>
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<td>Include complementary therapies in care packages</td>
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<td>Written education for families</td>
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<tr>
<td>Blending curative and palliative care</td>
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Priorities for further consideration are based on an assessment of the amount of evidence available, the quality of evidence, the effect of interventions and the extent to which initiatives are already being implemented in the NHS. It is important to emphasise that not all possible interventions are listed here. Also, in many cases there is not a strong evidence base. This does not mean that an intervention does not work well; only that it has not been well researched. For this reason, the Department of Health used the evidence as just one of the components considered when developing high impact changes. Expert opinion, consensus workshops and other methods were used to form a well rounded picture, underpinned by this rapid evidence review.
References


