

How could free social care at end of life work in practice?

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Title	How could free social care at end of life work in practice?
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Foreword

Like many people living with a chronic degenerative condition, the care available to me towards the end of my life is a big concern.

As my condition advances, I will rely on carers for all my basic hygiene needs, food preparation needs, movement, and use of vital equipment such as ventilation machines and feeding tubes. As these are social needs, their provision will probably be subject to a means test. As well as being time consuming and stressful, going through a means-test forces me, and thousands of others in my position, to use my limited life savings to pay for this basic care.

As this report highlights, there is a huge variability in terms of who currently gets free end of life social care, who provides it and how it is co-ordinated. The STARS programme in Liverpool is a good example of a service that has been set up to provide social care in the last months of life in the same way as NHS care is: free at the point of use. However the lack of such initiatives illustrates the unfairness of the current system where what you get depends on where you live.

As a former local authority senior manager I know that social services budgets are under enormous pressure. By using existing resources better, and pooling health and social care budgets at the local level, there might be a way to make the system fairer for people like me.

However this report also needs consideration from the top of Government. Decision makers need to consider ways of incentivising this to happen on the ground, and thus to take free social care at the end of life from an aspiration to a reality.

Mark Styles

A person living with Motor Neurone Disease in Kent.

Executive summary

Introduction

As a coalition of six charities, Macmillan Cancer Support, Sue Ryder, Motor Neurone Disease Association, Help the Hospices, The National Council for Palliative Care and Marie Curie Cancer Care have been working together to campaign for free social care at the end of life to support people to die in the place of their choosing.

The call for free social care for people at the end of life is gaining momentum with much discussion across government about the importance of and merit in free social care at the end of life^{1 2 3 4 5}. There is still much work to be done to ensure that free social care for people approaching the end of life becomes government policy and a reality 'on the ground', but the aspiration is apparent. It is against this context that the coalition for free social care at end of life commissioned OPM to undertake a research study to provide an understanding of end of life care systems in the UK where no costs (stemming from social care) are borne by the individual or their family.

Our research

We looked at a range of service models throughout the course of the research. These service models can be grouped into Hospice at Home, voluntary and community sector initiatives, CCG funded service models, and national service frameworks and policies (see appendix 2 for examples). It is important to note that within the time and resources available, this research was not intended to be an exhaustive review.

We found considerable variation in: definitions of 'end of life'; drivers for the development and provision of free social care at end of life; who can access services; who can refer into services; time periods over which services are available; the capacity and capability of providers; and the quality of care available. Not only is there considerable variability between the different service models, there is also significant variability within individual service models. Although a number of the examples identified were short term pilots or focused on crisis management until a more sustainable package of care was put in place, it signalled that different individuals and localities

¹ Dilnot, A. (2011). 'Findings of the Commission on Funding of Care and Support'. Slideshow. The King's Fund website.

² Hughes-Hallett T, Craft A, Davies D (2011). Funding the right care and support for everyone. Report of the Independent Palliative Care Funding Review. London: Department of Health.

³ HM Government (2012) Caring for our future: reforming care and support.

⁴ Joint Committee on the Draft Care and Support Bill (2013). Draft Care and Support Bill Report.

⁵ Barker, K et al (2014) A new settlement for health and social care: Interim report. The King's Fund

are trying to make free social care at end of life possible in different settings. Nonetheless, it must be acknowledged that our research found there are still many barriers and challenges in the current system to making free social care at end of life a reality.

The selection of the two case study service models included in this report was purposive, and drew on feedback from key stakeholders. It combined an interest in exploring innovative potential and investigating what is currently available. With this objective in mind, we produced case studies of both an established service model: Continuing Healthcare Fast Track; and a new and innovative service model: STARS Care Liverpool. The case studies were used as a springboard to look at different elements and consider what works. It is not our intention to imply, through the selection of case studies, that these are the most important or that no other model exists.

Case study – An established service model: Continuing Healthcare Fast Track

The evidence suggested that Continuing Health Care (CHC) Fast Track Funding warranted further exploration. It was the service model most frequently mentioned in relation to free social care at the end of life in both the literature and our ‘call for evidence’.

NHS Continuing Healthcare (CHC) is a package of ongoing care, covering health and social care, designed for individuals over the age of 18 who have long-term health needs. It is free to the individual as it is funded solely by the NHS, and can be provided in any setting. CCGs are responsible for assessing eligibility, and then commissioning and managing care packages.

The Fast Track Pathway seeks to address the needs of people at the end of life by providing a faster, easier route into CHC-funded care, which bypasses the longer assessment. National guidelines were introduced by the Department of Health for CHC Fast Track Pathway (in 2009), seeking to provide a consistent approach in CHC provision. However, our research found that in practice there is still much variation in how CCGs interpret and apply these guidelines. Some referrers reported that certain conditions with clear prognoses, such as cancer, were easier to refer than other conditions whose trajectories were harder to predict such as Motor Neurone Disease.

Providers of care will vary depending on the locality and where the individual chooses to receive their care. Local capacity and capability to provide suitable care can be a limiting factor in choice and quality considerations.

Where the Fast Track system works well, it can achieve several positive outcomes: A free package of health and social care is arranged quickly and easily for an individual at the end of life; An individual’s choice of care setting is achieved; Discharges are speeded up as a care package can be put in place quickly, and readmissions can also be reduced, and this can imply a cost saving for health services as people are kept out of hospital beds.

However, it must be reiterated that challenges with the Fast Track system are well documented. Speed of implementation may not result in the best care package being set up; poor capacity and quality of providers can affect the care provided and in some cases lead to unnecessary readmissions; continuity of care when moving into Fast Track may not always be maintained; and the review process can be a source of anxiety for individuals and families.

Case study - A new and innovative service model: STARS Care Liverpool

Having explored an established model and recognising the challenges associated with CHC Fast Track funding as well as how implementation may be improved, we wanted to explore a new and innovative model of free social care at end of life. In the context of the other models identified it has some unique qualities: it is specifically commissioned to meet the needs of those at the end of life; the social care is fully funded by the CCG and therefore free to the individual; it offers a full package of social care; and is provided for the last 12 weeks of life (a generous length of time compared to many other models).

The STARS (Support, Talk, Act, Review, Share) Liverpool Care service is commissioned by Liverpool CCG and delivered jointly by Crossroads Care Cheshire, Manchester and Merseyside, and Marie Curie. STARS provides high quality personal and social care services delivered by staff trained in end of life care (including registered nurses, Carer Support Workers and Health Care Assistants with an NVQ and Qualifications and Credit Framework (QCF) in End of Life Care). Care is provided in the patient's place of choice (usually their home setting) during the last 12 weeks of life.

The budget for the STARS service in 2014-15 is £700,000, funding patient contact time at £14 per hour for 50,000 hours. A project manager is funded by Marie Curie (c£40,000). The funding comes from the CCG's end-of-life funding pot, which also covers hospice and palliative care services and training for those working in this area.

Anyone can access the STARS service as long as they are: 16 or over, registered with a Liverpool GP and living within 10 miles of the city boundary; estimated to be within the last 3 months of life; identify their preferred place of care to be their usual place of residence; and on the local District Nurse team case load.

The service contributes to the social and emotional wellbeing of the individual and their carer. It enables patients to die at home, in a familiar and comfortable environment, and to feel supported in doing so. More people are dying in their place of choice than before STARS was in place.

Nonetheless, demand for the STARS service currently exceeds capacity. As well as demand, key pressures on capacity are double-ups (two carers are needed to move the patient) and patients living beyond 12 weeks. Groups who the service is not currently reaching effectively are

those with a diagnosis other than cancer, homeless people, prisoners allowed home to die, and BME communities.

Lessons and recommendations

Through our wider research it is evident that, within current legislation and commissioning arrangements, different organisations and localities are trying to make free social care at end of life a reality in different settings. Nonetheless, the different models still face significant challenges and the huge variability means that some people do not get access to basic, *free*, social care support that could help keep them out of hospital and provide genuine choice at end of life. Considering the evidence and the views of a wide range of stakeholders from across the end of life care field gathered during our research, outlined below are some of our key lessons and recommendations:

Integration

The models discussed could be described as being essentially a 'sticking plaster' which bridge the gap between free NHS care and means tested social care. We cannot fail to recognise that true integration (i.e. a single ring-fenced budget for health and social care, which is singly commissioned) would mean that many of the barriers and challenges to free social care at end of life would be removed. However, we are realistic in recognising that true integration is some distance away, and in the meantime, there is a need to do other things.

It is telling that the majority of the models we identified were funded by either the NHS or the charitable sector or a combination of the two. Local authority social care funding was generally absent. In the current climate of austerity both social care funding and NHS funding are under increasing amounts of scrutiny and strain.

Recommendation: We recommend that, at a national and local level, steps are taken to both improve what is already available in terms of free social care at end of life (i.e. CHC Fast Track), and to innovate (i.e. like the STARS programme in Liverpool), to address some of the unmet need.

Recommendation: To be able to both improve what is already available and innovate, we would recommend that different stakeholders involved in providing social care at end of life (including CHC Fast Track) should be required to collect and monitor data, including all inputs, outputs and outcomes. Better monitoring would also help ensure services are effectively reaching those across all relevant diagnosis and BME communities. More robust, outcomes focussed, cost saving data would be beneficial in persuading commissioners to re-direct money within the current system. Central government has an important role to play in supporting a more coherent approach to demonstrate outcomes, costs and benefits.

Variability

Our research found that there is significant variability in the different models being delivered on the ground, as well as *within* each model.

Recommendation: It is essential that the government puts systems in place to ensure that commissioners at a local level prioritise holistic, person centred packages of care at the end of life. All local commissioners should be required to undertake a joint end of life care needs assessment to fully understand local needs, and including meaningful involvement of patients and the public in that assessment. Special attention should be paid to assessing the needs of people dying from diseases other than cancer, as this group is underrepresented even in innovative services like the Liverpool STARS service.

Recommendation: There is a need to raise the confidence of and to educate commissioners, clinicians, and other professionals working in the end of life area about the services and support that are available. For example, there needs to be much better guidance around CHC Fast Track funding which is less open to interpretation at a local level, accompanied by training for referrers and case co-ordinators about who is entitled to what, how to access this support and funding, and how to challenge a local commissioner, should they believe they are not following national guidelines.

Consistency

Even when we do embrace the positive reasons for variability, such as innovation; responding to different local needs; and the involvement of different sets of local players, there is still a case for trying to encourage some level of consistency and quality. Through our research we think there are a number of different factors that need to be considered by commissioners in order to encourage consistency including:

- establishing common routes or triggers into the system which would signal entitlement to free social care such as the Gold Standards Framework, the Electronic Palliative Care Coordination System (EPaCCS), or the DS1500 form;
- reducing the room for interpretation in current guidance or issuing new guidance and developing consequences or penalties for those consistently failing to follow it;
- developing a common end of life outcomes framework;
- delivering top down training for professionals responsible for referral, assessment and co-ordination on end of life care, which educates them about national entitlement and expectations rather than local interpretations of entitlements and expectations;
- simplifying and reducing the referral and application processes;
- some form of coordination role, such as a case manager. Although there is recognition that this may convey the message that it is only some people's business and not everybody's business; and

- ensuring that individuals with a terminal diagnosis do not have their package of care revoked once they have been found eligible due to fluctuations in their condition.

Recommendation: Developing quality standards and guidance to support effective implementation of both what is currently available (such as CHC Fast Track) and to encourage commissioners to innovate is essential. Nonetheless, as discussed above with regards to the positive reasons for variability, such as innovation; responding to different local needs; and the involvement of different sets of local players, it should also be acknowledged that there cannot be a one-size-fits-all approach, as there still needs to be some level of flexibility within any model.

Recommendation: Quality standards and guidance alone are not enough. As our research has shown, for example, the CHC Fast Track eligibility criteria and guidance is open to local interpretation based on local resources, despite the fact it should not be. NHS England must take a lead in investigating the reasons behind why existing guidance is not being adhered to, and to put in place relevant measures to overcome the ‘implementation gap’.

Ensuring quality

A key consideration in terms of consistency is its link with the quality of care provided. This is the overarching concern. It is not about consistency for consistency’s sake but it is about maintaining high quality services, which can be achieved in different ways.

Recommendation: At both a national and local level there is a need to make an explicit commitment to quality, particularly in terms of clarifying standards and expectations around workforce development and around service quality. The workforce of carers responsible for delivering social care should have specific end of life care training in order to deliver the best quality care. Linked to this is also the need for quality standards and monitoring to strengthen accountability.

Partnerships

Throughout our research, partnership has been a predominant and recurring theme. Partnership working will be central to delivering free social care at the end of life.

