Dying with Dignity

APPLYING PERSONALISATION TO END OF LIFE CARE

by **Simon Duffy**

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About the author

Simon Duffy

Simon Duffy is Director of The Centre for Welfare Reform. He invented individual budgets and self-directed support and led the reform of adult social care services as CEO of In Control from 2003 to 2009. Previously Simon developed a series of organisations and innovations in England and Scotland, including Inclusion Glasgow and Altrum. Simon has a doctorate in philosophy and has a special interest in better understanding and promoting social justice. In 2008 Simon was awarded the RSA's Prince Albert Medal for his work in developing personalisation and in 2011 the Social Policy Association awarded him with their award for Outstanding Contribution by a non-academic. Simon is also an Honorary Senior Research Fellow at the University of Birmingham's Health Service Management Centre and policy advisor to the Campaign for a Fair Society. Simon lives in Sheffield with his wife Nicola and their son Jacob.

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Preface

Anyone who has anything to do with the care of the elderly or the chronically sick in community settings knows that all is not well in the UK. Since the early nineties policy-makers have encouraged the healthcare system to be converted into a quasi-market system of care provision. In 2008, English health service policy recognised another category of provision, that of "End of Life Care"; and it is those patients that are due care at the end of life, that best reveal the flaws in the current system.

Epidemiology and pathophysiology of men, women and children nearing death dictates a variation in the quality and time of dying that leads to inevitable unpredictability of need in individuals. Any system that equates equity of provision with equal services for all is therefore simultaneously wasteful and inadequate for the one percent of our population dying this year.

The problem lies in the distance between the commissioner of care and the recipient. If we do not wish our building society to choose our house, why do we allow the health service finance officer to choose our circumstances at the time of death? Personal Health Budgets have the potential to tailor care to personal need and personal preference while eliminating waste.

In a strategic approach that is informed by the needs of the dying population, patients and their own health professional are in a position to trigger timely packages of care, without the arbitrary intervention of a remote, slowly moving bureaucracy. It is essential that any care coordinating centre puts patients, their family and their professional attendants in control.

The involvement of professionals may be the best safeguard against inadequate quality and waste. Involvement of the dying and their family may ensure that society begins to address its obligations to the most vulnerable.

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Summary

This paper proposes a Personalised Model for End of Life Care (PMELC), one which is both realistic and positive. If implemented this model would:

- Help more people die at home
- Help more families plan positively for death
- Make better use of existing resources
- Help professionals design more responsive supports

The **Personalised Model for End of Life Care** involves 4 key elements:

1. GP-led commissioning
2. Individual budgets
3. An expert coordinating body for palliative care
4. Community-based support systems

Putting the PMELC into practice would make good use of existing institutions and would be feasible within the current economic and political context and the proposed development of a tariff for End of Life Care. Although it would also require further thought and testing this could be safely done within existing constraints.

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Introduction

In England, by international standards, care at the end of life is good (Gray, 2011). Yet it could be so much better. We remain wedded to systems which struggle to provide the kind of timely and flexible support which will help people stay at home. We struggle as a society to think about, talk about and plan for our own deaths - even at the very end. Change will not be easy.

This report is a limited and early attempt to think through our alternatives. It uses some of the available data to make it much clearer how far we are from enabling us to die with dignity in a way of our choosing. It also demonstrates that the level of funding is not the problem - it is how that funding is used.

It also offers some different ways of thinking. We need to understand the value that personalisation - properly understood - can bring to the end of life. Not as some new funding mechanism, but as an approach that is rooted in a deeper appreciation of the nature of our humanity.

The report also offers a framework for rethinking the organisation of End of Life Care. This is not a simple model - there are too many variable to allow for a simple solution. Instead our model is a respectful way of building understanding, partnership, combined with better incentives to do the right thing for the individual who is at the end of their life.

It is good that the government is currently reviewing funding for End of Life Care (Palliative Care Funding Review, 2011). Our hope is that the kind thinking we explore within this report will be useful and influential in ensuring we really move towards a system that promotes personalisation and dignity and away from a system that promotes institutionalisation.

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Dying with Dignity

APPLYING PERSONALISATION TO END OF LIFE CARE

1. The Value of Personalisation

1.1 Outcomes in End of Life Care

The twin goals of End of Life Care (or palliative care) are to combine high quality medical care, (treatments that extend life), with a focus on maximising the quality of the end of life experience.

Often these goals are highly compatible and focusing on one goal naturally supports the others. Sometimes these goals are in tension and clinicians and individuals have to decide how to achieve the best possible balance between those two outcomes. From the perspective of the system as a whole these twin goals present two distinct risks:

- Some people may find that they are receiving medical care and attention when they would either prefer to be focused on living their last days in a different way. In particular (although this is to simplify a complex matter) people may prefer to be at home or with their family rather than being in hospital.
- Some people may find themselves not getting the right kind of medical care during their last days and may die with more discomfort or more quickly than was really necessary.

An excellent palliative care system will try to steer between these two risks and will have the following competencies:

1. Ensure that the person gets every chance shape the pace and character of their care during the end of life phase and to die a good death - with dignity
2. Provide expertise and high quality care in ways that are responsive and flexible both supporting the individual's choices and respecting their individuality and circumstances.
3. Ensure the community - both family, friends and the wider community - can prepare for and appropriately respond to the death of a loved one.
4. Make available a fair and reasonable level of resources to meet individual needs - without undue waste or institutionalisation.

