

Getting serious about prevention:

enabling people to stay out
of hospital at the end of life



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Executive Summary

This report sets out key steps that commissioners can take in collaboration with service providers to enable people who are approaching the end of life to avoid being admitted to hospital when this is possible and appropriate, as well as enabling those who are admitted to make a transition to a community setting quickly.

In this report, we recommend:

For commissioners:

- commissioning the increased provision of 24/7 care in community settings, through care homes and hospices, and community health and social care services that can provide care in people's homes;
- commissioning anticipatory prescribing of medicines for people approaching the end of life;
- working with Public Health leads to commission public health approaches to end of life care;
- using available funding, through e.g. System Resilience Groups, the Better Care Fund, and Integrated Personal Commissioning, to improve co-ordination between hospitals and community settings, including hospices, for people approaching the end of life.

For service providers:

- encouraging the use of Advance Care Planning, and working with other service providers to facilitate the sharing of records;
- hospitals working more closely with local hospices, care homes and other community providers, to explore how they can better meet people's care and support needs;
- working with commissioners to enable different hospital teams to work together to help identify people who may be approaching the end of life.

For health and social care staff:

- GPs taking steps to identify patients who are at the end of life, and working with practice managers, nurses and administrators to ensure that such identification is recorded and that these people and those important to them are supported;
- health and social care staff identifying carers of people who are approaching the end of life and referring them for local authority assessments.

Introduction

NHS England's Five Year Forward View made clear that a gap of £30 billion in NHS funding needs to be closed by 2020.¹ The cost to the NHS of avoidable hospital admissions is considerable, in terms of both the financial costs of emergency admission into hospital² and beds being used by people who could be cared for outside of hospital. At the moment the NHS is paying too much to care for people in a setting where they don't want or need to be.

This is a significant problem, with NHS England responding to the build up of pressures on urgent care services through the funding of System Resilience Groups (formerly focussed on 'winter pressures' on these services). NHS England's report on winter pressures identifies the two central problems: **demand** for bed spaces, which can be managed by prevention of admission, and **supply of capacity**, which can be managed by enabling people to be transferred to community services.³

Commissioners and service providers will be acutely aware of the pressures on NHS services – in terms of staff time, beds and other equipment. This report is intended to show how end of life care services can be designed and commissioned to help relieve the NHS of some of these costs. In particular, it sets out **key steps that can be taken to enable people who are approaching the end of life to avoid being admitted to hospital, as well as enabling those who are in a hospital bed to make a transition to a community setting quickly**. In particular,

System Resilience Groups are encouraged to take note of these recommendations.

Commissioners who read this report are encouraged to work with service providers to act on these recommendations. Health and social care staff must be involved in shaping services to enable these recommendations to be put into practice effectively.

As well as reducing the costs to the NHS, enabling people to stay out of hospital at the end of life can make a significant difference to the experiences of dying people and their families. Multiple surveys have shown that most of us would prefer to die at home⁴, yet many people continue to die in hospital: the 2008 End of Life Care Strategy highlighted this problem⁵, and it was also recognised in 2014 in the Nuffield Trust's report on social care and hospital use at the end of life.⁶ In the process of relieving costs of care, commissioners and service-providers can help to facilitate a significantly better end of life experience for those who neither wish to die in hospital nor have any medical need to be there.

Why now?

Acting to reduce emergency admissions at the end of life is in line with a number of priorities for healthcare that have been recognised on a national level.

NHS England is calling for a move towards co-ordination between hospital based and community based services: the Five Year Forward View calls for out-of-hospital care “to become a much larger part of what the NHS does”⁷, and acknowledges the importance of people getting the “right care, at the right time, in the right setting, from the right caregiver”.⁸ The 2014 VOICES survey showed that for most recently bereaved people, the right place for their loved one to die was at home or in a hospice.⁹

As we have seen, the NHS faces increasing pressure on A & E departments, as well as considerable funding challenges, both of which could be alleviated to some extent by ensuring that fewer people approaching the end of life are in hospital when they neither need nor want to be. Recommendations in this report will require decisions about how to prioritise funding, but in doing so can save the NHS money: a 2014 study of emergency admissions of people in the last year of life at two hospitals found that 35 out of the 483 admissions were avoidable. According to this study, preventing these and providing care in alternative locations would have saved the two hospitals £5.9 million per year – though this would have to be offset against the increased cost in community care.¹⁰ The challenge for commissioners is to ensure that savings in the acute sector are used to build capacity in community settings.