Recommendation: When commissioning free social care at end of life commissioners should work with providers in a way that encourages collaboration. There are a number of ways this could be achieved; for example, through pre-commissioning conversations with collectives of potential providers, commissioners can help engender a more trusting and collaborative approach.

Introduction

As a coalition of six charities, Macmillan Cancer Support, Sue Ryder, Motor Neurone Disease Association, Help the Hospices, The National Council for Palliative Care, and Marie Curie Cancer Care have been working together to campaign for free social care at the end of life to support people to die in the place of their choosing.

The call for free social care for people at the end of life is gaining momentum. The Dilnot Commission (2010)⁶ and the Palliative Care Funding Review (2011)⁷ both recommended giving people in the last 12 months of life access to social care, free at the point of delivery; acknowledging the transformative impact that this could have on end of life care in England.

The Government and opposition have both been supportive of this recommendation. The Government's Care and Support White Paper (2012)⁸, which provides a vision for the future of social care in England, stated that the Government saw 'much merit' in the provision of free social care for people approaching the end of life.

The Joint Committee on the Draft Care and Support Bill (2013)⁹ also reiterated the importance of social care at the end of life. In their report, which was produced following full scrutiny of the Draft Bill, they agreed that free social care at the end of life has merit and should be introduced 'at the earliest opportunity'.

There is still much work to be done to ensure that free social care for people approaching the end of life becomes government policy and a reality 'on the ground', but the aspiration is apparent.

Currently, end of life care services in England are funded and delivered by a mix of providers from the NHS, local authorities, and the voluntary and private sector. Levels of funding for services vary according to the priority local commissioners place on end of life care, resulting in differences in local provision. This variability is compounded by the additional challenge of a person's needs being viewed as either primarily medical (NHS funded) or primarily social (local authority funded and more often than not means tested), and of course a person's needs can fluctuate and change.

⁶ Dilnot, A. (2011). 'Findings of the Commission on Funding of Care and Support'. Slideshow. The King's Fund website.

⁷ Hughes-Hallett T, Craft A, Davies D (2011). Funding the right care and support for everyone. Report of the Independent Palliative Care Funding Review. London: Department of Health.

⁸ HM Government (2012) Caring for our future: reforming care and support.

⁹ Joint Committee on the Draft Care and Support Bill (2013). Draft Care and Support Bill Report.

Indeed early findings from the independent Commission on the Future of Health and Social Care in England¹⁰ argue that the post-war settlement, which established separate systems for health and social care, is no longer fit for purpose. It argues that a new settlement is needed to meet the needs of 21st Century patients and service-users. In their view, this means moving towards a single, ring-fenced budget for health and social care, with services singly commissioned and entitlements more closely aligned. The report raises hard choices about how to pay for fairer entitlements and ensure adequate funding to meet future needs.

The Commission argues that it is *'incredibly hard to draw a distinction between what is health care and what is social care around the end of life. There is little logical division between what is means tested under social care and what is free at the point of use as health care'*. If there were better integration between primary and secondary care, and better integration between health and social care, along with better arrangements between the two at the end of life, this would either avoid many hospital admissions in the first place, or would allow faster discharge once treatment was completed.

Over recent years a number of different and innovative approaches and initiatives have been developed to improve the quality of end of life care, promote care co-ordination, further integrate health and social care, promote choice and personalisation, and enable patients and their families to choose their preferred place of death; but these have also led to further variability at a local level.

It is against this context that the coalition for free social care at end of life commissioned OPM to undertake a research study to provide an understanding of end of life care systems in the UK where no costs (stemming from social care) are borne by the individual or their family.

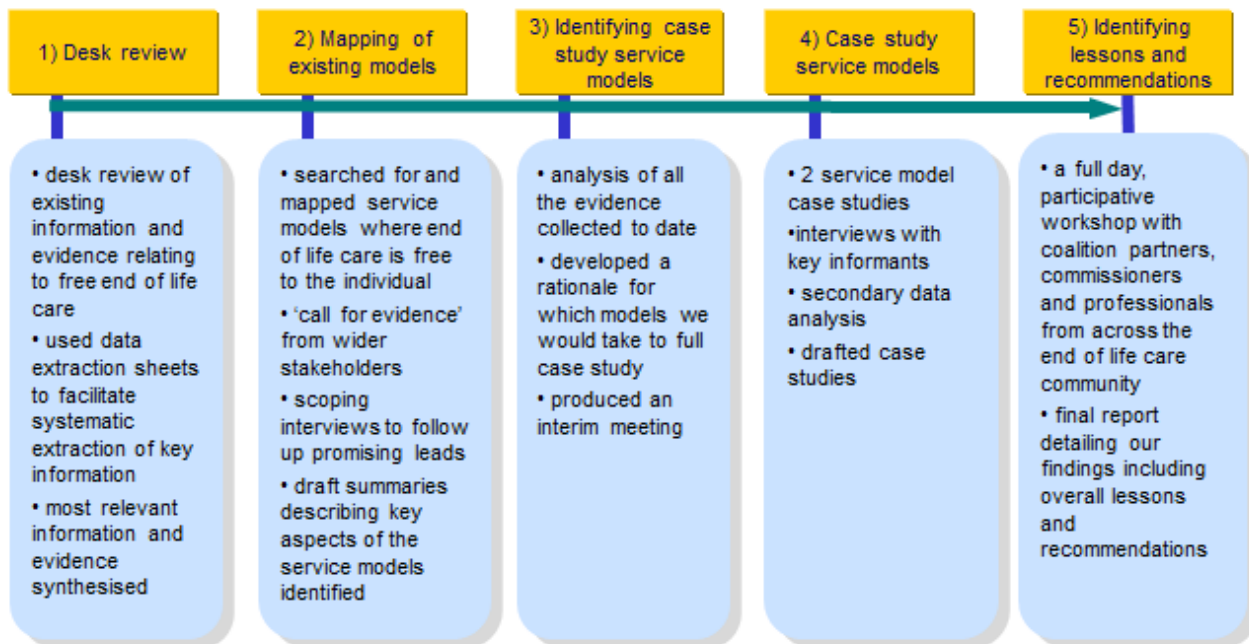
The coalition recognises the gap between the aspirations discussed above and the on the ground realities of delivering a holistic, person-centred, package of end of life care (where no costs are borne by the individual or their family). The purpose of this research was to explore how free social care at the end of life could work in practice. The intention is to move the debate beyond the principles and moral arguments, and to translate the aspirations into practice on the ground.

¹⁰ Barker, K et al (2014) A new settlement for health and social care: Interim report. The King's Fund

Our research

Our research approach is summarised in Figure 1 below. We discuss our approach further and what we found in more detail below.

Figure 1: Summary of our approach



It is important to note that within the time and resources available, this research was not intended to be an exhaustive review. The focus and emphasis emerged as the project developed, which involved us working closely with representatives from the coalition and drawing on feedback from wider sets of stakeholders, so that we could make joint decisions about what aspects to concentrate on and explore further.

We began by undertaking a desk review of published evidence to understand the context and to search for and to identify tangible models of end of life care where social care is free. We found that in the evidence reviewed the focus was very much on the principles behind free social care at end of life and making the case for change. There was very little information about how to effectively implement a package of end of life care where no costs (stemming from social care) are borne by the individual or their family.

Table 1 below provides a very brief overview of the key findings from our desk review and references of the documents reviewed can be found in appendix 1.

Table 1: Brief overview of the key findings from our desk review

Definitions of end of life care	<ul style="list-style-type: none"> • Tended to vary considerably. • Definitions tended to refer to a set period of time which ranged from as much as the last 12 months of life to as little as the last two weeks of life. • No discernible trends in the definitions of end of life across different care services.
Drivers for the development and provision of free social care services at end of life	<ul style="list-style-type: none"> • One of the most common drivers identified was the aim to increase choice and enable people to be cared for at home at the end of life, rather than in other settings such as hospitals or hospices. • To reduce or prevent unnecessary admissions to hospitals, and reducing the length of stay in hospitals • To provide support for and relieve pressure on District Nurses and other statutory providers • To provide a more integrated health and social care service or a 'holistic' package of support • A dearth of qualified, specialist services in the local area to support people to be cared for at home at the end of life.
Common routes and triggers for people to enter free end of life care systems	<ul style="list-style-type: none"> • Some specification of prognosis, and as discussed above, this ranged between patients being in the last twelve months of life to being in the last two weeks of life • A common trigger was some formal recognition of a person's prognosis such as being on the Gold Standards Framework register, the Electronic Palliative Care Coordination System (EPaCCS), or having been issued a DS1500 form • The primary source of referrals into free end of life care systems tended to be District Nurses. This tended to be followed by Macmillan or Marie Curie nurses, community nursing teams, hospitals, discharge planners or hospices • Very few referrals tend to come from GPs • Very few services operate an open referral systems by which family and friends can directly refer to a service
Desired outcomes resulting from free social care at end of life	<p>For individuals</p> <ul style="list-style-type: none"> • Enables people to die at home if that is what they choose. • A dignified and comfortable death • High quality of care provided to patients due to the flexibility and responsiveness of the care, provided by highly experienced and well trained carers that are compassionate and empathetic <p>For families</p> <ul style="list-style-type: none"> • The respite and support provided to carers was linked to enabling people to die at home but also helps prevent carer breakdown and the potential health costs associated with this. It can also contribute to making the bereavement experience a little easier. <p>For statutory services</p> <ul style="list-style-type: none"> • Free social care can help prevent costly hospital admissions, prevent delayed discharge and prevent people dying in hospital • Better working relationships between health and social care

The literature did point to a number of good practice examples in end of life care relating to integrated working, rapid discharge, advance care planning and workforce training. However, these tend to be described as activities and stages, and not in terms of a holistic model.

We followed up and gathered further insights into some of these examples (i.e. the Midhurst Macmillan Community Specialist Palliative Care Service¹¹ and integrated care examples such as Torbay, Staffordshire and Redbridge¹²) but it became apparent that although there is good practice going on in these areas around, for example, single point of access, care co-ordination and co-ordinated assessments, they are still generally operating within the traditional service models of continuing healthcare funding or means tested local authority social care.

From our experience and from speaking with a number of stakeholders, we understand that key stakeholders often perceive that there is a wide range of practice 'on the ground' but a lack of awareness of what is 'out there'. As a result we issued a 'call for evidence' to ask wider stakeholders to submit their own examples and ideas. The 'call for evidence' gave us an opportunity to unearth potential service models that are less well-known and therefore less cited in the evidence. The call for evidence was widely circulated via OPM's networks of commissioners and providers in both local authorities and health, the National Council for Palliative Care's Policy Round-Up (a policy bulletin), the E-Hospice bulletin, NHSIQ, the coalition's wider networks and also via Twitter.

Responses to the 'call for evidence' proved fruitful and provided insight into the current lay of the land and a number of examples of innovative services and some different service models we would otherwise not have identified.

Table 2 below provides a summary of the main focus of the responses to the call for evidence.

Table 2: Main focus of the responses to the call for evidence

Main focus	N	Summary of content
Continuing Health Care Funding	12	The most commonly cited service model was Continuing Health Care (CHC) funding with a number of respondents saying they rely on the current Fast Track model to provide free social care to people at the end of life. Even a number of those citing Hospice at Home services said that the service was funded via CHC. A few respondents also cited a number of ways in which they were working to make CHC funding a smoother and more successful process.

¹¹ Thiel, V et al (2013) Midhurst Macmillan Community Specialist Palliative Care Service. The King's Fund.