The idea of personalisation - although it began with disabled people - is well fitted to offer insight into the kinds of systems that will help achieve these twin goals of palliative care and to enable the development of a competent system.

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1.2 Personalisation

The idea of a good death may seem paradoxical; but it only takes a little reflection to realise that how we die - how we live our last few days, weeks or months - is of tremendous importance. It is not only a defining end point to our own life - it is a critical moment for all those who love us.

How we, and those around us, respond to death will be altered by wider factors:

1. **Resilience** - how we respond to death will depend upon our spirit or attitude, this will then shape how we make use of the other resources in our lives. For some the role of faith and belief will be vitally important.
2. **Strengths** - we each have things we enjoy doing, books we like, music, hobbies, collections, housework - our tastes and pleasures, what we particularly enjoy. These things become particularly important and poignant for many people as life comes to an end.
3. **Relationships** - our relationships with family and friends will not only be the most important source of external support; often we want to see family and friends - to talk about the past and to remind ourselves of shared love or affection.
4. **Community** - towards the end of life it is likely that we will want to see and experience the familiar - our home, our street - places and people who have been important to us. For many there will be a strong desire to be 'back' in one's own bed - with one's own things.
5. **Control** - we value control, the ability to shape and direct the course of our life, although at the end of life we may not want to be distracted with technically difficult tasks, money problems or worries, or questions of employment. Control will tend be expressed by control of important details, environment and those with whom we spend time.

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Figure 1. The Five Dimensions of Real Wealth

These five dimensions are the dimensions of our Real Wealth (Murray, 2010) and they are expressed in Figure 1. When we make any decision these decisions are always informed by our understanding of our own real wealth (e.g. 'What would my wife like?' 'Can we afford it?' etc.).

Personalisation is an effort to systematically design systems that support the development and utilisation of these different aspects of our real wealth. It reverses the tendency of public services to define people as 'service users' or 'patients'. Instead personalisation recognises that the individual has a whole life, their own real wealth, and it works to enable services to fit into the context of that whole life.

1.3 Technologies of personalisation

Although personalisation is a powerful methodology for reforming public service systems it is still rather misunderstood. There is a tendency for commentators to focus on some of the most radical aspects of personalisation - such as individual budgets and direct payments - without understanding wider, and often more important, system changes.

It is more useful to understand personalisation in a broader way, as involving 5 systemic developments:

1. self-direction
2. community-based support
3. expert coordination
4. individual funding
5. coproduction

1. Self-direction

Personalisation assumes that people can and should largely shape their own pathway - getting the best possible advice as they do so - constrained by rules and resources that are fair and reasonable. For people who are dying and their families this means making increased control both possible and easy. Self-direction does not mean doing everything for yourself or taking on unhelpful burdens - it means setting the direction and making sure support and treatment fits within the wider context of your life.

2. Community-based support

Personalisation means investing in an infrastructure that can support and enable effective decisions - this will be a mix of professional and other supports. Professionals will ensure that their expertise is communicated in a number of ways to strengthen this architecture. However it is important to note that professional expertise will be at its most effective if it is used to guide, inform and teach others. This wider community support system will range from professional groups (e.g. general practitioners) to community and faith groups (e.g. local churches).

3. Expert coordination

Personalisation demands that professional systems focus on simplifying and clarifying the conversation that they have with the person. Much greater effort is required to ensure clarity about who supports the person with decisions and in accessing appropriate resources. While it will be appropriate for more complex cases to be seen by those most qualified to understand that complexity there is also a need to ensure that coordination at lower levels is sufficiently competent and supported. It is likely that a competent system of service coordination at the end of life would combine specialist support with support from GPs, practice nurses, ward staff and staff from the independent sector - including hospices and organisations like Macmillan Cancer Support.

4. Individual funding

Personalisation means getting resources to work effectively - this will often mean more individualisation and flexibility. There are at least 4 different funding systems that are useful for personalisation:

- **Vouchers & Prescriptions** - These are systems that enable people some choice and control but where professionals define the product, service or treatment to be purchased. They are most useful when there is reliable evidence that a certain kind of response is required, but several options for exactly how this is achieved.
- **One-off Grants** - These are arrangements that allow professionals to give people the means to bring about important changes in their environment, lifestyle or social arrangements. These are particularly useful for important one-off changes, particularly when a flexible intervention could bring about significant efficiencies.
- **Individual Budgets (or Personal Health Budgets)** - These are systems for assigning a budget to an individual that can be used flexibly to achieve particular outcomes. These are useful when needs are clear, but the particular response to those needs has to be personal, flexible and responsive. Individual budgets can be controlled by individuals, families, service providers, community organisations or professionals themselves - they enable a flexible and tapered system of control (see Figure 2).
- **Direct Payments** - These are systems for giving cash directly to an individual so that they can purchase their own support. It is useful where needs are clear and people have the desire and capacity to take full control.

Direct payments have proved for useful for people with disabilities and long term conditions because they give people direct control over the funding necessary for the delivery of any support services and enable people to employ their own staff. However they are unlikely to be as attractive to people at the end of their life or to families who are preparing for a death.

In the context of palliative care, direct payments will tend to be only useful in exceptional circumstances. It is much more likely that a system that allows for flexible grants or individual budgets that can be managed by others will be more effective for palliative care. Such a model will need to be compatible with and inform current tariff systems and the emerging work on the funding of palliative care (Palliative Care Funding Review, 2011).