The government's manifesto commitment to improve end of life care through supporting commissioners to combine and work in integrated ways is an important direction of travel. Commissioners should consider how to use integration schemes to pool end of life care spending and build services around people.

Recommendations and case studies from this report may also prove useful for Clinical Commissioning Groups in designing and implementing Transformation Programmes, to enable more out-of-hospital care.

In addition, reducing avoidable admissions is in line with a number of the Secretary of State's key priorities for improving health and social care:

- **Out of Hospital Care**
- **Improving Care and Quality**
- **Prevention**

Commissioners are also encouraged to refer to the recently published ‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020’. This document from the National Palliative and End of Life Care Partnership builds on the 2008 End of Life Care Strategy. It sets out a new vision and ambitions for end of life care to 2020, which provide a wider framework for commissioners and which are consistent with the recommendations in this report.

Managing Demand: keeping people out of hospital when they are approaching the end of life

There are three key areas that offer opportunities to keep people who are approaching the end of life out of hospital:

- **Improving identification of people who are approaching the end of life**
- **Improving planning and co-ordination for people who are approaching the end of life**
- **Increasing care and support in community settings**

Improving identification of people who are approaching the end of life

To ensure that people have personalised care available for them in their place of choice at the end of life, it is of course essential to be aware that they are at or near the end of life. Identification is the first quality statement in the National Institute for Health and Care Excellence (NICE)'s guidance on end of life care for adults: all other aspects of care follow from this.¹¹

Statistically, approximately 1% of people who are on a GP's patients register will have a year or less to live.¹² The Dying Matters website offers practical advice on how GPs can work to identify them – such as asking the 'surprise

question' ("would I be surprised if this person were to die within the next 12 months?") as well as looking for general clinical indicators of deterioration and frailty.¹³ As clinicians, GPs have a responsibility to identify these people and have conversations with them, and those important to them. Other GP practice staff, such as nurses, practice managers and administrators, may also have a role in ensuring such identification is recorded and offering support to the person and those important to them.

We recommend GPs taking steps to identify patients who are at the end of life, and working with practice managers, nurses and administrators to ensure that such identification is recorded and that these people and those important to them are supported.

There are several practical resources available to help with this, including:

- the Gold Standards Framework Identification Toolkit¹⁴
- a Quick Guide to Identifying Patients for Supportive and Palliative Care¹⁵
- the Supportive & Palliative Care Indicators Tool¹⁶

These are all available online.

Kate's story – identifying dying

Proper identification of people at the end of life and planning for their care is a hugely important first step to ensuring that people are not admitted to hospital unnecessarily. This includes recognising that somebody might be imminently dying as well as identifying people who might have several months still to live.

Kate Ibbeson is one person who can testify to this: her dad had been diagnosed with incurable cancer, and was admitted to hospital one night after his GP identified problems in his blood test results – but had not recognised him as being near to the end of his life. Sadly he died in hospital the following morning. She says:



"...no-one really seemed to appreciate that [Dad] was dying...I do wish that Dad had remained at home with some support from Mum and I, and he had not had the time in hospital. It was a confusing and stressful time for us all".

Improving planning and co-ordination for people who are approaching the end of life

Identifying people who are approaching the end of life allows for better planning of their care. There are several ways of ensuring that proper plans are in place:

- Helping everyone who is approaching the end of life (and has sufficient mental capacity) to create an **advance care plan**, to record their wishes. This should be based on conversations between the person approaching the end of life and health and social care staff. Guides for this include Planning for your future care, jointly produced by NCPC, NHS Improving Quality and the University of Nottingham.

There are also practical tools to help facilitate these, including:

- o Preferred priorities of care (NHS Improving Quality)
- o It all ADSE up (NHS Improving Quality)
- o Advance care planning information (Macmillan Cancer Support)
- o Advance care planning information (Gold Standards Framework)

Helping people to make advance care plans enables key information about their wishes to be recorded, and enables care providers to meet these wishes as far as possible.

- Ensuring that recorded wishes for care, as well as details about condition, treatment and equipment needs, are readily accessible

by all of the different health and social care providers who may be involved in a person's care. Records for people with long-term conditions should be maintained throughout their conditions, including at the end of their life.