¹² National End of Life Care Programme with support from ADASS (2013) Sharing successful strategies for implementing 'Supporting people to live and die well: a framework for social care at the end of life.' A progress report on implementing the end of life care Social Care Framework 2010 by local authority adult social care departments in England. NHS Improving Quality

Main focus	N	Summary of content
Hospice at Home	11	<p>Hospice at Home was the next most commonly cited service. Nonetheless, it was evident that the Hospice at Home service models vary across different locations. Often the 'social care' being provided is fairly limited and generally covers personal care (i.e. washing and dressing) although some do also offer respite, alternative therapies and counselling services. The Hospice at Home service was also more often than not very short term (i.e. generally 2 weeks but occasionally up to 6 weeks maximum) and will not be provided indefinitely. Funding for this service came from a number of sources such as CHC funding, CCGs and charitable contributions. A number of responses also talked about offering the service until statutory provision kicked in such as means tested local authority care or CHC funding.</p>
CCG commissioned services	3	<p>We received a small number of responses from CCGs who have identified a gap in their end of life provision and commissioned some innovative services which include social care provision to address this gap. These proved some of the most interesting examples. For example, Liverpool CCG End of Life Care programme (STARS Programme) (discussed in more detail in chapter 4); The Reablement and Community Home Support service (REaCH), Stockport CCG; and Initial Response and Integration Service (IRIS), Tameside and Glossop CCG. (summaries of these service models are provided in appendix 2)</p>
Voluntary and Community Sector initiatives	2	<p>Two responses received gave details of services provided by the voluntary and community sector:</p> <ol style="list-style-type: none"> 1. Crossroads Care, Cheshire East and Cheshire West, which is a leading provider in support for carers and the people they care for. It employs Care Support Workers that primarily provide personal and domiciliary care and respite for carers. 2. Macmillan volunteer community helpers, an initiative just recently started in Belfast to provide volunteer help to those suffering from cancer and not specifically at end of life. <p>We followed up the Crossroads Care example and produced a summary in appendix 2. The Macmillan example, although interesting, is in its infancy, relies on volunteers and is not specifically aimed at end of life – although it will be worth monitoring the progress of this initiative in the future.</p>

Main focus	N	Summary of content
DS1500	1	One person mentioned the DS1500 form as a fast track to benefits at the end of life and that it is sometimes used as a trigger into the end of life care system.
Individuals with experience of the system	3	We received a small number of responses from people who had a personal experience of someone close to them approaching the end of life. Two of these responses focussed on the nursing care their loved one had received rather than social care. The one respondent who did talk about social care mentioned the Hospice at Home service.

Following the desk review and call for evidence we identified a range of service models that warranted further inspection. We conducted a number of scoping interviews with representatives from some of these service models to gather more details about the service and produced a number of summary fiches describing key aspects of these service models. These summaries can be found in appendix 2.

Although a number of the examples identified were short term pilots or focused on crisis management (such as the REaCH service, Stockport CCG; or the IRIS service, Tameside and Glossop CCG) until a more sustainable package of care was put in place, it signalled that different individuals and localities are trying to make free social care at end of life possible in different settings. Nonetheless, it must be acknowledged that our research found there are still many barriers and challenges in the current system to making free social care at end of life a reality.

Not only is there considerable variability between the different service models, there is also significant variability within individual service models. For example, the way CHC funding is implemented differs greatly from one area to the next. The 11 Hospice at Home services we looked at varied considerably both in terms of the types of service and support provided, and also how these are delivered.

Across both the desk review and the evidence from the ‘call for evidence’, we also found that robust outcomes data was scarce, with most being qualitative and/or anecdotal and a paucity of cost-benefit material.

For the purposes of this research and to further explore how a tangible service model of free social care at end of life would work in practice we agreed with the coalition partners that it would be more fruitful to develop selective in depth case studies. The case studies could then be used to trigger discussion and exploration of implementation issues, and what we can learn from them. The selection of case studies was purposive, and drew on feedback from key stakeholders. It combined an interest in exploring innovative potential and investigating what is currently

available. With this objective in mind, we produced case studies of both an established service model: Continuing Healthcare Fast Track; and a new and innovative service model: STARS Care Liverpool.

We convened a workshop including more than 40 commissioners, providers, academics, professionals and practitioners from across the end of life care field from health, social care, local government and the voluntary sector. We presented the evidence from these case studies, and lessons from the wider literature, in order to encourage participants to think about what lessons we could draw from these existing models and from other effective practice that they may be aware of. In particular, the workshop guided participants to focus on clarifying the key components and processes underpinning effective implementation, and how good practice may be replicated elsewhere in a way that is sustainable given continuing transformations.

The remainder of this report is set out as follows:

- Chapter 3: Case study of an established service model: Continuing Healthcare Fast Track
- Chapter 4: Case study of a new and innovative service model: STARS Care Liverpool
- Chapter 5: Lessons and recommendations

It is important to reiterate that within the time and resources available, this research was not intended to be an exhaustive review. We did look at a range of examples throughout the course of the research (see appendix 2 for further examples) and the following case studies were used as a springboard to look at different elements and consider what works. It is not our intention to imply, through the selection of case studies, that these are the most important or that no other model exists.

Case study

An established service model: Continuing Healthcare Fast Track

Introduction

The evidence suggested that Continuing Health Care (CHC) Fast Track Funding warranted further exploration for a number of reasons. It was the service model most frequently mentioned in relation to free social care at the end of life in both the literature and the 'call for evidence'. We need to make recommendations that are realistic and do-able. CHC Fast Track Funding is a service model that is currently in place and many professionals working in the end of life care arena are aware of it and have experience of it. For many this is the only model of end of life care where social care can be provided free to the individual. There could be an argument that if the national guidance was being adhered to, everyone at end of life should get automatic access to CHC Fast Track funding. However, our research found there are many challenges in the current system and people are being denied access to CHC Fast Track funding.

For this case study we conducted interviews with professionals in 5 different areas including social workers, community nurses, CCG commissioners, care brokers and local authority leads. This was supported by extensive desk research into primary sources and secondary literature.

Context

NHS Continuing Healthcare (CHC) is a package of ongoing care, covering health and social care, designed for individuals over the age of 18 who have long-term health needs. It is free to the individual as it is funded solely by the NHS, and can be provided in any setting. CCGs are responsible for assessing eligibility, and then commissioning and managing care packages.

CHC is not exclusively for individuals at the end of life, and the normal route into accessing CHC care packages is through an often long and difficult multi-stage assessment process, which many see as unfair and overly bureaucratic. The Fast Track Pathway seeks to address the needs of people at the end of life by providing a faster, easier route into CHC-funded care, which bypasses the longer assessment. It is designed for people with a rapidly deteriorating condition, where the condition may be entering a terminal phase, so that they may receive care in a place of their choosing. According to national guidance, eligibility for Fast Track funding should not be based on a particular length of prognosis. However in practice we have found that many CCGs do impose time limits on Fast Track eligibility.

Data collection on Fast Track, at both local and national levels, is poor; national statistics on CHC recipients overall are not broken down by Fast Track cases, or by condition. The Palliative Care Funding Review states that in 2010/11, 47,124 people received CHC Fast Track funding, with a total spending of £136m, equating to a mean cost of £2,883 per person,¹³ although it is not known how much of this funding was spent on end of life care. In addition, not everyone at the end of life receiving CHC-funded care will do so through the Fast Track Pathway, as some may already be receiving CHC-funded care through the standard process before they become end of life cases.

National guidelines were introduced by the Department of Health for CHC overall (in 2007) and for the Fast Track Pathway (in 2009), seeking to provide a consistent approach in CHC provision. This replaces a previous system where each Strategic Health Authority set out its own guidelines and eligibility criteria. However, it has been found in our research and elsewhere that in practice there is still much variation in how CCGs interpret and apply these guidelines to local CHC procedures, including for access to Fast Track funding. It is with this in mind that the following discussion looks at ways in which CHC implementation has been less than optimal, and how implementation may be made more consistent so as to achieve tangible improvements in processes and outcomes.

The referral process

Referrals into Fast Track need to be made by ‘appropriate clinicians’ involved in the care of an individual, when they decide that the individual may be entering the end of life and would be eligible. This could be by any registered practitioner or nurse, such as a GP, consultant, District Nurse, or a clinician in a hospice. They need to fill out the Fast Track Tool explaining why they believe the individual is eligible and give evidence for this. However the Tool does not specify that any particular types of information must be included to support this decision.

The Fast Track Tool also requires some basic information on the individual, including for equality monitoring. A ‘care plan’ should also be sent with, or soon after, the Fast Track Tool, detailing the individual’s care needs and preferences. The Tool is then usually faxed to the CCG for approval.

In practice, we have found that some of the clinicians who would be able to refer a case into Fast Track may not always do so. They may not know they can make referrals, not have the experience to do so confidently, or be hampered by time constraints. Other professionals, such as social workers in hospices or from local authorities, may also often make the initial decision to refer, start the process, and then contact a relevant clinician to support referral.

¹³ Hughes-Hallett T, Craft A, Davies D (2011). Funding the right care and support for everyone. Report of the Independent Palliative Care Funding Review

Factors supporting effective referrals

- **Quality of information given in the Tool:** Referrers we spoke to indicated that the amount of detail about an individual they give in the Tool, including if it contains a care plan, can speed up the process. It can also support requests for particular care packages by justifying them clearly in terms of the individual's condition and need.
- **Guidance for referrals:** This varies greatly, with some CCGs giving much guidance and training, and others none. Many referrers criticised the lack of guidance around completion and referral, suggesting that more would be helpful.
- **Clarity of process:** Where referral paths, expected timescales, and contact details at the CCG end are not clear this can complicate the process. In many cases referrers may only get this kind of knowledge experientially, rather than from the CCG itself.
- **Dedicated case managers:** Referrers who know their local Fast Track processes well and have the time and confidence to follow a referral through tend to make more successful referrals. They may see themselves as 'advocates' for individuals and are able to keep the process moving along, e.g. where there are delays or negotiations with the CCG over the care packages required.
- **Communication and relationships:** good links between referrers and CHC teams are crucial in supporting a smooth process. Effective examples include regular forums, meetings, named contacts, and continuity of roles, all supporting mutual trust between referrers and CHC teams.

Assessment

A key aspect of the Fast Track pathway is that it bypasses the longer assessment procedure of the normal route into CHC. Rather than the CHC team within the CCG organising an eligibility assessment after a referral has been made, it is the clinician making the Fast Track referral that is responsible for deciding if an individual is eligible. Once they submit a referral, guidance states that the CCG must decide that the individual is eligible.

Fast Track guidance specifies that the only eligibility criterion is that an individual has '*a rapidly deteriorating condition and the condition may be entering a terminal phase*', and that this eligibility should not be linked to strict time limits on an individual's expected end of life. Yet in practice we found most, but not all, CCGs do have time limits based on which referrers should decide whether to refer an individual through Fast Track, or through the longer CHC process. This limit ranged from one month to 12 weeks in the areas we looked into.

Related to this, some referrers reported that certain conditions with clear prognoses, such as cancer, were easier to refer than other conditions whose trajectories were harder to predict such

as Motor Neurone Disease, or individuals nearing end of life due to general ageing. Some professionals may also feel uncomfortable initiating discussions about end of life with individuals and this could prevent assessments and referrals being made. Nevertheless we have also found referrers processing cases purely based on need and the criterion of 'rapidly deteriorating, possibly terminal', regardless of condition or the (availability of) prognosis.

Our research found that CCGs do decide all Fast Track referrals submitted are eligible. Generally they respond to a referral the same working day or the next. CHC teams may then ask for further information or decide to send their own assessors to determine the care needs, particularly where scant information and/or no care plan has been sent in the referral. The CCG usually then commissions and arranges for a care package to be implemented.

CCGs may have a single CHC team assessing and confirming eligibility, and then commissioning and managing the care packages; or these functions may be separate, with different teams responsible for each. Issues with CHC teams we identified were around capacity (teams being busy); continuity (cases being passed around between different individuals or teams); and capability (not having the local or medical knowledge to arrange an appropriate care package).

Once a care package is implemented, CCGs would then review the case to determine if the individual's care needs are being met; but also, whether the individual should remain eligible. If, how and when a CCG organises reviews of a Fast Track case varies in practice. This can potentially be a source of distress for individuals and families.

Care

Commissioning, arranging and managing care packages for individuals at the end of life referred through Fast Track is also the responsibility of a CCG's CHC team. Once a referral has been deemed eligible, a care package needs to be put together for the individual. This could be based entirely or in part on the care plan, where one has been submitted, or the CHC team may conduct its own assessment. We have not found cases of CCGs overturning a care plan, but when referrers write these they will often already know what types and amounts of care a CCG will normally offer, and what they can ask for.

Once this has been decided either the CHC team or the referrer would then liaise with potential providers to put this package into place, and arrange for the care to be delivered. After this is done, depending on the locality, either the CHC team, referrers, or care providers (such as District Nurses) would monitor and review whether the individual's needs are being met.

Providers of care will vary depending on the locality and where the individual chooses to receive their care. Generally their choice of setting is maintained: it could be in a care home, nursing home, hospice, or in their own home. In the latter case the social care element could be provided

by District Nurses, care agencies, palliative care teams, hospice at home services, or local authority social workers.

Many CCGs will have preferred provider lists for homes and care agencies, and in practice it may be difficult for individuals to choose other ones not on the list, for example in a different CCG area, or where a different care home is too expensive for the CCG. This will impact individual's choice. It can also affect the continuity of care, where an individual is moving from local authority or self-funded care to CHC care and is not able to keep the same provider.

Although the amount of care received by individuals in their own homes varies by case, we have found many localities have a typical amount offered, usually up to 4 visits a day, with 2-3 overnight visits per week. Obtaining more night visits or 24/7 care can be much more difficult. There are also certain elements of social care, delivered in a person's home, which CCGs may not offer, such as cleaning, laundry, and shopping, unless it can be justified exceptionally based on an individual's condition.