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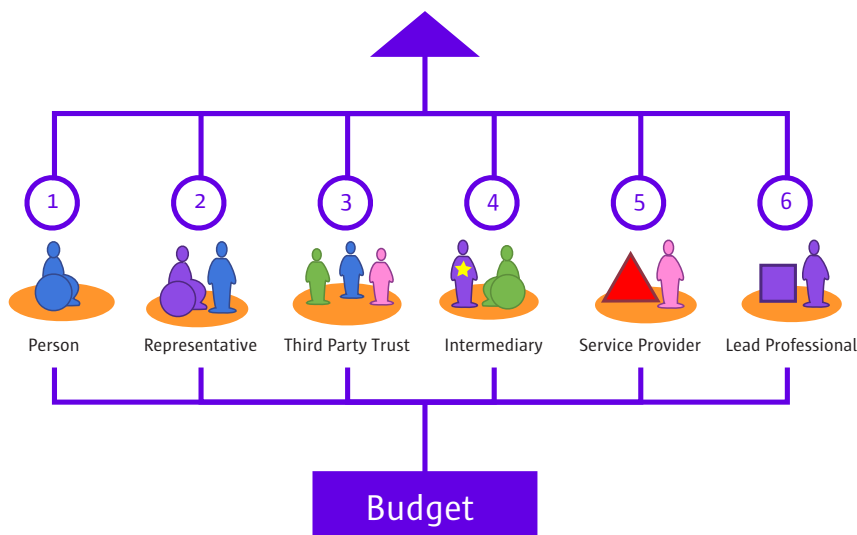
Figure 2. Tapered Control

5. Coproduction

Although the concept of personalisation seems to place the central focus on the person who is receiving support it is just as valid - and in this context perhaps more useful - to think of personalisation as a form of coproduction. That is, it is a way in which the professional and the citizen work together to achieve the best possible outcomes.

Coproduction stresses the need for the professional and the person to bring together different forms of expertise to develop the personal plan that makes the most sense. Resources need to be organised to support the fulfilment of this plan as is shown in Figure 3.

In the rest of this paper we will explore some of the issues that make applying personalisation and coproduction in palliative care different to the areas where it first developed. We will then suggest a number of ways in which suitable adaptations could be made to ensure personalisation could be effective in palliative care.

Figure 3. Coproduction in Palliative Care

2. Personalisation in Palliative Care

2.1 Decision-making in Palliative Care

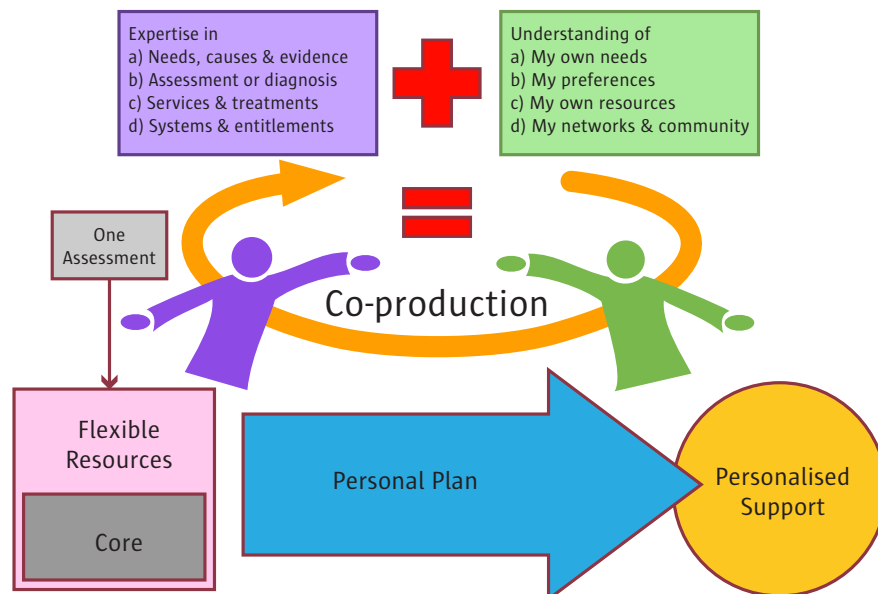The limited value of Direct Payments in palliative care is only one example of the need to think carefully about how to develop these personalisation technologies within the context of palliative care. There are also several other good reasons to think that personalisation will need further development or adaption to work in the context of palliative care. The following factors seem particularly important:

1. **Unexpected death** - Many people die suddenly or unexpectedly. Whether the cause of death is an unforeseen accident, an unusual and undiagnosed condition or a sudden complication of a diagnosed condition these circumstances make the planning of end of life care impossible. Of course there may be measures that would have enabled prevention or an earlier diagnosis or better prognosis - but for the purposes of this paper those factors will not be considered. Instead it will be necessary to accept that some deaths will occur in ways which are unexpected and which fall outside any system of palliative care.

2. **Uncertain prognosis** - It is sometimes possible to say, if a condition has been successfully identified, that an individual will suffer an early death. But there is still often a high degree of uncertainty about when such a death may occur. This is a very important factor if it is also the case that high quality care also needs to be an intensive form of care.