One widely-used method for maintaining and sharing such records is **Electronic Palliative Care Co-ordination Systems (EPaCCS)**. Using electronic systems allows those who are caring for people in different settings to access these details quickly, especially on information about where they wish to be cared for at the end of life. Evidence from Public Health England has shown that areas where EPaCCS were used reported a higher proportion of people dying at home.¹⁷ One CCG reported 47% of people on EPaCCS dying at home, compared with 20.6% of all those receiving end of life care in the local area dying at home. The report from the recent review of Choice in End of Life Care, 'What's important to me', recommends that EPaCCS are used in every locality by April 2018.¹⁸

We recommend that service providers in all care settings encourage the use of Advance Care Planning, and work with other service providers to facilitate the sharing of records across health and social care at every stage of a person's condition.

Increasing care and support in community settings

There is ample evidence that providing care in community settings at the end of life reduces admissions to hospital. The Nuffield Trust's report on the community nursing service provided by Marie Curie showed that only 11.7% of people being cared for by Marie Curie community nurses – who provide care in people's homes during day and night – were admitted to hospital, compared to 35% of those who were not under the care of a community service.¹⁹ International evidence of specialist palliative care teams providing community care shows a similar trend in avoiding admissions.²⁰

Further positive impact of this, more significantly, is that people are able to die at home in accordance with their wishes. The choice to die at home was highlighted as important for people in *What's important to me*.²¹ National data shows that the numbers of people dying in their usual place of residence – in homes and care homes – vary significantly across the UK: in 2014, 52.1% of people who died in Devon, Cornwall and Somerset died in their usual place of residence, compared to 37.2% of those who died in London.²²

In order to improve community care, three key elements must be provided:

- i. 24/7 community-based care**
- ii. Treatment and equipment**
- iii. Support for carers**

i. 24/7 community-based care

Improving provision of community-based care has financial benefits: the Nuffield Trust's study mentioned above showed that the cost to the NHS per person receiving care from Marie Curie Community Nursing was on average £1,140 less than for those who were not.²³ The Midhurst Macmillan Community Nursing Specialist Palliative Care service shows similar evidence, where the total cost to the NHS of care in the last year of life²⁴ could be reduced by 20% partly through more proactive use of community-based care.

In order for this care to be provided, some health and social care staff need to be available in community settings, with support made available 24/7 – not just 9am-5pm Monday to Friday. Ensuring that people can access the care they need in the middle of the night prevents them having to be admitted to hospital at this time, simply because they did not have access to the care they needed at home. Care needs will vary according to people's conditions, and how this is provided may vary according to region, but is likely to include, as a minimum, enabling access to pain relief and symptom control (discussed more below), and advice and support to help informal carers provide what is needed effectively.

24/7 care: what do we mean?

This report refers frequently to 24/7 care, because people need access to care at any time of day or night regardless of the setting they are in. This reflects the recommendations in the National Institute for Health and Care Excellence (NICE)'s Quality Standard for end of life care for adults (see Quality Statement 4). We strongly discourage the use of “out of hours” language, which reflects only the perspective of care providers and not the people who are being cared for, and implies that only minimal care should be provided outside 9am-5pm Monday-Friday.

Why is this important?

A study of Marie Curie's 'Delivering Choice' Programme in Somerset and North Somerset, a service which included support during evenings and weekends as well as arrangement of care packages that included night nurses and personal carers, found that those who used the service were 30% less likely to die in hospital or have an emergency hospital admission in the last few days of life than those who were not.²⁵

Multiple responses to the consultation for *What's important to me* raised the issue of a lack of 24/7 care as a barrier to care being transferred to a community setting. Examples given by respondents contrasted areas where 24/7 care was available, which often meant people could die at home, with areas where such care was not provided, which was associated with distress for family and carers.

The need for increasing the provision of care in this setting is clearly recognised on a national level. It is important to recognise that care homes and hospices have a significant role in providing 24/7 care in these settings – a point recently highlighted in national media.²⁶ *What's important to me* describes 24/7 community care as a cornerstone of palliative and end of life care, and recommends that this be made available in every local area by the end of 2019.²⁷ In addition, the Health (Select) Committee called in its report on end of life care for Health Education England and NHS England to address shortfalls in community nursing.²⁸

We recommend commissioning the increased provision of 24/7 care in community settings, through care homes and hospices, and community health and social care staff who can provide care in people's homes.

ii. Treatment and equipment

To avoid hospital admissions, it is also important that people approaching the end of life have access to the treatment they need in community settings – especially for pain relief and symptom control. Despite the importance of this, the 2014 VOICES survey showed that only 17.9% of respondents reported that their loved one's pain was managed “completely, all the time” at home.²⁹ Providing the equipment that people need at the end of life can also enable them to be kept at home. This may, for instance, include enabling people to sleep in hospital beds when they are at home.