Capacity and capability of care providers can affect care provision. In some instances where CCGs have limited preferred provider lists, there may be occasions when no agencies or homes have the capacity to provide any, or appropriate amounts of care for a Fast Track case, which can delay discharges. The quality of agency care provision is often criticised as well, in that agency staff may not have training in end of life care and only provide generic personal and domiciliary care. Care agencies can also lack other technical skills and may send many different carers to look after an individual, impacting on the continuity of their care. Local capacity and capability to provide suitable care can therefore be a limiting factor in choice and quality considerations even when CCGs may strongly support free social care for those at the end of life.

Outcomes

Where the Fast Track system works well, it can achieve several positive outcomes. However, as data collection on Fast Track cases itself is often limited, we have not been able to obtain hard data that measures these in terms of numbers dying in their place of choice, hospital admission figures, etc. Outcomes that our research has been able to identify are:

- A free package of health and social care is arranged quickly and easily for an individual at the end of life. The process for obtaining care is far easier for individuals and referrers than the normal route into CHC funding. The fact that care is free removes a major source of worry for individuals and families.
- An individual's choice of care setting is achieved.

- Families have the assurance that their relative has a care package to look after them. They may also benefit from respite care themselves. This can lead to a better bereavement process in the longer term.
- Discharges are speeded up as a care package can be put in place quickly to allow an individual to receive care outside a hospital setting. By receiving care in their own home or a residential setting, readmissions can also be reduced, and can imply a cost saving for health services as people are kept out of hospital beds.

However, it must be reiterated that the Fast Track system does not work perfectly and can be affected by a number of problems, as seen earlier in this report, which can have negative outcomes. Speed of implementation may not result in the best care package being set up; poor capacity and quality of providers can affect the care provided and in some cases lead to unnecessary readmissions; continuity of care when moving into Fast Track may not always be maintained; and the review process can be a source of anxiety for individuals and families.

Transferability

Since the Fast Track Pathway is an existing national service, there is no reason why individual elements that work well in some areas could not be made to work elsewhere too. Particular factors which should be paid attention to in improving the process and outcomes are:

- Clarity and consistency for each stage of the process
- Communication and guidance for referrers
- Good relationships between referrers, CCGs, providers, and local authorities
- Dedication and commitment to improving individuals' outcomes
- Close scrutiny of the quality of end of life care provision arranged under CHC

Indeed, in their 2014/15 – 2016/17 business plan NHS England have an objective to '*develop and implement a single operating model for Continuing Healthcare (CHC) including the assurance framework; improved patient and carer experience; developing the competency and capability of the CHC team; and supporting the roll out of personal health budgets*'. It remains to be seen the impact this will have on the Fast Track process.

Case study

A new and innovative service model: STARS Care Liverpool

Introduction

Having explored an established model and recognising the challenges associated with CHC Fast Track funding as well as how implementation may be improved, we wanted to explore a new and innovative model of free social care at end of life. We believe STARS Care Liverpool is one of the most interesting and innovative models we identified and deserved further exploration. It has been in place for some time having first been piloted by the former PCT. In the context of the other models identified it has some unique qualities:

- it is specifically commissioned to meet the needs of those at the end of life;
- the social care is fully funded by the CCG and therefore free to the individual;
- it offers a full package of social care; and
- is provided for the last 12 weeks of life (a generous length of time compared to many other models).

This case study was produced with the input of the commissioner of the STARS service (Liverpool CCG) and staff at the delivery organisations (Marie Curie and Crossroads Care); we also drew on documentation including the service specification and monitoring data.

Context

The STARS (Support, Talk, Act, Review, Share) Liverpool Care service is commissioned by Liverpool CCG and delivered jointly by Crossroads Care Cheshire, Manchester and Merseyside, and Marie Curie. It was launched in October 2012. STARS provides high quality personal and social care services delivered by staff trained in end of life care (including registered nurses, Carer Support Workers and Health Care Assistants with an NVQ and Qualifications and Credit Framework (QCF) in End of Life Care). Care is provided in the patient's place of choice (usually their home setting) during the last 12 weeks of life.

The service was conceived in response to an increase in demand from patients wanting to die at home, and a lack of trained personnel to support them during this process in terms of personal and social care. CHC funding was not adequately addressing the needs of people at the end of

life because the care provided was generic, rather than tailored to end of life needs, and the quality of care services was sometimes found to be lacking.

The service aims to: provide personal and social care and support and advice to patients and families; operate alongside other services (GPs, District Nurses, specialist palliative care services); prevent inappropriate hospital admissions; and enable more people to die in their own home (or sheltered housing, or care home) if that is their wish.

The partnership arrangement for delivering the service brings different knowledge and expertise to it: Marie Curie specialises in end of life care, while Crossroads Care has extensive experience of delivering complex care packages at home. Having two pools of staff also provides the flexibility to cover sickness or absence leave.

The budget for the STARS service in 2014-15 is £700,000, funding patient contact time at £14 per hour for 50,000 hours. A project manager is funded by Marie Curie (c£40,000). The funding comes from the CCG's end-of-life funding pot, which also covers hospice and palliative care services and training for those working in this area.

The STARS service is further complemented by the Marie Curie 'Helper' service also commissioned by Liverpool CCG to provide social care. The Crossroads Care team can also provide up to 8 hours additional social care support funded by a grant from Liverpool City Council.

Referral

STARS is promoted through Liverpool CCG's bulletin and intranet and work was done with community groups and health services to raise awareness of the service, particularly with community palliative care and District Nursing teams. Posters and leaflets were produced, tailored to patients and professionals.

Any healthcare professional with a contract for NHS services within Liverpool can make a referral. Referrals come primarily from District Nurses but can also come from GPs, hospitals, discharge planners and hospices. Referrals are accepted from Monday to Friday, from 9am to 5pm, to a single point of referral within Marie Curie. Referrals may be made by email or fax. A rapid discharge process, established as a trial for Aintree Hospital, can get care in place quickly for patients discharged from hospital with up to 72 hours to live. A referral call received by 2pm leads to care being in place by 5pm the same day.

The referrer completes a 6-page referral form, which includes: eligibility (see below); personal and medical information; practical details of the home environment and how carers will gain access; GP and next of kin contact details; a care plan; and a timetable covering 24 hours, seven days a week (including care to be provided by STARS staff, District Nursing, other professionals,

family and friends). The referral form was developed with the input of staff from different organisations who refer to the service.

The referral process generally works well and the vast majority of referrals received from Monday to Friday get a decision within 24 hours on whether they will receive care. However there are number of challenges outstanding in order to further refine the referral process, including:

- The STARS referral form is different to the CHC referral form, which means that when a patient is referred to STARS and has their request declined, the referrer has to complete another, different form for CHC. This is burdensome to referrers and it would be preferable if the same form could be used to save repetition.
- The 24-hour response time to referrals only applies Monday to Friday, so patients who need a referral at the weekend can be left waiting until the following Monday to receive a response. Ideally referrals could be dealt with seven days a week, or at least on Saturdays as well as weekdays.

Anyone can access the STARS service as long as they are: 16 or over, registered with a Liverpool GP and living within 10 miles of the city boundary; estimated to be within the last 3 months of life; identify their preferred place of care to be their usual place of residence; and on the local District Nurse team case load.

For the year from April 2013 to March 2014, STARS received 524 referrals. About half were referred by health professionals working in a community setting; a third came from hospitals. Slightly more patients were female (54%) than male. The most common age group was 80+ (41%). People can be referred into the service with any disease type or condition; the most common diagnosis was cancer (85%).

Demand for the STARS service currently exceeds capacity. As well as demand, key pressures on capacity are double-ups (two carers are needed to move the patient) and patients living beyond 12 weeks. Groups who the service is not currently reaching effectively are those with a diagnosis other than cancer, homeless people, prisoners allowed home to die and BME communities.

Assessment

Contact is made with the patient within 24 hours of referral receipt, Monday to Friday. The referral form is reviewed by a senior Marie Curie nurse, who visits the patient at home to undertake an assessment and review the care plan proposed in the referral form. Assessments are undertaken Monday to Friday, between 9am and 10pm. Patients referred within the last 72 hours of life get access automatically.

The service aims to provide patients with up to 58 hours per week, which can take place at any time over the 24 hour period and include different services according to the patient's needs.

When a patient is admitted to hospital, their STARS care package is held in place for 72 hours and will resume if they are discharged from hospital during this time.

Patients are reviewed after 4 weeks and 8 weeks. At 8 weeks, if the patient is no longer considered to be at end of life then staff will raise the idea of moving to an alternative form of care provision. At 10 weeks the District Nurse will refer the patient to CHC. STARS care stays in place until alternative provision can take over, so there is no gap. Reviews also take place as and when there is a change in the patient's condition or need.

Care

The STARS service is delivered in the usual place of residence where this is the patient's own home, a residential home or sheltered accommodation. The service primarily provides personal care to patients (washing, dressing and so on). The social care side includes supporting the family through conversations, reassurance and support, and simply being there when needed – for example, if the relative needs to go out for an hour the STARS carer may stay with the individual during that time to ensure they remain safe and comfortable. The STARS carers can answer questions and signpost to District Nurses and GP.

STARS carers do not usually do housework, but may do some light tasks while they are there such as changing bed linen. What they do is explained at the outset in order to ensure clear expectations.

Services are delivered by staff in both partner organisations. Each patient is likely to have more than one STARS carer coming to their home, but patients and families can get to know their carers from a small pool. Patients and GPs have offered compliments saying that they appreciate the continuity of care, that the service feels unified and the carers work well together. Requests such as having a female or male carer can be accommodated.

The service is flexible and responsive around the 24-hour period, over 7 days a week. It can be offered on an occasional or regular basis, for a few hours or longer periods, during the daytime, evening or overnight. Each visit from a STARS carer can last an hour or more (longer than many home care agencies offer). In reality the service delivers, on average, 59 hours per patient per week. The amount that each patient receives and at what times of the week and day depends on their needs and their family and friends support network. Most patients receive care on a daily basis, i.e. at least one hour each day of the week. Day time is the most in demand and the service tends to deliver about a third more daytime hours than night (on average per month there are 2513 day hours and 1703 night hours).

Numbers receiving the service at any one time between April 2013 and February 2014 varied from 58 to 86 individuals per month - on average, 70 individuals per month. Between April 2013 and March 2014 the service cared for 524 people in total.

Marie Curie also draws on its Helper service, delivered by specially trained volunteers who can offer one-to-one support according to an individual's needs. This includes companionship and emotional support and/or a short break for carers to have some time for themselves.

Outcomes

The Crossroads Care team also provide social care support with a grant from Liverpool City Council, to all palliative care patients and their informal carers, i.e. relatives and friends. This support can be up to 8 hours a week and helps informal carers to maintain as normal a lifestyle as possible. Support may include caring for the individual while their informal carer attends hospital appointments.

Data on outcomes is captured in a spreadsheet completed by the STARS operational manager and submitted to the commissioner on a monthly basis. The outcomes captured in the spreadsheet are guided by NICE quality standards.

The service contributes to the social and emotional wellbeing of the individual and their carer or family, by providing care to individuals which respects their needs and wishes, and demonstrates sensitivity and understanding during the end of life. It enables patients to die at home, in a familiar and comfortable environment, and to feel supported in doing so.

STARS carers are confident in having conversations about death with patients and relatives; rather than shy away from this sensitive topic leaving families confused or ill-informed. They also provide a break from caring.

STARS helps patients to maintain dignity, for example, an elderly female who only has a son nearby is likely to prefer not to rely on him for personal care such as washing and dressing.

There are many compelling examples of where STARS has enabled individuals and families to do things that are important to them, including having a christening, getting married, holding a party, or even playing bingo. The following is an example of a thank you message from a family to STARS staff:

“Just wanted to thank you all for all your help and support you gave me to keep my husband at home with his family. You do a great job and without you this would not have been possible. All the carers took great care of him and kept his dignity til the end.”

STARS works to reduce unplanned admissions by helping the family to understand the dying process, so that they are well informed about what is going on and what support they can get at

home rather than by calling an ambulance. STARS senior nurses do reviews of patients, so that they can bring in District Nurses at key points to avoid ambulance calls.

The service has yet to see the decrease in the number of patients being admitted to hospital that they would like, but they are not sure why this is. It may be to do with the way the figures are collated, because they include planned admission.

More people are dying in their place of choice than before STARS was in place. This is a positive outcome both for families, who report that knowing the patient has been able to die where they wanted to makes their bereavement process a little easier, and for services, as it reduces deaths in more resource-intensive settings such as hospital.