3. **Uncertainty of decision-making** - Often people will not have thought about their deaths or will find themselves changing their thinking as death approaches; fear and uncertainty is a feature of approaching death. People's thinking about death and treatment will also vary in both directions. Some people will be eager to pursue every avenue for extending life - right up until the end of life; others will be more focused on their quality of life and the ability to stay at home. Moreover people who initially take one approach may find themselves shifting their perspective as they approach death. Although planning and the opportunity to reflect more deeply about the end of life may lead to more clarity it will be impossible to rule out changes in perspective.

4. **Family and friends** - The end of life is a time of grief and people need help and support and will not always feel able to take on responsibilities or make decisions. It is not reasonable to simply assume that family and friends can provide support or manage problems on their own. However its also important to remember the reverse; in fact most care and support is provided by family and friends and the primary role of professionals must be to support the individual and their family through the final days. In the UK the current estimate is that families provide six times more care than paid professionals. Successful support will often mean strengthening the capacity of the family to cope and provide direct support themselves.

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All these factors reinforce the fact that someone who is dying is not to be treated as simply a consumer or confident rational agent who can simply be left to get on with making their own decisions. However it is also a mistake to think that personalisation requires people to be confident and rational decision-makers. Personalisation is powerful because it helps people make sensible decisions - together - in difficult and uncertain circumstances.

In fact it is at least arguable that the likely value of personalisation in palliative care reflects the fact that many of the factors that will make for a good death can only be understood from the perspective of the person. Straightforward clinical questions of life and death diminish in importance. In their place are left questions of how someone wants to live their last days - **these are personal questions**.

2.2 Principles for a more personalised system

It is also important to recognise that personalisation is not simply about the narrow questions of individual choice. Choices are framed by wider systems - social norms, organisational structures and community resources. If we want to help people achieve good deaths then we may also want a model that has the following features:

1. **Neighbourhood-based** - most people would get their support from local agencies, people, families and this would be coordinated from within neighbourhoods.
2. **Provides experts as educators** - experts in palliative care would support people with information, skills, training and approaches to care.
3. **Makes personal control easy** - control and decisions would be with the person dying or with someone close to them.
4. **Offers flexible resources** - care would be whatever was most likely to maximise someone one's well-being, control and dignity.
5. **Timely** - there would be the smallest possible delay in adjusting the level of support to help someone manage their own situation and maximise their capacity to stay at home and die well.
6. **Positive** - people would plan for their death or the death of a loved one in a way which maximised dignity and avoided unnecessary pain, confusion and misery.
7. **Avoids crisis** - people would not go to hospital to die when hospital cannot offer any further useful help or helpfully lengthen life.
8. **Avoids bureaucracy** - people would not find themselves confronted with peculiar bureaucratic burdens or responsibilities that add to their worries.
9. **Avoids organisational confusion** - different systems overlapping and debating - especially health and social care.

These are the nine principles that have guided the discussion that follows. Self-direction and personalisation are necessary to a good system; but they are not the only important principles.

3. End of Life Care in Practice

End of Life Care (EOLC) begins when someone is diagnosed with a condition which (if you don't die of something else) will cause you to die within one year. Nationally it has been estimated that £20 billion is spent on EOLC - a little less than 20% of the NHS budget. For an average GP practice with 5,000 patients about 50 patients will die each year.

Each year 5,000 people die in Sheffield. Of these 3,000 people die in hospital and 175 die in the Palliative Care Unit (PCU). However the PCU provides assessments to 3,000 people of whom 50% get some kind of end-of-life support. Overall only 17.2% of people died at home (See Table 1).

Place of death	Percentage
Hospital	59.0%
Hospice	5.3%
Care Home	16.4%
Home	17.2%
Elsewhere	2.1%

Table 1. Place of Death in Sheffield

Many people die unexpectedly or from causes that are not identical with their diagnosed condition. However, an analysis of all deaths in Sheffield identified that only 8% of those deaths were unexpected (See Table 2) and most deaths were associated with frailty, cancer or chronic conditions. If you have cancer your chance of dying at home is higher - but is still only 24%.

	Cause of Death	share of whom died at home
Cancer	30%	24%
Chronic Disease	20%	21%
Frailty	42%	8%
Unexpected	8%	7%

Table 2. Cause of Death in Sheffield

Moreover national and local analyses point to a paradox. While most people die in hospital most people say they would rather die at home. Moreover for those who die in hospital many surveys seem to indicate that, perhaps as many as 50% of those who die in hospital, suitable care could have been organised to enable discharge.

Not everyone who dies in hospital could be safely supported to die at home or in a less clinical environment but this would be possible for a significant proportion, if care packages could be developed quickly enough. A review of the case notes of 200 of the

patients who died in Sheffield in 2007 found that 80 patients (40%) who died in hospital could have safely died at home or in another setting. Figure 4 shows the possible alternative place of death and the cause of death (Balance of Care. National Audit Office End of Life Report (2008)).
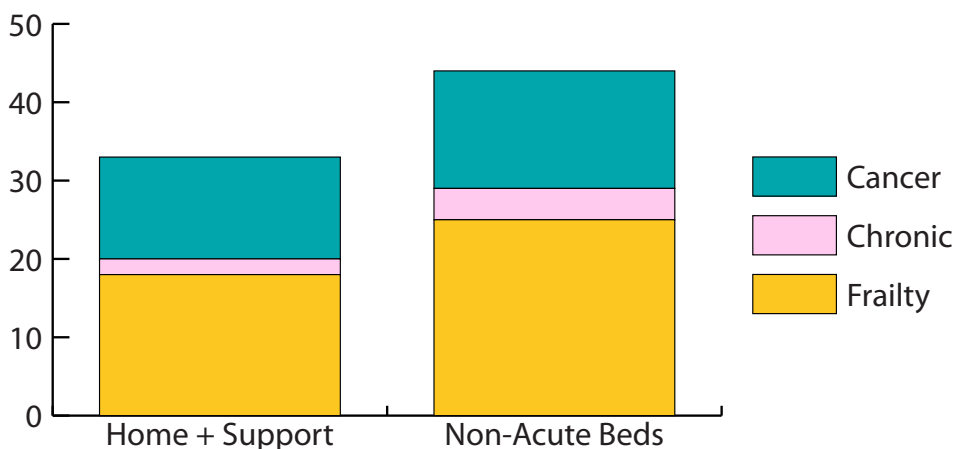