Anticipatory prescribing enables people to have medicines available at home ready for when symptoms develop, helping people to avoid an emergency admission to hospital

simply because they could not readily access the medication they needed at home. A ‘Just in Case’ package of medicines to help with symptoms such as pain, breathlessness, nausea and anxiety ensures that the person has them available at home, ‘just in case’ they need them. The British Medical Association (BMA) offers advice on providing anticipatory medicines for end of life care.³⁰ As of 29th July 2015 the National Institute for Health and Care Excellence (NICE) proposed, in its draft guideline for care of the dying adult, that anticipatory medication be prescribed for “anticipated or changing needs for symptom control medication in the last days of life”.³¹

We recommend commissioning anticipatory prescribing of medications for people approaching the end of life.



iii. Support for carers

It is important to recognise that informal carers make a significant contribution to provision of care in community settings, and that without them it would not be possible for many people to receive the care they need out of hospital. A recent study by University College London has shown that unpaid carers to people with terminal cancer provide health and social care worth £219 million each year, equivalent to one third of the cost of end-of-life care for people with breast, lung, colorectal and prostate cancers.³² It also highlighted the concern that older people may be less likely to have informal carers, and that this problem is likely to increase with an ageing population and growing social isolation and loneliness.

Under the **Care Act 2014**, carers are now entitled to assessments of their support needs by the local authority where it appears they may have support needs currently or in the future³³. All carers may at some point need support, particularly if they are caring for a long period of time. Therefore, in addition to identifying those who are approaching the end of life, it is important to identify those who are caring for them, and to ensure they are referred for assessments of their support needs. It is crucial that carers' needs are assessed and their support needs are met, to prevent later breakdowns in their own health, and potential crisis admissions. As part of this, carers need respite breaks where possible. Our recommendation for increasing community provision also includes enabling carers to take these respite breaks.

We recommend that health and social care staff working in end of life care be supported to identify carers of people who are approaching the end of life and refer them for local authority assessments.

It is also important that carers are able to access support from those who are part of their communities – including friends, neighbours, colleagues, and fellow members of the various community groups of which they may be a part (such as faith communities, sports clubs, or trade unions). NCPC, with support from Public Health England, is working with eight 'Pathfinder' organisations across England to pioneer a public health approach to end of life care, through the 'Dying Well Community Charter'. The Pathfinders are working with their local communities to increase support for people approaching the end of life and those who are caring for them.³⁴ There have also been "compassionate communities" projects in the UK & Ireland with similar aims. Funding these kinds of approaches can enable people approaching the end of life and their carers to be part of more supportive communities, and again prevent potential breakdowns in their health. Such approaches are also recommended in *What's important to me*.³⁵

We recommend working with Public Health leads to commission public health approaches to end of life care.

Building capacity: getting people out of hospital when they are approaching the end of life

Why is this important?

Whilst some emergency admissions may not be avoided, it is important to ensure that people can still move to a community setting as soon as this is appropriate, as this is where most people want to be as they approach the end of life. The recommendations above will also help ensure people receive the support they need once they are discharged. In addition, two similar key areas of focus will also help:

- **Better identification of people in hospital who are approaching the end of life**
- **Better co-ordination between care services**

Better identification of people in hospital who are approaching the end of life

It is important that people in hospital who are potentially approaching the end of their life are identified so that the transfer of their care to a community setting can be facilitated as soon as possible, if this is in accordance with their wishes. Hospitals may take different approaches to identifying people as being near the end of life.

Different approaches may work in your local area. **We recommend that commissioners work with local service providers to enable different hospital teams to work together to help identify people who may be approaching the end of life.** Once they are identified as approaching the end of life, assessments can be made regarding whether alternative care options may be more appropriate for them.

Example: Palliative Care “In-Reach” Service

In Wroughtington, Wigan and Leigh Foundation Trust, an end of life care facilitator was funded by Macmillan Cancer Support to identify gaps in service provision. The facilitator set up an ‘In-Reach’ service, where a dedicated palliative care nurse proactively seeks out people who may be at the end of life in the A & E department, Medical Assessment Unit (MAU) and Clinical Decisions Ward (CDW). Emergency care staff can bleep a dedicated number for the palliative care team 7 days a week. People who are identified via this service are offered assessments within 24 hours of the team being notified, and follow-up support is arranged to plan for the end of life, and for them to be discharged and cared for out of hospital. The service has led to much improved communication between emergency care staff and the palliative care team, and data collected in December 2011 showed that it facilitated discharge for 17 people out of the 27 who were directed to the service.