Transferability

The commissioner and providers feel that STARS has excellent potential to be replicated elsewhere. Having been running since October 2012, the STARS service has responded to patients' and referrers' needs in order to develop a more effective service over time. Staff identify the key factors to making STARS work as:

- A holistic approach, including the needs of both patients and their carers/families; or, as expressed in the terminology used by the service, a 'supportive and end of life' programme
- Training to enable provision of specialist end of life care, not just the generic care that would be provided to a patient who is not at end of life
- Strong partnership working between providers and other services including District Nursing
- Flexibility and an ethos of continuous improvement.

The STARS team feel strongly that in the context of local authority budget cuts and changes to service eligibility and provision, it is important to place a degree of protection around the social care element of end of life care. Funding the service from the CCG budget means that it is protected from local authority cuts.

Lessons and recommendations

Through our wider research and as illustrated by the case studies above it is evident that, within current legislation and commissioning arrangements, different organisations and localities are trying to make free social care at end of life a reality in different settings. Nonetheless, the different models still face significant challenges and the huge variability means that some people do not get access to basic, *free*, social care support that could help keep them out of hospital and provide genuine choice at end of life.

Considering the evidence and the views of a wide range of stakeholders from across the end of life care field gathered during our research, we draw out the following lessons and recommendations:

Integration

The models discussed could be described as being essentially a 'sticking plaster' which bridge the gap between free NHS care and means tested social care. We cannot fail to recognise that true integration (i.e. a single ring-fenced budget for health and social care, which is singly commissioned) would mean that many of the barriers and challenges to free social care at end of life would be removed. There is a need to continue to push forward on true integration in order to make it a reality and this will require both political will and commitment at both a national and local level.

However, we are realistic in recognising that true integration is some distance away, and in the meantime, there is a need to do other things. Across the different sources of evidence we looked at, it is clear that both within and across identified service models, there is room for improvement. There is no single 'perfect' model, and we need to avoid coming up with solutions that introduce unnecessary complexity. Simply because a model may not be operating optimally does not, in every case, mean that it should be abandoned in favour of 'the new'. At a time when the NHS and local authorities are facing a substantial and prolonged budget squeeze, there is a case for continuous improvement to secure better quality and efficiency. At the same time, we need to acknowledge that austerity can both stifle and encourage innovation. While seeking to improve current practice, we must still have the courage to innovate and to learn from innovations. In order to improve and innovate, we need to be far clearer about how we measure quality and efficiency.

It is telling that the majority of the models we identified were funded by either the NHS or the charitable sector or a combination of the two. Local authority social care funding was generally absent. In the current climate of austerity both social care funding and NHS funding are under increasing amounts of scrutiny and strain.

Macmillan Cancer Support (2013) in their 'Making the Case' publication, report that there is a cost saving potential of providing free social care. They quote findings from the Nuffield Trust that have shown people with higher social care costs tend to have lower hospital costs and that the cost of caring for someone in hospital can rise considerably in the final few months of life to as much as £90,000. They also quote findings from the National End of Life Care Programme that show that there is an estimated net saving of £958 per person who dies in the community rather than in the hospital. One of the key barriers in providing free social care at end of life, currently, is that without genuine integration across health and social care, especially with respect to their budgets, different commissioners are grappling with the issue of 'who puts in what', and 'who benefits from what'. This silo mentality can inhibit commissioning practices, making them less person-centred and losing sight of the whole system benefits that accrue over and above those experienced by individual commissioning bodies.

With this in mind, there is a growing demand for better and more robust outcomes and cost-benefit evidence to help commissioners make decisions. As discussed, our research found that at a local level there was a paucity of robust outcomes data, with most being qualitative and/or anecdotal. There is also a lack of cost-benefit material. These observations are still applicable when we look across the wider evidence base.

Recommendation: We recommend that, at a national and local level, steps are taken to both improve what is already available in terms of free social care at end of life (i.e. CHC Fast Track) and to innovate (i.e. like the STARS programme in Liverpool) to address some of the unmet need. We have discussed in more detail, throughout this report, some of the factors that need to be considered whilst trying to improve and innovate.

Recommendation: To be able to both improve what is already available and innovate we would recommend that different stakeholders involved in providing social care at end of life (including CHC Fast Track) should be required to collect and monitor data including all inputs, outputs and outcomes. Better monitoring would also help ensure services are effectively reaching those across all relevant diagnoses and BME communities. More robust, outcomes focussed, cost saving data would be beneficial in persuading commissioners to re-direct money within the current system. Central government has an important role to play in supporting a more coherent approach to demonstrate outcomes, costs and benefits.

Variability

Our research found that there is significant variability in the different models being delivered on the ground, as well as *within* each model (for example, the variability we have discussed in the implementation of CHC Fast Track or Hospice at Home). A consistent observation was that many professionals are not aware of what is being delivered elsewhere.

Variability can stem from different reasons. For example, positive reasons for variability may be due to innovation; the intensification of the localism agenda; responding to different local needs; and the involvement of different sets of local players. However, variability can also be the result of disparities in levels of awareness about entitlement and services available, and a lack of consistency in understanding and application. While the 'positive' drivers behind variability are to be embraced, we need to be assured that the observed variability is indeed because of a keen awareness of, and response to, local needs. This is often very challenging, as we consistently hear that commissioners, clinicians, patients and the public have very low levels of awareness of, or confidence in, entitlement; what is available (in terms of services and support) and what the quality of these services may be. There are also doubts as to how well commissioners and clinicians understand local needs as genuine involvement of patients and the public is still very patchy and inconsistent.

Recommendation: It is essential that the Government puts systems in place to ensure that commissioners at a local level prioritise holistic, person centred packages of care at the end of life. All local commissioners should be required to undertake a joint end of life care needs assessment to fully understand local needs, and including meaningful involvement of patients and the public in that assessment. Special attention should be paid to assessing the needs of people dying from diseases other than cancer, as this group is underrepresented even in innovative services like the Liverpool STARS service.

Recommendation: There is a need to raise the confidence of and to educate commissioners, clinicians, and other professionals working in the end of life area about the services and support that are available. For example, there needs to be much better guidance around CHC Fast Track funding which is less open to interpretation at a local level, accompanied by training for referrers and case co-ordinators about who is entitled to what, how to access this support and funding and how to challenge a local commissioner should they believe they are not following national guidelines.

Recommendation: Further to this there is a need to raise awareness amongst patients and the public about entitlement and what services and support are available. The voluntary sector have a large role to play in this awareness raising. The voluntary sector also have a role to play in challenging local commissioners they believe are not following national guidelines.

Consistency

Even when we do embrace the positive reasons for variability, such as innovation; responding to different local needs; and the involvement of different sets of local players, there is still a case for trying to encourage some level of consistency and quality. Through our research we think there are a number of different factors that need to be considered by commissioners in order to encourage consistency including:

- establishing common routes or triggers into the system which would signal entitlement to free social care such as the Gold Standards Framework, the Electronic Palliative Care Coordination System (EPaCCS), or the DS1500 form;
- reducing the room for interpretation in current guidance or issuing new guidance and developing consequences or penalties for those consistently failing to follow it;
- developing a common end of life outcomes framework;
- delivering top down training for professionals responsible for referral, assessment and co-ordination on end of life care which educates them about national entitlement and expectations, rather than local interpretations of entitlements and expectations;
- simplifying and reducing the referral and application processes;
- some form of coordination role, such as a case manager. Although there is recognition that this may convey the message that it is only some people's business and not everybody's business; and
- ensuring that individuals with a terminal diagnosis do not have their package of care revoked once they have been found eligible due to fluctuations in their condition.

Recommendation: Developing quality standards and guidance to support effective implementation of both what is currently available (such as CHC Fast Track) and to encourage commissioners to innovate is essential. Nonetheless, as discussed above with regards to the positive reasons for variability, such as innovation; responding to different local needs; and the involvement of different sets of local players, it should also be acknowledged that there cannot be a one-size-fits-all approach as there still needs to be some level of flexibility within any model.

Recommendation: Quality standards and guidance alone are not enough. As our research has shown, for example, the CHC Fast Track eligibility criteria and guidance is open to local interpretation based on local resources, despite the fact it should not be. NHS England must take a lead in investigating the reasons behind why existing guidance are not being adhered to, and to put in place relevant measures to overcome the 'implementation gap'.

Ensuring quality

A key consideration in terms of consistency is its link with the quality of care provided. This is the overarching concern. It is not about consistency for consistency's sake but it is about maintaining high quality services, which can be achieved in different ways.

In relation to this, better, more consistent monitoring and having good data is very important in terms of its role in helping to improve accountability, equity of access and the quality of services delivered.

The delivery of high quality social care may also be achieved through a preferred provider approach, although there is recognition that this can limit choice and may be costly.

A key aspect of both consistency and quality is the role of the social care workforce. Those involved in delivering social care at end of life should have the relevant competencies and qualifications, especially in terms of end of life care (and not just care in general). It is evident that there is a need to up-skill the social care workforce and develop and implement specific end of life care training or qualifications.

Recommendation: At both a national and local level there is a need to make an explicit commitment to quality, particularly in terms of clarifying standards and expectations around workforce development and around service quality. The workforce of carers responsible for delivering social care should have specific end of life care training in order to deliver the best quality care. Linked to this is also the need for quality standards and monitoring to strengthen accountability.

Values

While there are steps that can be taken to improve training, resources, structures, monitoring etc. everything needs to be underpinned by a clear commitment to delivering high quality care in a person-centred manner. It should not be about 'ticking off' a list of 'to dos', and is not a bean-counting exercise.

While commissioners may embrace these values for high quality, person-centred care, there needs to be a greater recognition of the realities 'on the ground', particularly looking for barriers in how such values are translated into practice. There was a strong sense from our research that these values are not being translated into practice on the ground. For example, a commissioner we spoke to expressed frustration that some providers do not seem to understand what 'person-centred care' means, and thinks that it is only about 'doing things'.

Recommendation: The provision of free social care at end of life needs to be underpinned by a clear commitment to delivering high quality care in a person-centred manner from all of those

involved. This should be reinforced through the training, outcomes based commissioning and procurement practice based on a clear needs assessment, and ongoing monitoring and accountability with regards to what is being delivered and how it is being delivered.

Partnerships

Throughout our research, partnership has been a predominant and recurring theme. Partnership working will be central to delivering free social care at the end of life. Partnerships were talked about in different ways and at different levels:

- **Partnerships between commissioners, professionals, providers and patients, families and carers.** This multipartite partnership is vital if services are to be commissioned, designed and delivered in a way that genuinely meets the needs of patients and their families and carers.
- **Partnerships between health and local authority commissioners.** There is currently a disconnect between health commissioners and local authority commissioners. This is evident both from the under-representation of local authority commissioners at the workshop that fed into this report and the lack of truly integrated commissioning practices. As discussed, it is telling that the majority of the models we identified were funded by either the NHS or the charitable sector or a combination of the two. Local authority, social care funding was generally absent.
- **Partnerships amongst providers.** The marketization in the health and social care market is another issue worth considering, as is the observation that this has led to perverse practice ‘on the ground’. For example, different providers not sharing information due to ‘commercial confidentiality’, and adopting a competitive approach to ‘win contracts’ and ‘tout for business’. There is recognition of the challenges in voluntary and community sector providers partnering with big corporate, private sector providers, where the latter may undercut the former in terms of low ‘unit costs’ but may not deliver the quality. There is further recognition that even within the voluntary and community sector, different providers find it challenging to form partnerships. For example, different VCS organisations have to compete amongst themselves for contracts.

While we acknowledge the competitiveness amongst different players in the field and the down-sides of this; we also recognise that competition can drive up standards, particularly when providers with specialist skills in end of life care come into the market, forcing others to raise their game.

With partnerships, the issue of leadership comes to the fore. Who has responsibility for service provision?; Who takes the lead amongst partners?; How does this affect decision-making and information-sharing?

Recommendation: When commissioning free social care at end of life commissioners should work with providers in a way that encourages collaboration. The importance of this was evident in

the Liverpool STARS service in that the partnership arrangement for delivering the service brings together different knowledge and expertise: Marie Curie specialises in end of life care, while Crossroads Care has extensive experience of delivering complex care packages at home. There are a number of ways this could be achieved; for example, through pre-commissioning conversations with collectives of potential providers, commissioners can help engender a more trusting and collaborative approach. Commissioning and procurement protocols may also be designed to actively encourage and support partnership bids, as well as to support local and/or small providers through making the commissioning/procurement process more accessible. Commissioners should commission in a way that keeps a clear focus on outcomes for patients and their families, marshalling local resources and providers more effectively to bring all the relevant skills and expertise to bear.