Figure 4. Analysis of Cause of Death and Possible Alternative Place of Death

It would appear that one of the main reasons why individuals who would choose to die at home end up dying in hospital is that existing services do not appear to support people in choosing to die at home. In the case of Sheffield, the following service constraints were identified:

- A review of Sheffield's Intensive Home Nursing Service identified a significant lack of capacity in the service to support people to die at home.
- A review of palliative care services in Sheffield found that outside cancer care, few patients who died were known by palliative care services. A large number were, however, known by social care.
- Most decisions about death in end of life services were taken in the week before a patient died, making it hard to make arrangements or meet an individual's preferences for where they died.
- Other important factors may include the fear of family and nursing care home staff that they cannot cope or the lack of flexible support or education for families or care home staff. For example, families may need to change work and care patterns in order to cope and yet no support is available for this.

Moreover, given the particularly high-costs associated with acute hospital beds it would seem to benefit everyone if the over-use of acute hospital provision could be minimised.

The 80 patients for whom alternative places of death were identified used 1,501 bed days. This is 19 days in hospital per patient that could have been avoided for those particular patients. The average per patient of these unnecessary hospital deaths was £4,609 (based on a conservative cost per inpatient day of £250 which is roughly in line with current tariffs).

There are 5,000 deaths a year in Sheffield and 3,000 of these are in hospital. If 40% of these did not need to be in hospital we go on to assume that 40% of all existing hospital deaths in Sheffield were did not need to happen in hospital then this means that 1,200 people could have died elsewhere. This also suggests that up to £5.5 million was spent on hospital services that were not needed.

As part of understanding the likely financial impact of extending personalisation to palliative care we also examined the cost of nursing homes and end-of-lie home care packages put in place through the NHS fast-track for continuing care. Table 3 below sets out the main findings. This data is only for the financial year 2009-10 and it includes people who were still living at the end of the year.

		Average length	Expenditure	mean daily rate
Total Number of People	471	70.7	£1.59 million	£71.60
Number in Nursing Homes	242	71.1	£1.08 million	£85.27
Number with support at home	229	70.3	£0.52 million	£57.16

Table 3. Fast--track Care Packages in Sheffield

This data is interesting for a number of reasons:

- It is significantly less expensive to support people outside hospital than within hospital. Hospital care is 3.5 times more expensive than non-hospital care and 4.5 times more expensive than care at home.
- It is significantly less expensive to support people to be at home, where most people (at least in principle) say they would prefer to die than in nursing or care homes. Care homes costing 1.5 times more than care at home.
- Funding for support at home, rather in a care home, seems to last almost exactly the same amount of time as being supported within a care home.

So again we are faced with a similar imperative - to make it easier and more effective for people to get any necessary support to enable them to die at home if that is feasible. Personalisation - which is primarily an approach that builds on natural and community assets and reduces undue reliance on standardised solutions would seem to offer some positive options.

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4. Applying Personalisation

Just as it is a mistake to imagine that personalisation is all about direct payment or individual budgets so it is a mistake to think that personalisation is a fixed model which can be imposed on something as complex as End of Life Care. In fact many of the methodologies which have been deployed by Adult Social Care services under the banner of personalisation cannot be exported into healthcare and do not define personalisation. In fact it can be useful to distinguish four different uses of the term personalisation (see Figure 5):
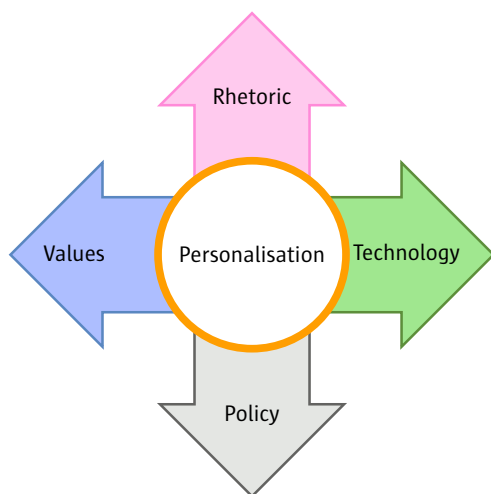

Figure 5. Different Uses of the Term Personalisation

Rhetorical - there is a tendency to use the term in a way that is appealing but which is empty of any specific content. Personalisation in this sense is an attempt to direct people towards more flexible and person-centred ways of working; but often it means little more than that.

Policy - there is also a tendency to use the term personalisation to describe government policies that seek to 'promote' personalisation - however there is often a rather loose relationship between policy goals, the regulatory framework and practice on the ground.