*For further information, please contact Lucy Lyon, End of Life Care Facilitator at Wroughtington, Wigan and Leigh Foundation Trust:
Lucy.J.Lyon@wwl.nhs.uk.*

Better co-ordination between care services

Once people have been identified as approaching the end of life, it is essential that there is sufficient co-ordination between the hospital and community care services, to ensure a smooth transition for people from one service to the other. Communication of information between services is fundamental to this, and again EPaCCS can be useful for this (see page 8).

To enable the efficient transferring of people's care from hospital to community services, it is essential that there is effective communication and collaboration between hospitals and community-based services.

There are local examples of hospitals and hospices collaborating to provide a more integrated and coordinated approach to alternative care options, including the use of step down bed facilities. **We recommend that hospitals work more closely with local hospices, care homes, and other community providers to explore how they can better meet people's care and support needs.**

Collaboration between hospitals and hospices: two examples

Woking and Sam Beare Hospices worked together with Ashford & St. Peter's main hospital, enabling the two organisations to support each other in two main ways.

Sharing the hospice consultant

Woking and Sam Beare hospices donated a consultant's time to support the hospital's palliative care team. The donation of the consultant's time enabled far better communication between the hospital and the hospice.

Hospital beds in the hospice

The hospital also commissioned two of the hospice's beds to be, effectively, a "sub-ward" of the hospital. This enabled people to be transferred from hospital to the hospice setting as efficiently as possible, and also allowed their families to access the support services that the hospice offered.

For more detail, see Rosie Brown, 'How are hospices successfully working with hospitals?' (24th July 2014) www.ehospice.com/uk/Default/tabid/10697/ArticleId/11537/

In 2015-16, the Better Care Fund will continue to provide financial support for councils and NHS organisations to jointly plan and deliver local services. This funding provides an opportunity to help ensure co-ordination between hospital and community care services for people approaching the end of life. The fast-track pathway for Continuing Health Care assessment can also be used as a tool to help people move to a community setting as quickly as possible.

Integrated Personal Commissioning, which enables people to be involved in shaping the care that is made available to them, should also be considered as an important way of co-ordinating care for people approaching the end of life.

We recommend that commissioners use available funding, through e.g. system resilience groups and from the Better Care Fund, and Integrated Personal Commissioning, to improve co-ordination between hospitals and community settings, including hospices, for people approaching the end of life.

Co-ordination between services, to enable people approaching the end of life to make a transition from hospital to community settings, naturally requires that there be sufficient care in community settings to enable this. Once again, this must include care and support for people and their carers at any time of day or night, not just from 9am to 5pm Monday to Friday.

For Neil Bonser, who died of cancer in 2009, it made a huge difference that he was able to express a wish to go home, and that there was effective 24/7 co-ordinated care to enable this. His parents, Tony and Dorothy, said:

“His discharge was clearly the result of fully integrated consultation and co-operation conducted in the 16 hours between 4.30pm on one day and 8.30am on the next...as a result of [the Macmillan nurse] coordinating his discharge and support, Neil had a good death and our memories of his final hours are much more positive than they would have been had he died in hospital”.

What next?

There is no doubt that taking steps to enable people to keep out of hospital at the end of life is in the interests of dying people and those important to them, and in the interests of the NHS. Commissioners can reduce the costs of emergency admissions by facilitating people to remain out of hospital, or to be transferred from the hospital as soon as possible, if they have no wish or clinical need to be there.

It is hoped that the recommendations in this report for commissioners and service-providers - to invest in identification, and planned, co-ordinated, 24/7 care - will enable them to help people to avoid spending time in hospital at the end of life when this is in accordance with their needs and wishes, and in the process of doing so, both improve people's experience and make more effective use of NHS funds.

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The 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. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

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NCPC leads the Dying Matters coalition which aims to change public attitudes and behaviours around dying, death and bereavement.

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Hospice UK

Hospice UK is the national charity for hospice care. We champion and support the work of more than 200 member organisations, which provide hospice care across the UK, so that they can deliver the highest quality of care to people with terminal or life-limiting conditions, and support their families.

We support the breadth, dynamism and flexibility of modern hospice care by: influencing government and decision makers; improving quality of care through the sharing of good practice; and providing training, education and grant programmes.

www.hospiceuk.org
info@hospiceuk.org
Twitter @hospiceukPA

Marie Curie

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

www.mariecurie.org.uk
Twitter @MarieCuriePA
@MarieCurieEOLC

**THE
NATIONAL
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CARE**

The National Council for Palliative Care

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