Recommendation: When commissioning free social care at end of life commissioners and providers should involve service users, carers, and families meaningfully to understand needs and to design and deliver services that meet these needs in a sensitive, person-centred way. As discussed providers and commissioners have a responsibility to ensure that the workforce are appropriately trained in providing care at the end of life.

Recommendation: Localities should put in place structures and protocols that support and sustain effective partnership and engagement throughout the commissioning cycle, so that localities can be confident that not only are the right services commissioned, they are also delivered appropriately and to a high quality. This ensures an in-built mechanism within localities for 'quality checks' that can come from all three parties. The partners effectively hold one another to account, through support and challenge, for delivering high quality and efficient social care at the end of life.

Recommendation: Commissioners should look at ways through which they may incentivise the development of the local social care economy so that, over time, there is a growing pool of high quality providers with the capability and capacity to provide the full range of end of life social care services and support in their local areas. Information about providers should be collated, updated regularly, and disseminated widely to ensure that people are aware of not only what is available but also the quality of what is on offer.

Acknowledgements and thanks

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Appendix 1

Documents included in our desk review

Alakeson, V. and Duffy, S. (2011) Health Efficiencies: The Possible Impact of Personalisation in Healthcare. The Centre for Welfare Reform

Bardsley, M., Georghiou, T. and Dixon, J. (2010) Social Care and Hospital use at the End of Life. Nuffield Trust

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Department of Health (2012) National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care

Georghiou, T., Davies, S., Davies, A. and Bardsley, M. (2012) Understanding Patterns of Health and Social Care at the End Of Life. Nuffield Trust

Hughes-Hallet, T., Craft, A., Davies, C. (2011) Funding the Right Care and Support for Everyone. The Palliative Care Funding Review

Leadbeater, C. and Garber, J. (2010) Dying for Change. Demos

Macmillan (2010) Summary of the Midhurst Macmillan Community Specialist Palliative Care Service. Macmillan.

Macmillan Cancer Support (2013) Making the Case for Free Social Care at the End of Life. Macmillan

Macmillan Workshop Write-up (unpublished) Making Free Social Care At The End Of Life A Reality.

Paget, A. and Wood, C. (2013) Ways and Means. Demos

Payne, S., Seymour, J., Ingleton, C. and Chatwin, J. (2009) Independent Evaluation of the Marie Curie Cancer Care “Delivering Choice Programme”: CHES and CAPCCS work streams”. Lancaster: Lancaster University

Payne, S. and Ingleton, C. (2008) Independent Evaluation of the Marie Curie Cancer Care ‘Delivering Choice Programme’. Lancaster: Lancaster University

SCIE (2013) Dying Well at Home: Research Evidence. SCIE

Scottish Government (2009) National Standard Eligibility Criteria and Waiting Times for Personal Care for Older people - guidance

Appendix 2

Summaries of relevant service models identified

As discussed in chapter 2, following the desk review and call for evidence we identified a range of service models that warranted further inspection. We conducted a number of scoping interviews with representatives from some of these service models to gather more details about the service and produced a number of summary fiches describing key aspects of these service models. This appendix provides an overview of these summaries, each of which set out how the different models work, the drivers for development, how people access the services as well as the challenges and successes associated with each model. We have grouped them as follow:

Hospice at home services

1. Paul Sartori Foundation, Hospice at Home service, Pembrokeshire.
2. St Johns Hospice, Hospice at Home service, North West London
3. St Giles Hospice, Hospice at Home service, Staffordshire

Voluntary and community sector initiatives

4. Midhurst Macmillan Community Specialist Palliative Care Service
5. Marie Curie Cancer Care Delivering Choice programme – the Complex and Palliative Continuing Care Service (CAPCCS), Leeds.
6. Crossroads Care Palliative Care Service, Cheshire East and Cheshire West.
7. Sue Ryder Partnership for Excellence in Palliative Support (PEPS), Bedfordshire.

CCG funded service models

8. Liverpool CCG End of Life Care programme (STARS Programme) **(Please see full case study in earlier section)**
9. The Reablement and Community Home Support service (REaCH), Stockport CCG
10. Initial Response and Integration Service (IRIS), Tameside and Glossop CCG

National service frameworks and policies

11. Continuing Health Care Fast Track Funding, England **(Please see full case study in earlier section)**
12. Free personal care for over 65s, Scotland

Hospice at Home services

Paul Sartori Foundation, Pembrokeshire.

Overview of service

The Paul Sartori Foundation (the Foundation) is a charitable organisation in Pembrokeshire that provides hospice at home services to people in Pembrokeshire. It provides hands on nursing care, many aspects of which can be described as social care. This includes overnight care and day respite to relieve carers so that they can shop, attend appointments, sleep and work. This also includes rapid response personal care (washing and handling) until social services are set up. Finally, it also includes a 'standby service' which provides a telephone contact service for people who at the moment don't need any hands on care. Other services provided include equipment free of charge, bereavement and counseling support, physiotherapy, advance care planning, complementary therapies and a Clinical Nurse Specialist who works with the Macmillan team in Pembrokeshire. The management team consists of 6 people and care services are provided by a small team of 30 qualified and experienced Registered Nurses (RNs) and Health Care Assistants (HCAs). The HCAs receive NVQ 3 training and all staff receive regularly updated training based on staff needs assessed at appraisals every six months.

In 2012-2013 approximately 205 people used the home nursing service and 94% were able to die at home compared to 89% in the year before. The Foundation report that in any given week they tend to provide nursing care for 15-30 people. Additionally, 142 people registered with the standby service in 2012-2013 and the Foundation tend to have 30-50 standby patients in any week. Approximately 65% of the patients cared for by the Foundation have a cancer diagnosis whereas 35% have other diagnoses, including health failure, lung diseases, Motor Neurone Disease and Parkinson's Disease.

Services are provided free of charge and the Foundation has a number of sources of funding. Approximately 70% of its funding is from charitable donations, fundraising activities and charity shops, and 25% is from the Welsh Government. A further £90,000 is from the local health board and approximately £7000 is from the local authority.

Drivers for development

The Foundation were established approximately 30 years ago out of a recognition that there are not enough services in the area to support people to be cared for at home at the end of life. They state that they aim to support statutory services rather than replace them. They also aim to provide a holistic package of support that meets the needs of people at the end of life, and that enables them to get the very best possible care in their own homes.

Accessing services

Services are available for adults over the age of 18 who live in Pembrokeshire and who have a life limiting

illness with a prognosis of approximately 6 months. They report using the Royal College of General Practitioners' Gold Standard Framework prognostic indicators as a rough guide to determine eligibility for services. However they also consult clinical letters and meet potential patients to determine eligibility. They have an open referral system and report that approximately 40% of referrals are from District Nurses, 20% are from Macmillan nurses, 15% are from family and friends and the rest are from hospitals. Very few referrals come from GPs.

Challenges and successes

One of the key strengths of the Foundation is their ability to provide access to care very quickly which they feel is a result of the fantastic flexibility of their staff who understand what the job requires and are happy to tolerate a great deal of unpredictability in their working lives. Registered Nurses often put together packages of support on the same day with a record time of 40 minutes from referral. Immediate availability of care services therefore makes home care an option for people who otherwise would not have been able to cope at home. This leads to high levels of patient and carer satisfaction and avoids hospital admission in some cases. Unsurprisingly, the unpredictability of demand is also the key challenge faced by the Foundation. The Foundation also report that they have a lot of public support and are well known in the area. The management team are also very conscious of how they spend their budgets and are committed to ensuring that they are using publicly donated money well.

St Giles Hospice, Hospice at Home service, Staffordshire.

Overview of the service

St Giles Hospice is a registered charity providing individual care and support for people from across their local area with cancer and other serious life limiting illnesses. St Giles Hospice has been providing Hospice at Home services for about thirty years. These services tend to include personal care, respite care and psychological support, all of which is delivered by a team of 16 Health Care Assistants (HCA) who are trained to NVQ level 3 or equivalent. There are also two Registered Nurses in the team who sometimes do assessments (when referrals are from sources other than the community nursing team). The Hospice at Home services are provided primarily to patients in the last two weeks of their lives and this tends to include two visits a day as well as a night service if needed. Services are also provided on an interim basis to patients who may have a longer prognosis but who have deteriorated suddenly and are waiting for packages of care to be arranged and approved. Similarly, services are also provided on an interim basis to post discharge patients, to enable hospital discharge and provide care for the patient until packages of care are organised.

There is no charge to patients or families for the services they offer. The hospice receives 30-40% of its funding from the NHS, and the rest is through fundraising activities, voluntary contributions, and legacies.

Drivers for development

The aim of the Hospice at Home service has been to enable people who would like to be cared for at home to be able to die at home. By doing this, they also aim to reduce unnecessary admissions to hospitals.

Accessing the service

The majority of referrals come from the community nursing team, but referrals are also received from other District Nurses, Palliative Care Discharge Liaison teams, hospitals or GPs. The hospice provides services to patients who are over 18 years of age, who are in the last year of life and are also ideally on the GSF register. Although the services are open to people with all types of diseases, the majority of patients tend to have cancer.

Challenges and successes

The service feels that its key strength is that it can respond very quickly to requests for care and can be very flexible with respect to the changing needs of patients. They also have a caring and compassionate workforce that is appreciated by patients and families. They report that they have helped enable 95% of their patients die at home. With respect to challenges, the hospice reports that many agencies offering care in the home have opened over the years thereby increasing competition. However, the hospice singles itself out by highlighting that they provide specialist end of life care, rather than generic social care.

St Johns Hospice, Hospice at home service, North West London.

Overview of the service

St John's Hospice, an independent charity located within the Hospital of St John's and St Elizabeth in St John's Wood, provides specialised palliative care. The Hospice at Home Team aims to offer general hands on nursing and personal care for patients requiring end of life care in their own homes. Hospice at Home provides support by placing Health Care Assistants experienced in community work and trained in palliative care into the homes of patients who want to remain in familiar and comforting surroundings during the later stages of their illness. Hospice at Home is tailored to the need of the patient, and can provide a minimum of four hour blocks of care, through to being able to deliver twenty four hour care in the terminal phase of a patient's illness. Care is usually provided for up to two weeks. People tend to get 5 x 24 hours of care over two weeks. Carers assist with all aspects of personal care from bathing and preparing meals to escorting patients to appointments for treatments such as chemotherapy or easing patients' discharge from hospital to their homes (they try not to do shopping, cleaning etc. but will do if

required). Another important part of the service is to lessen the strain for family members who are caring for the patient.

The Hospice at Home service is funded by the CCG. CHC in the area does not fund night care so the service can plug this gap – having CHC funding does not exclude people from the service.

Drivers for development

The service was developed to enable patients to have a realistic choice of where they are cared for, whether this is to facilitate a death at home, enable a patient to stay at home for as long as possible, reduce admissions to acute or hospice settings or to provide respite for family carers.

Accessing the service

The Hospice at Home service is provided to patients registered with a GP in the Kensington & Chelsea, Brent and Westminster boroughs. Generally patients have a life limiting condition, are in the last few weeks of life and need respite or are experiencing an acute event. Most users are cancer patients although they do cater for any life limiting condition.

Referrals generally come from a healthcare professional (palliative care nurse, hospice, hospital). The service tends to go on what the referrer has said and they do always try and speak directly to the referrer. The Hospice at Home co-ordinator then sets up the package of care

Challenges and successes

The service offers people flexibility and choice and allows people to die at home. It prevents unnecessary admission to hospital/hospice; and supports early discharge from hospital/hospice. The service also caters for those not entitled to CHC funding.

The key challenge the service faces is that they only have limited capacity and demand fluctuates.

Voluntary and community sector initiatives

Midhurst Macmillan Community Specialist Palliative Care Service

(Taken from The Kings Fund, Co-ordinated care for people with Complex Conditions Programme (2013). www.kingsfund.org.uk/publications/midhurst-macmillan-community-specialist-palliative-care-service)

Overview of service

The Midhurst Macmillan Service is a community-based, consultant-led, specialist palliative care service in a rural community in the south of England. The service is run by a dedicated and multidisciplinary team of nurses and palliative care consultants, occupational therapists, physiotherapists, and a large group of volunteers. This core team works with other care providers in the local area to provide care in people's own homes. This includes general practitioners (GPs), District Nurses, social services and continuing care teams.

The medical professionals who are part of the Midhurst team focus on care management and care co-ordination, liaising with GPs, District and Community Nurses, specialists and other relevant medical staff to arrange or change treatment for patients. There are seven clinical nurse specialists (CNS) on the team who hold a caseload based on allocated GP practices. The clinical support staff consists of trained nurses and health care support workers who carry out the majority of the hands-on clinical care, with consultants and CNSs conducting more specialist procedures or providing care in emergencies. The service employs a physiotherapist and an occupational therapist, roles that are not typically involved in community-based palliative care. A counsellor works with patients and families pre- and post-bereavement.