Technological - the practical technologies of personalisation were developed by social innovators who were seeking to make improvements in society and public services: direct payments, individual budgets, support planning, personalised support etc. These technologies are essentially modifications of existing systems and can only be evaluated in that light.

Values - there are ideas and values behind the technological developments that are associated with personalisation. Many of the key innovators of personalisation are motivated by desire for greater social justice, increased control for citizens and a stronger role for both families and communities in society.

What this means in practice is that applying personalisation into End of Life Care will only work if there is an attempt to innovate and improve existing systems by people who are prepared to examine existing systems critically, with a positive commitment to collaborative change. Any attempt to 'impose' personalisation on existing systems - especially new systems for which it has not been adapted - will fail and will be a waste of time and effort.

The opportunity is to avoid making this mistake and, instead, to work collaboratively towards developing better systems. It is in this spirit that the following thoughts are offered about how to reform End of Life Care.

4.1 Building on current resources

There are several sources of funding which are directed towards people who are at the end of their lives:

- NHS funding within General Practices
- NHS funding within Primary Care services
- NHS funding from the NHS CHC Decision Support Tool
- NHS funding from the Fast-track Pathway Tool
- Local Authority Social Care funding (children and adults)
- NHS funding for people in hospital beds (tariff-based)
- NHS and charitable funding for places in hospices
- Funding from charities, e.g. Macmillan Cancer Support, Marie Curie
- Carers Resources, e.g. Carers Centre

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The current pattern of NHS provision is certainly not simplistic nor monolithic. Moreover each of these different sources of funding reflects the important role played by different stakeholders within the wider community and within different public services.

The proposed model aims not to threaten or control all those resources, but instead to work mindfully towards their better coordination around individual and community solutions. Existing services and service structures are capable of changing and adapting to new ideas and taking on new roles; however this requires genuine efforts rooted in an understanding of front-line practice.

4.2 Framework for personalisation

At the risk of simplification the proposed model for personalisation has four major components:

1. **Community-based support** - The social and economic supports that exist for people and families in ordinary communities and neighbourhoods.
2. **Primary Care** - In the UK primary care is led by the GP and is the first gateway to all forms of healthcare and is often an on-going partner in someone's management of their own health.
3. **Specialist EOLC -** For example, in Sheffield, focused expertise about EOLC exists within the Macmillan Palliative Care Unit and other important specialist structures (including hospices like St Lukes).
4. **Acute Hospital Care** - Acute hospitals are the places where most emergency or complex healthcare is delivered.

As we have seen, in the current system there is a strong gravitational pull towards acute hospital care - despite the people's preferences, despite the cost, and despite the existence of alternative forms of support. The following framework tries to use all the energy of the different partners - but in a way that focuses on avoiding unnecessary hospitalisation (see Figure 6).

We will go on to explore funding options for this model below - and given the policy uncertainties at the moment it would be wise to be pragmatic. However the practical consequences of the model would perhaps be:

1. **Community-based support** - Public services need to focus on identifying, connecting to and supporting community and neighbourhood sources of support. There will be distinct roles here for GPs (based in specific communities) and Specialist Services (with topic-based expertise). But it is particularly important that each can provide both flexible financial support (where necessary) and, more importantly, guidance and expertise. In particular people may need help to access community resources that they may not be aware of. Community-based support extends from national charities, (e.g. Macmillan Cancer Support) to local groups (e.g. a local church).

2. **Primary Care** - For many people the GP-led community health care service may be enough to support people successfully in the community. If there are about 50 deaths a year per GP practice the need to focus on supporting the best deaths for local people should be paramount. It may be particularly useful if funding for flexible support or short-term grants was better delegated to GPs. Or, if that proves too risky for GPs, it will be necessary ensure that they have ready-access to such support from a clear coordinating body.

3. **Specialist EOLC** - The specialist End of Life Care service should play a vital role in supporting and educating both the wider community and other professionals. Moreover there is great value in building on its strategic leadership and ensuring that there is a coordinated effort to drive forward progress across the wider community. Flexible resources could be managed for the whole city from within the team - this could speed up decision-making, cap risk and shift the balance of incentives in the wider system towards non-hospital support.

4. **Acute Hospital Care** - Acute hospitals must be treated as assets in this model. Current incentives seem perverse - although tariff payments are much lower over time - they still run at rates that are higher than the cost of community or other care options. Clearly there is also an important role for coordination and organisation of discharge on the ground - although again - GPs or specialist coordinators may actually be better equipped to make the necessary judgements of risk and to ensure appropriate services are in place.

The proposed model leaves many unanswered questions; and this is as it should be, as it is only through piloting and experimentation that such a new model could be delivered. It is only the piloting process itself that will answer these questions.

However what the model does do is demonstrate that a collective approach, one which respects the different roles of the existing services and professionals is feasible. Innovative approaches are often undermined by simplistic understandings that create 'winners' and 'losers' and this in turn leads to organisations and professionals responding to possible changes in a more defensive and less open spirit. This is fatal to real innovation.

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Instead our model offers a respectful framework, building on current strengths, but inviting all parties to participate in a shift in focus towards the patient. This kind of systemic approach is also being used in other areas in order create the conditions for positive systemic change (Fisher, 2011).
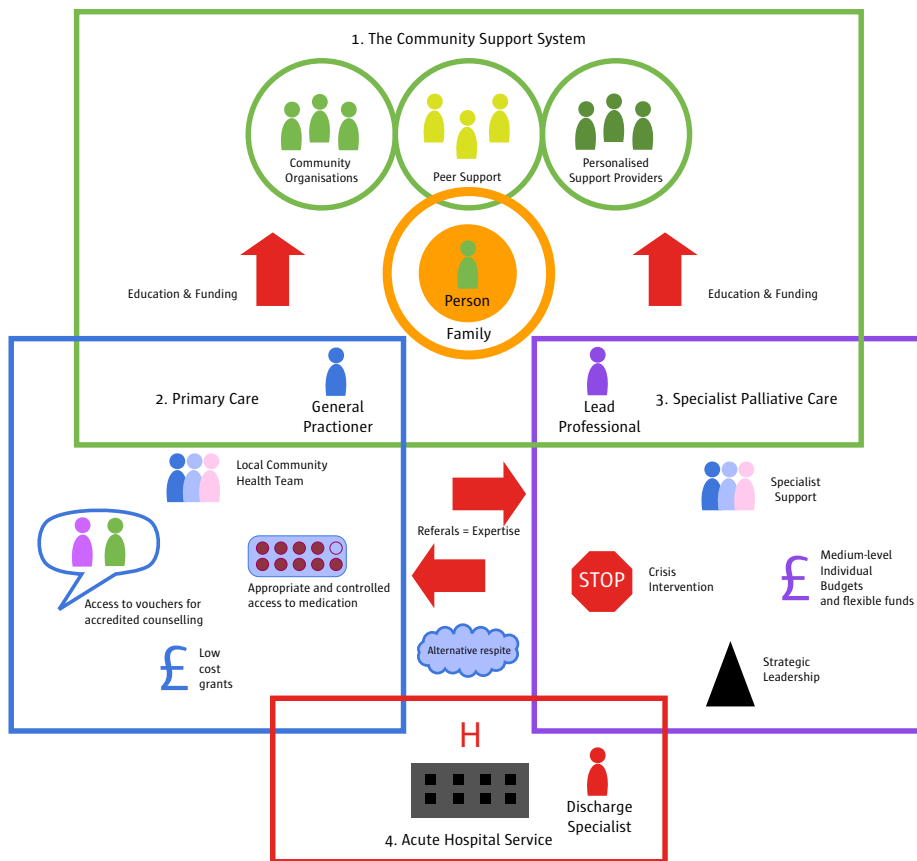

Figure 6. Personalised Model for End of Life Care

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5. Innovations in End of Life Care

If we work within the model as it is outlined above we can also identify a range of possible innovations which could be developed over time to increase personalisation within End of Life Care.

1. Funding innovations

The community includes families, friends, neighbours, volunteers, charities, local businesses, care agencies and care homes. Currently any funding available tends to be rooted in PCT and local authority commissioning arrangements. So some other options seem appealing:

- If decisions about funding can be moved closer to the front-line, be made speedily and with full knowledge of local resources then the capacity to engage community will be stronger.
- If the flexibility of those resources increases then better use can be made of community options.

These kinds of approaches might include all of the following options:

Individual Budgets - Create a system of individual budgets (known with the NHS as Personal Health Budgets) for people who need on-going support by developing a Resource Allocation System that enables resources to be identified quickly and appropriately.

Budget-holding by Lead Professionals - Give front-line practitioners a flexible and capped budget that can managed directly to respond to immediate problems quickly using professional discretion.

Individual Service Funds - Give service providers the freedom to manage flexible budgets (sometimes called Individual Service Funds) on behalf of individuals. This would avoid burdening individuals and families and reduce any risk that of over-payment to grieving families.

A recent pilot in Doncaster used individual budgets to support a man at the end of life. According to Debbie, the man's daughter:

> *Dad died on 23 December 2009. In the end he only received his Personal Health Budget for two and a half months. However, the pilot scheme helped transform our lives beyond recognition. Had the Personal Health Budget not been in place I would never have forgiven myself if I had been forced to move Dad out of my house and into a nursing home. The Personal Health Budget worked well for me because I felt in control. Previously it felt as if care was "done to us". A Personal Health Budget made Dad and I feel as though we were valued participants.*

2. Support innovations

Whatever model is applied it will be crucial to ensure that front-line practitioners - working in direct partnership with people - can make resources work as hard as possible to give people the best death possible. In practice this should mean:

1. Improved service coordination
2. Adapted environments
3. Family-centred support
4. Personalised plans and information

Service coordination

At the end of life few people are likely to want to manage budgets or to directly employ staff themselves. However it may make sense to give an Individual Budget to someone close to the individual (a professional or a family member) who can then manage the budget flexibly to ensure:

- Professional support and family support are coordinated
- Support is sensitive, appropriate and respectful
- Rapid response to changing needs
- Life can still be lived to the full

High quality care and support is vital at the end of life; but it is not an end in itself. It is there to serve the individual who will want to ensure they can spend their last days in ways that they value.

Adapted environments

One of the advantages of Individual Budgets is that they can be used to help create the conditions by which people can live at home or with their family. In order to make this possible it is often necessary to find ways of paying for:

- Expenses
- Physical adaptations to buildings
- Equipment, wheelchairs and transport
- Alarms and tele-healthcare

These kinds of one-off costs can change the physical and social environment for the individual and can make it much more likely that they can die in a place that is right for them. This does not always mean that individuals buy their own equipment - this approach needs to be linked to effective use of equipment stores and leasing arrangements.