The service also has around 70 volunteers who take on a host of roles, from practical tasks, e.g., helping with the shopping or gardening, to complementary treatments, such as Reiki or aromatherapy. Volunteers are matched to the needs of the patients rather than providing a fixed set of services. Some volunteers have been trained in bereavement counselling and visit the family and/or carers after a patient has died. Others with legal expertise support patients and families with wills and related matters, and Macmillan Cancer Support provides access to a financial adviser from Citizens Advice Bureau. The volunteers within the Midhurst service fulfil the holistic component of this care co-ordination model, supporting patients and carers with everyday tasks to enable them to live well, and contributing to the skill mix of the core team.

Drivers for development

The service was set up in 2006 in response to the sudden closure of a local hospital with a Macmillan Cancer Support palliative care unit. It has since evolved to offer an innovative solution that provides end-of-life services to local people at home. The service is jointly funded by the NHS and Macmillan Cancer Support to the total value of approximately £1.2 million per year. The service seeks to prevent avoidable admissions into hospital, to enable patients with complex needs to be cared for at home, and to allow them to die in the place of their choosing.

Accessing services

The Midhurst service caters for approximately one-quarter of all patients needing end-of-life care in the area. The majority of patients supported by the service have a diagnosis of cancer, but the service supports a growing number of patients with other conditions including dementia, heart failure and

neurological disorders. In 2010/11, 409 patients benefited from the service.

Referral criteria for the service are based on World Health Organization (WHO) and National Institute for Health and Care Excellence (NICE) guidelines for palliative patients. Referrals often come from GPs and hospitals, but also from specialist nurses and community hospitals. Referral criteria are:

- severe, intractable complex symptoms that have persisted after palliative care by generalist
- patients and their carers having difficulties in adjusting to/coping with their disease, psychologically, spiritually or emotionally
- information and explanation is required relating to the illness, treatment, care options and allied support services
- patients and carers experiencing difficulties in bereavement, who would benefit from specialist support/further psychological intervention
- to assess the need for further specialist unit services, i.e. day care or inpatient care
- health care professionals require specialist advice and support with case management.

(Source: Midhurst Macmillan Service Referral and Discharge leaflet)

Referral is made to one of the clinical nurse specialists who act as the single point of contact for the patient and families. The CNS then assesses patients at their home, taking their wishes and needs on board.

Challenges and successes

Data from the Midhurst Macmillan Service for 2011/12 shows that the service supported people to die in their preferred place of care (71% in 2010/11; this has increased to 84% in 2012/13).

Key lessons of the Midhurst model of care co-ordination arises from the team structure and skill mix, with a fully integrated mix of consultants, senior nurses, health care support workers, allied health professionals and volunteers. Clinical staff are allocated to specific patients, enhancing continuity, and the floating CNS is able to pick up cases and respond quickly to urgent situations. Professionals have the time and freedom to conduct joint visits assessing medical, social and holistic needs at the same time, reducing the need for multiple visits. Volunteers are integrated into the service, supporting patients and carers as and when needed. Finally, knowledge about the patient and their circumstances is shared within the team through meetings and logged on the internal IT system.

Nonetheless, the service has had to overcome a series of challenges to achieve its current success, some of which remain. These challenges can be categorised either as challenges related to the wider context (that the service has little or no influence over) or challenges relating direct to the organisation and delivery of a community-based service.

Contextual challenges include ongoing NHS reforms, the ongoing sustainability of funding and geography. The catchment area covered by the service straddles three counties, which poses logistical challenges,

not only in terms of gaining commitments from a number of different agencies, but also in meeting the different governance and accountability rules of each one. The rurality of the local area (400 square miles) and poor public transport has also posed limitations on what can be provided and has defined how the service operates.

Organisational challenges include developing and maintaining positive relationships between the various partners in care. This has been important in developing trust and legitimacy (and therefore more referrals) to the service as well as to improve care co-ordination for patients. The service has also had its challenges in ensuring an adequate numbers of staff are available with the right skill mix to support its goals.

Further information can be found at: Noble B. et al (2014) *Can comprehensive specialised end-of-life care be provided at home? Lessons from a study of an innovative consultant-led community service in the UK.* European Journal of Cancer Care published by John Wiley & Sons Ltd.

Marie Curie Cancer Care Delivering Choice programme – the Complex and Palliative Continuing Care Service (CAPCCS), Leeds.

Overview of service

CAPCCS in Leeds was part of Marie Curie's Delivering Choice Programme which aimed to give patients more choice at the end of life. It was a pilot initiative launched in 2008 and included the employment of specially trained Health and Personal Care Assistants (HPCAs) to perform routine and non-medical tasks in order to ease the workload on District Nurses. HPCAs are very carefully and rigorously recruited and undergo a 'robust' training and induction programme which lasts at least a month and includes shadowing other HPCAs, accompanying District Nurses, spending time at hospices and receiving formal training on end of life care such as moving and handling, medications, hygiene and catheter use. The District Nurses, who are the care leads, prepare care plans for the HPCAs which provide detailed instruction on a patient's care needs, for example, when a patient needs to be given a meal and how they should be moved or turned.

Drivers for development

One of the primary aims for CAPCCS has been to increase choice at end of life and to enable the delivery of care services to be supported in the home environment. It also aimed to help support the District Nursing workforce and to prevent inappropriate admissions and readmission into hospitals. The pilot also aimed to integrate health and social care in that the HPCAs, in addition to providing healthcare, also assisted with everyday tasks such as washing and changing the patient, and preparing a simple meal.

Accessing services

Referrals to CAPPCCs can only be made by District Nurses and is through the computerised information system. A referral form called CAPCCS 1 is filled which is followed up with a call to a customer support officer. The referral is placed on a patient's case record and passed to a senior nurse. Senior nurses talk to the referrers, and if a patient is accepted, fill out a form called CAPCCS 2 to confirm acceptance. The eligibility criteria for acceptance to the service is that (i) patients are over 18, (ii) patients are registered with a GP in Leeds, (iii) patients meet the continuing care criteria for fast track status and (iv) have an individual business case written and agreed (for patients requiring ongoing complex continuing care).

Challenges and successes

An evaluation report published in 2009 indicated that the carers were full of praise for the HPCAs, in terms of both their professional and personal qualities. They were particularly impressed with their attention to detail and their recognition that these details have a great impact on the quality of care. There were comparisons made with some agency staff that did not attempt to build rapport with patients. Carers also reported that HPCAs relieved the burden of care on carers which meant that they were able to take some time for themselves. Many indicated that they would not have been able to carry on caring for their loved ones at home without the help of the HPCAs therefore indicating that the programme facilitated patients dying at home. There was also reportedly very good communication and mutual respect between District Nurses and HPCAs, as well as between District Nurses and the CAPPCCS administration team. The training and selection of HPCAs was seen as very important – they needed to have the right approach and professional attitudes and skills. Very few issues were reported with the service which seems to have been evaluated favourably. However, some stakeholders interviewed felt that the referral system could have been wider because District Nurses are often away from their desks all day and this can result in delays to referrals and therefore care being provided.

Crossroads Care Palliative Care Service, Cheshire East and Cheshire West.

Overview of service

Crossroads Care is a leading provider in support for carers and the people they care for. It employs Care Support Workers that primarily provide personal and domiciliary care and respite for carers. In Cheshire East and Cheshire West the service also provides palliative care services for people whose preferred place for care at the end of life is their own home. The service is provided by Care Support Workers who are trained to the level of a Nursing Auxiliary/Health Care Assistant and have received additional palliative care training. The service is flexible and responsive to carer and patient needs and can be offered on an

occasional or regular basis.

Care services provided are person centred and can include personal care, respite care as well as more specialist care such as medication management and feeding via abdominal/nasal tube. Additional specialist training can enable the team to carry out other tasks. Care Support Workers also provide bereavement support and visit families for a short time after the loss of a loved one. There is also a bereavement support group that carers can attend. Crossroads Care is funded through a range of sources. This includes grants from the local authority, health services and charities. It also includes donations and fundraising activities.

Accessing the service

The service is available free at point of delivery for adults who have an advancing, progressive, incurable illness with a prognosis of less than 12 months. The patient should also be registered by their GP practice on the Gold Standards Palliative Care Framework Register. Patients also need to meet one of three levels of priority of care which will determine the type of care they receive.

1. 'Urgent' or priority 1: A patient has a prognosis of hours to days, a rapidly deteriorating condition, uncontrollable symptoms and the carer is unable to cope. The patient has expressed a wish to be cared for at home or is going home on the Rapid Discharge Pathway. A maximum service is required for a short period, possibly including overnight care.
2. 'Changing needs' or priority 2: The prognosis is of days to weeks, the patient has symptoms that are unstable and there are high levels of patient/carers anxiety. The patient is on the Gold Standard Framework register or with plans to be placed on the register. A responsive service is needed with daily support and carer breaks which may need to increase as the patient's condition deteriorates.
3. 'Stable needs' or priority 3: The prognosis is of weeks to months, the patient requires low level healthcare support and their symptoms are well controlled. The patient is on the Gold Standard Framework register or with plans to be placed on the register. Minimal support, for example weekly carer breaks, with some health care support is required.

The service operates an open referrals system and most referrals tend to be from hospices but hospitals and community matrons also often refer to the service.

Challenges and successes

The service works well as the team delivering care are highly experienced and well trained in end of life care and in supporting carers. They are empathetic and provide compassionate care thereby improving the end of life experience. Support continues after bereavement for a short time and this is felt to be important as it provides families with a familiar face and source of comfort. The service also enables patients to stay at home at the end of life, therefore saving on hospital admissions. By supporting families it also helps prevent carer breakdown, thereby potentially resulting in savings to other health services, particularly mental health services.

Sue Ryder Partnership for Excellence in Palliative Support (PEPS), Bedfordshire.

Overview of the service

The PEPS service was implemented as a pilot in Bedfordshire to coordinate palliative care across the county and was led by Sue Ryder and NHS Bedfordshire. Since then Sue Ryder has secured funding to continue delivering it. The service provides a single point of telephone access available 24 hours a day for palliative care services, bringing together a network of 15 different local organisations from the health, social care and voluntary sectors, including hospitals, hospices, GPs, ambulance services and community services. Calls are taken by qualified senior nurses who are skilled in palliative care identifying the most appropriate health or care provider to respond to the caller's needs. Services are coordinated using a shared electronic record on SystemOne which ensures that patients' records are readily available and that their needs and preferences can be easily shared with all services.

Over the twelve months that the service was piloted, 1051 people signed up to the scheme, of whom 620 people died. Diagnosis information was only available for 915 patients and of these 91% had a cancer diagnosis. Analysis of the received and dialled phone calls revealed that unsurprisingly a high proportion of the calls were to or from a carer/relative (37%) or a patient (11%). Similarly, 10% of calls were to and from District Nurses and 9% to and from Macmillan nurses which reflects the close working between the coordination centre and nurses in the community.

Drivers for development

The service was introduced to improve outcomes for patients in the last 12 months of life and for their carers. Intended outcomes included reduction in unplanned hospital admissions and length of stays in hospital as well as increase in deaths occurring in patients' homes or their preferred place of care.

Additionally, prior to the introduction of the service palliative care services in the area, although of high quality, were very disjointed. Services tended to work in isolation and there was confusion about who to call. It was therefore hoped that the service would provide a more coordinated and equitable approach to end of life care across the county. The service, through its shared electronic record, also fulfilled the requirement to have an electronic register of palliative patients (EPaCCS) which although in place, had been inconsistent with no central register for the county.

Accessing the service

The majority of referrals to the service were from community nursing teams with 68% of referrals from Macmillan Nurses, 5% District Nurses and 5% from Nursing homes. Only 1% of referrals were from GPs. No information about eligibility for referral has been provided.

Challenges and successes

The evaluation of the service reported that 65% of patients who died were supported to die at home, 19% died in hospice, with only 11% dying in hospital. Additionally, patients registered with PEPS had 30% fewer emergency hospital admissions compared to before they joined the service and their length of stay in hospital was also reduced by 30%. The service was also valued by stakeholders. For example, 91% of GPs consulted with (n=21) reported that the coordination centre had made a difference in terms of help or advice for patients and 87% (n=20) felt that it had made a difference to the coordination of palliative care across the county. Additionally, feedback from Macmillan nurses indicated that they had a good relationship with the PEPS co-ordination team. Some challenges and areas for development included the need for greater clarity about who has responsibility for information being entered on the electronic system and the need for identifying and registering patients with a non-cancer diagnosis.