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Family-centred support

Most care and support is provided by family and friends. Moreover, at the end of life, love and relationships become increasingly important. So it makes sense to provide End of Life Care in a way that is family-centred and encourages and supports families to be part of the support arrangements. This may mean:

- Enabling respite for family
- Economic help or jobs for families
- Practical help around the home
- Giving families more control

Overall all of these changes require that resources can be used more flexibly. Paradoxically, allowing money to be spent on a wider range of things can be more efficient than restricting expenditure to expensive professional or institutional solutions.

Personalised plans and information

Bringing all of these different elements together involves promoting systems that make it easier for people to plan and respond to crises in ways that are personalised and robust. It will be particularly useful to make use of technologies like:

- Advanced directives
- Person-centred support plans and individualised working policies
- Online medical records (for example see www.paers.net)

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Any system that removes professional distance and puts useful information into the hands of family or staff on the ground will be a powerful tool for avoiding the fear and anxiety that often drives emergency hospital admissions (from homes and care homes). In addition familiarity with person-centred planning approaches will help families to think more positively about even the most difficult of situations.

3. Primary Care innovations

If GP practices (or consortia) were commissioning support for people from community options directly then they may find that they have a better incentive to promote efficiency and improve local practice. If we look at the range of costs for non-hospital options we find that while the average per capita cost is £3,375 the largest cost is over £25,000, although as we can see from Table 4 the risk of a any package costing over £20,000 is less than 2%.

Package costs	Number	Risk
> £20,000	8	1.6%
> £10,000	35	6.8%
> £5,000	92	17.9%
≤ £5,000	379	73.7%
	514	

Table 4. Distribution of Per Capita Package Costs

The risk to an individual practice of managing these package costs depends upon the overall financial context of the practice, the degree of slack between different funding sources, the ability of practices to carry savings or overspends over time and size of the practice. Furthermore it would also be possible for individual practices to carry such a risk and then pool the risk by some kind of collective city-wide system.

Of course the primary financial benefit of managing this risk would be to reduce the use of hospital beds and, as we have seen, the earlier data suggests that if a hospital bed is costing £250 per day for an average of 19 days for people who could have come home or used some form of residential care. This expenditure of £4,690 compares with the an average care at home cost of £1,072 for the same period.

Hence this suggests that up to £3,618 might be available per death to be invested elsewhere. For a single practice this would provide £180,000 per year that could be invested in local community services. In reality of course the figure may be lower, the daily rate may need to be increased, nursing home costs are higher and life could be extended further outside hospital.

Nevertheless this implies that, in principle, there could a powerful financial incentive to get people home (if the system were to be restructured correctly). But this incentive may or may not be enough to encourage GPs to take on the risk of increased costs for those who do not die very quickly. This raises the question of to what extent a GP surgery would seek to take on the risk and possible benefits of self-managing End of Life Care or whether it would seek to pool risk in some other way.

4. Specialist Care innovations

Specialist care offers a number of additional benefits and options. The central strategic question would be to determine to what extent its role could be developed to act as central hub for End of Life Care. The hub could provide:

- A flexible funding stream to purchase appropriate support
- Local support and service coordination, underpinned by
- Training and support from expert practitioners

This would create a form of vertical integration and support. Individual funding may be used to purchase support from a mixture of:

- GP services
- Community services
- Care homes
- Hospices
- Flexible individual budgets

The hub could be funded either by:

1. Block funding from GP commissioning consortia or
2. Individual tariffs agreed with consortia for individuals who went under the care of the hub
3. Using some kind of risk-pooling approach where the hub provided both technical expertise and cover for high-cost cases

By pulling together sufficient cases the hub would also effectively insure GP practices from the impact of the most costly patients (those needing long term and high cost ongoing support). In addition funding and assessments could be integrated with the local authority - providing full health and social care integration.

5. Acute Care innovations

It remains important to see acute hospital provision as an active player within the local system. It would seem counter-productive only to see it as a drain on resources and only to create better positive incentives for other organisations. It may be more useful to construct a model that sees discharge and prevention as the business of the hospital and to reward it for success in these approaches. Such a partnership model may make more sense than a more punitive tariff based approach. Recent work in Lewisham may provide a better model for rethinking commissioning along more community orientated lines (Fisher, 2011).

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Conclusion

The Ancient Greeks used to say that no man could be deemed happy until they were dead. They took the view that you had to measure a life in the whole - including death. While this view may seem alien to the modern world it may be helpful to maintain the same perspective when it comes to judging the value of our healthcare system.

We will all die. So, while we must evaluate our healthcare system by its effectiveness in giving health, we must also look at whether it also gives dignity in death. For most of us being in a foreign environment, surrounded by equipment, strangers and professionals (however well-intentioned) will erode the value of our last weeks, days or hours.

As we have tried to show in the analysis above, reversing the current trend for over-hospitalisation in death will not be easy. No budgetary system, organisational structure or new professional role definition will make the difference. The momentum that drives us towards hospitalisation is subtle and cultural and it is not just a reflection of the values within professional systems. **Each one of us has to face the reality of death and the limits of healthcare; each one of us has to evaluate what really matters at the end of life - to us. We have to do this for ourselves and we have to do this with those we love.**

Above all what this paper tries to do is to show that change is possible. If we address the real barriers to change and explore a combination of systemic and cultural measures we can make a difference to how we die. We can make dying with dignity the norm and not, as it is today, an exception.

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