CCG funded service models

Liverpool CCG End of Life Care programme (STARS Programme)

Please see full case study in earlier section

The Reablement and Community Home Support service (REaCH), Stockport.

Overview of service

The Reablement and Community Home Support service (REaCH) in Stockport offers people short term and flexible rehabilitation support in their homes. Its primary remit is providing domiciliary and personal care and it is therefore regulated by the Care Quality Commission.

These services are provided through the employment of a small team of 90 Home Support Workers (HSWs) of whom a little more than half are Assistant Practitioners (APs) with a Health and Social Care foundation degree. On average the team provides service users with approximately four weeks of care until they have regained a reasonable amount of independence.

The service has been piloting an end of life care service since December 2013 which is scheduled to run until March 2014. It is funded by Stockport Clinical Commissioning Group through demonstrator (innovative practice) funding.

The pilot service includes two teams of four APs working in two areas in Stockport with approximately 15-20 District Nurses. The APs work flexibly and support carers with a range of services and needs that include not only personal and domiciliary care, but also emotional and wellbeing support. This can include providing respite, signposting to other services, performing errands and daily tasks, and listening and providing advice. A shared care and support plan is created, which highlights medical as well as personal care and wellbeing needs. District Nurses and a lead AP tend to work on this together.

The APs have received end of life care training from a local hospice and the management team are exploring the option of securing funding from the North West Modernisation Hub for an EOL care module to add to the foundation degree. The APs are managed by the REaCH management team rather than by the District Nurses because their remit is primarily personal and domiciliary care, rather than clinical care. The APs work on a rotational pattern from 8am-10pm for 7 days a week and can therefore provide support outside District Nursing times. They also have access to an overnight support team that works from 9pm to 7am. Since the pilot started approximately 50 people have been supported. The majority of this group have suffered from cancer and have been over the age of 65.

Drivers for development

The pilot was developed because the service was increasingly receiving and accepting referrals to provide support for people nearing the end of life. The service accepted these referrals in order to relieve pressure on District Nurses who focus on clinical support and therefore didn't have the time to provide the emotional and wellbeing support that patients and carers also need at the end of life. This pilot therefore aims to provide District Nurses with additional support to help meet the needs of patients. Other intended outcomes include (i) increase in the number of people able to die at a place of their choice and (ii) a reduction in hospital admissions. There are plans in place for an evaluation of the pilot service.

Accessing services

Referrals come to District Nursing teams through GPs and are discussed at daily locality meetings attended by REaCH staff members. The potential need for support provided by REaCH APs for each referral tends to be discussed at these meetings. At times District Nurses visit patients and then assess the need for AP support.

Challenges and successes

The service feels that the pilot service has enabled people to choose to die at home, and report that 54% of patients have died at home, approximately 12-14% have been readmitted to hospital, and the rest have been in hospice care or the care of family members. Feedback about the APs has been very positive from GPs, District Nurses and patients and carers. Carers report that the APs have supported their loved ones to have a dignified, respectful and comfortable end of life. Additionally, working together with District Nurses has helped to break down barriers between health and social care and created greater understanding and mutual respect of each sector's work. The District Nurses have been able to see the benefit of having a qualified and skilled workforce that they can trust and that can offer services that they

themselves don't have time for. An associated challenge has been that it took some time for District Nurses to respect and trust the skills of the APs particularly in relation to performing lower level clinical tasks. However through exposure, communication and working together in an integrated way this has started to change.

Initial Response and Integration Service (IRIS), Tameside and Glossop CCG.

Overview of service

Tameside and Glossop CCG are currently 6 months into a 12 month pilot for a new Initial Response and Integration Service (IRIS). Its aim is emergency admission avoidance and to keep the patient at home by meeting an individual health and social care needs in their own home. This health and social care model is free for 6 weeks for those patients who are in a crisis situation.

The service was developed and discussed with multi-disciplinary providers, a lead GP, and the CCG. Support is there for patients who are in a crisis situation. There are eight pathways that patients are classified onto; mainly falls, confusion, or elderly frail patients off their feet/infection. There is also a palliative pathway. More of the patients may be on an end of life care pathway but they are classified for IRIS on the presenting condition.

There is one referral and one holistic assessment. An integrated service is much more efficient around staff resource than separate teams going to see a patient on several occasions. Communication, shared learning and discussions have impacted upon staff knowledge and team building to create a strong network. Trust in colleagues is key. Patient satisfaction and referrer satisfaction surveys have been very positive and one of the nurses has been nominated for a national award. IRIS attends the Accident and Emergency (A and E) board round daily; in January 34/367 patients were taken out of A and E and treated at home. The pathway was set up and they work closely with the ambulance service to prevent admissions.

The patients are seen by the right professional in the right place at the right time. Duplication of assessment and patient stories are prevented by the single assessment. Costs are reduced by preventing unnecessary admissions, and long term care, and by streamlining the service to one referral process which reduced communication errors. There is a one hour response time when necessary. The care is free for 6 weeks. When the crisis is over the patient returns to their normal state of care, and the team will signpost the patients and carers to relevant groups and services that may help them with future care.

Drivers for development

Historically there were separate health and social care services that did separate assessments. This is

inefficient in terms of time and funding, and reduced the patient's experience.

Accessing services

There is one form to fill out and this goes to a single point of contact in the team. Any professional can refer a patient into the service; most referrals are from GPs, nurses and social care. Patients cannot refer themselves. In January there were 367 referrals and 106 were assessed within an hour. 250 of those patients were over 75 years old.

This is a 12 month pilot focussing on admission avoidance, and although not all patients are categorised as palliative, the majority are over 75 and therefore may be suitable to have an advance care plan in place.

Challenges and successes

The service is said to be designed to ensure patients get the right treatment in the right place at the right time. Carers and the patients are engaged in the treatment, crises are resolved and they are signposted to relevant services for the future. Patients do not need to tell their story to lots of different clinicians and they are cared for in a familiar environment.

Challenges include the fact that it is not a 24/7 service - only 8am-10pm. The service is borough wide which has travel time disadvantages - when it was set up they did not understand the capacity of the service so some nurses were taken on certain contracted hours - but they have worked together and resolved this. Initially the IT systems did not talk to each other but this has now been resolved. Further to this there are currently only 8 pathways which means that some patients may not benefit. As the main aim of the service is admission avoidance it means that they cannot be discharged from hospital into the service.

National service frameworks and policies

Continuing Health Care Fast Track Funding, England

Please see full case study in earlier section

Free personal care for over 65s, Scotland

Overview of the service

Free Personal Care is the term for the Scottish Government's policy that provides personal care services without charge to everybody over the age of 65 who is assessed as requiring them. People at home receive either the services direct from their local authority, or receive a payment allowing them to purchase the services elsewhere, and people in care homes receive a payment of £145 towards the cost of their overall care. People at home who require nursing care continue to receive it from the NHS while those in care homes receive a further £65. Nursing care is provided to everyone who requires it irrespective of age. Since 2002, all the countries of the UK have supported free nursing care for older people in care homes. But Scotland has also provided free personal care for older people, both in care homes and at home. Throughout the UK, older people who are assessed as having the means to do so pay for 'hotel' charges (such as 'bed and board') in care homes. If at home, they are expected to contribute towards the costs of services which are neither personal nor nursing care.

Personal Care refers to anything done for an individual that is of a personal nature such as

- Personal Hygiene - bathing, showering, hair washing, shaving, oral hygiene, nail care
- Continence Management - toileting, catheter/stoma care, skin care, incontinence laundry, bed changing
- Food and Diet - assistance with eating and assistance with special diets
- Assistance with food preparation
- Problems of Immobility - dealing with the consequences of being immobile or substantially immobile
- Counselling and Support - behaviour management, psychological support, reminding devices
- Simple Treatments - assistance with medication (including eye drops), application of creams and lotions, simple dressings, oxygen therapy
- Personal Assistance - assistance with dressing, surgical appliances, prostheses, mechanical and manual aids; assistance to get up and to go to bed; transfers including the use of a hoist.

Nursing Care is anything which involves the knowledge or skills of a qualified nurse

Drivers for development

The Scottish Government implemented the findings of the Sutherland Report (Royal Commission on Long Term Care, 1999) on long-term care. This report recommended that people should only pay for the accommodation element of their care, making both personal and healthcare services free. The Report of the Royal Commission on Long Term Care for the Elderly recommended that "The costs of long-term care should be split between living costs, housing costs and personal care. Personal care should be available after assessment, according to need and paid for from general taxation: the rest should be subject to a co-

payment according to means.” (Scottish Government, 2009)

The Scottish Government’s initial response in 200 to the Royal Commission report, in line with the Westminster response, agreed that nursing care, as opposed to personal care, should be provided free of charge in all settings. Subsequently, the Scottish Government determined that personal care should also be free and established the Care Development Group, comprised of professionals and representatives from relevant organisations in 2001. The Group’s remit was to make proposals for the implementation of both elements of the new policy. (Scottish Government, 2009)

The Community Care and Health (Scotland) Act 2002 established the statutory basis for free personal and nursing care and the policy was implemented from 1 July 2002. (Scottish Government, 2009)

Accessing the service

Those wishing to access free personal care must be aged 65 and over. There is a national framework for eligibility criteria that local authorities should use in setting local eligibility criteria for access to personal and nursing care services for older people. Local eligibility criteria indicate what level of need councils and their partners recognise as requiring services. In setting such criteria, local authorities must have regard to a range of factors including the overall level of resources available to meet need, the cost of service provision and ensuring equity in their service decisions. Eligibility is based on a) the severity of the risks and; b) the urgency for intervention to respond to the risks. The eligibility framework prioritises risks into 4 bands: critical, substantial, medium and low. (Scottish Government, 2009)

A social worker in Glasgow informed us that end of life patients would generally be classed as needing immediate or imminent care and that palliative care patients should be given priority. Individuals are normally referred by their GP, a District Nurse or a Hospice and there is a ‘first stop line’ which can be called for an initial screening to be undertaken. Nonetheless, people at the end of life still have to undergo an assessment which is fraught with delay and the delivery of care is based on local protocols.

Before an individual may receive payment towards personal care the guidance is very clear that they must undergo an assessment. Since April 2004, all of community care has been covered by the ‘single shared assessment’ process meaning that older people do not have to undergo multiple assessments for community care. The assessment process is a two-stage process: first there is the assessment of needs and then, having regard to the results of that assessment, the local authority decides whether the needs of a person call for the provision of services. The operation of local eligibility criteria applies to this second stage of the assessment process (Scottish Government, 2009).

The Community Care and Health (Scotland) Act 2002 requires local authorities, following this assessment of needs, to take account of the views of individuals and their carers, as well as the care the carer is willing and able to provide, before deciding what services to provide to the individual. Actions are required to determine the personal care element individuals will be receiving, either to ensure they are not charged for it or to make arrangements for a payment towards their care. Home Care (or Domiciliary Care) continues to be available to provide services that extend beyond definitions of Personal Care (such as help with cleaning, shopping and other domestic tasks). These services usually carry a charge within a

'means testing' framework. Supporting People grants may also be available to assist people to maintain their independence (Scottish Government, 2009).

Challenges and successes

The free personal care policy is complex. It is embedded in political debates about devolution and Scottish and UK governance, and symbolises in many respects the ability of the Scottish Parliament to exercise power. It is not therefore surprising that much myth and counter-myth surrounds it and that continuing debate is ill-informed (Bowes and Bell 2009).

Free personal care promotes more 'joined-up' approaches, reduces means-testing and money worries, and enables informal carers to continue caring. Thus, it can improve clients' quality of life and support their care choices.

Nonetheless, there is a need for balance between nationally agreed priorities and local authority autonomy. Currently, the lack of ring-fenced budgets increases local authorities' autonomy in funding care provision. This may be advantageous in allowing responsiveness to local conditions, but also compromises national policy priorities.

Although the Scottish Government has laid down the legislative basis for free personal care and has provided guidance for local authorities, the interpretation and implementation is still very much down to individual authorities in practice. This has had a number of implications for the execution of the policy. However, there has been some Local authority interpretation criticism that some areas have considerable waiting times for assessment, and this may be used as a way of rationing the provision of free personal care, particularly for those at home.

Indeed anecdotal evidence from the social worker we spoke to in Glasgow suggests there is a lack of capacity in the system to meet the needs of those who require care quickly, there are long waiting lists and very slow assessment and decision making processes which means the needs of those at end of life are sometimes not met.

Further to this changes since 2001 in provision for nursing care throughout the UK and for personal care in Scotland have caused the funding of the care systems in different parts of the UK to diverge. Therefore, applying free personal care in other parts of the UK would be extremely complex. It should also be noted that payments for nursing care in Scotland are fixed at £65 per week; the highest rate currently payable in England is £129 (Bowes and Bell 2009).