



**Compassion in Dying response to the
Green Paper consultation**

Shaping the Future of Care Together

November 2009

Introduction: Compassion in Dying

Compassion in Dying works for the welfare of people who are at the end of their lives. Compassion in Dying is a registered charity which was founded in 2007. We work alongside the non-charitable lobbying organisation Dignity in Dying. Compassion in Dying was set up to take over and expand the charitable work identified by Dignity in Dying as a by-product of their campaign for greater choice, control and access to services at the end of life. The two organisations share premises and some staff but have distinct aims and are governed by separate Boards.

Compassion in Dying's vision is for everyone to be able to access the care and support that is right for them at the end of life. This means:

- Access to expert information about end-of-life options;
- Support to make informed choices;
- Care from the provider that the patient feels is the most appropriate.

Response to consultation questions

Consultation question 1:

We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- prevention services
- national assessment
- a joined-up service
- information and advice
- personalised care and support
- fair funding.

a) Is there anything missing from this approach? b) How should this work?

Compassion in Dying response:

- On prevention services:

Compassion in Dying supports better investment in prevention and rehabilitation services to keep people independent for as long as possible. This will help people to receive care and support at home for much longer, and we know that this is important to many terminally ill people. While the majority of people would prefer to be cared for and die at home, 6 out of 10 people spend their last days in hospital¹.

Therefore, information about prevention and early intervention must be made widely available to the public. People want a system where they get the right support early enough². They also want to know what care and support services will be available to them so they can plan for their care; and stay well and independent as long as possible.

If, towards the end of their life, people feel very strongly about accessing prevention services in order to receive care and support at home, they can set out these wishes in an End-of-Life Care Plan. The *End of Life Care Strategy*³ states that health and social care staff should accommodate the wishes set out in the End-of-Life Care Plans as far as they possibly can.

The feasibility of accommodating a person's wishes in relation to care needs to be discussed at the time of the individual care assessment.

Reducing the need for care and support by investing in prevention services will improve individuals' quality of life while enabling the Government to do more with less money. Past initiatives, outlined in the Paper, need to be extended to go beyond older people.

As outlined in the Green Paper, it will be useful to further develop the evidence base on what works best for those needing care and support, and what gives best value for the resources invested. In addition to an independent body to provide advice on this issue, third sector organisations will have considerable expertise and valuable insights to offer, based on their experiences.

All the services involved in providing care and support in the context of prevention and early intervention must work closely together. The importance of integrating services in this context was also highlighted in the *High Quality Care For All: NHS Next Stage Review Final Report*⁴, which announced the trial of new integrated care organisations, bringing together health and social care professionals from a range of services. Close collaboration between all the services involved will be vital for the adequate and efficient functioning of any care and support system aimed at prevention and early intervention.

In the context of supporting people to stay at home and live independently as long as possible, Compassion in Dying supports the use of technologies such as "telecare", (this is covered in more detail in the information and advice section).

- On national assessment:

Compassion in Dying strongly supports the right for people to have their care needs assessed in the same way, wherever they live in England. This will make the care and support system far more predictable than it is now. People have the right to know what level of support and care they are entitled to in the different parts of the country. As pointed out by the Equality and Human Rights Commission, "equality and human rights outcomes are most likely to be achieved where people receiving care and support are able to move from one local authority area to another in the confidence that they will continue to receive an equivalent level and quality of support in their new place of residence, at least for an agreed transitional period."⁵

Compassion in Dying welcomes a new assessment process in order to tackle the existing postcode lottery in terms of the availability and offer of care and support services across the country. A "portable" assessment is essential in order to ensure that people are supported fairly wherever they live. The introduction of one assessment that will consider all the individual's needs, means and eligibility will also make the system far more simple and user-friendly. It will prevent people from having to answer the same questions over and over again.

People's needs change over time. Compassion in Dying attaches great importance to ensuring that reassessment takes place on an ongoing basis.

Compassion in Dying would also like to emphasize the need for integrating the needs and wellbeing of a person's loved ones and carers, if the person is being cared for by a relative or friend. It is vital that carers are involved in discussions around the care and

treatment with the person they are caring for. In particular, Compassion in Dying suggests setting out the right to a carer's assessment more clearly. (This will be discussed in greater detail under the section on carers).

Specifically for terminally ill people, the End of Life Care Strategy provides for all people approaching the end of life to have their needs assessed, their wishes and preferences discussed and their choices recorded in a care plan. Though not legally binding, health and social care professionals have a professional obligation under the Mental Capacity Act to take any wishes and preferences, as expressed in an End-of-Life Care Plan, into account. Given the importance the End of Life Care Strategy attaches to care planning for people who are approaching the end of life, it is important for all staff involved in conducting individual care assessments to be aware of the concept of End-of-Life Care Plans.

- On a joined-up service:

Compassion in Dying supports an integrated approach towards care. In order to enable a system of personalised care, the different services that a person needs must work together smoothly. Better joined-up working between health, housing and social care services would make a huge difference to the quality of care that is currently provided.

Regional and local initiatives have demonstrated the many different ways in which to improve working together to provide better and more cost-effective services for people who need care and support without necessarily involving organisational restructuring. Compassion in Dying welcomes the recently established Ministerial Group on Integration of Health and Social Care Services that will build further on what has worked well in places round the country to push forward joined-up working; as well as identifying the barriers to integrated working which government needs to remove. The new assessment process will also be an important means of considering people's individual needs, means and eligibility in a more joined-up way.

Joined-up working is particularly important for terminally ill people. In terms of end-of-life care, social care needs to link up with all the different services a person (and their family) receives towards the end of life. The End of Life Care Strategy rightly puts great emphasis on the coordination of care for people who are nearing the end of their life, across sectors and at all times of day and night. People may require services from multiple agencies and in different settings at different times. It therefore is essential that all the services which the person needs are coordinated effectively. According to the Strategy, each local health economy needs to establish mechanisms to ensure that each person approaching the end of life receives coordinated care. It is vital that social care services are fully integrated in this approach, for example, social care workers may need to be aware of a person's wishes as set out in their Advance Decision or End of life Care Plan, or need to know who a person has pointed as their Attorney (using the Lasting Power of Attorney legal tool under the Mental Capacity Act) the health and welfare decisions.

In order to realize a more joined-up system for the provision of care and support, Compassion in Dying agrees that changing mindsets and understanding is primary to structural changes. It is therefore crucial to raise awareness among staff in order to increase their willingness to work more closely together. Any future strategy aimed at improving joined-up working will need to highlight the importance of adequate education and training for staff on this matter.

Case study – Nicola and Alan⁶:

At the beginning, it seemed we were getting enough support, but that was because we didn't need much at that point, and preferred to do things ourselves, while we could. In reality, there wasn't a properly coordinated approach to the physical effects of the disease. Such an approach from an early stage, with increasing help as the disease inevitably made life more and more difficult, would have spared a lot of frustration and despair. The frustration and despair, caused by a complete lack of joined-up thinking and action, served to make the emotional difficulties of living with the disease, even harder.

- On information and advice:

Good information and advice is crucial in order to enable people to make informed choices about the care they wish to receive. Government has a major role to play in making sure that information about care and support is easily available to people.

Case study – Nicola and Alan⁷:

... It was also clear that we needed a specially adapted mobility vehicle as I was finding it extremely difficult to get Alan in and out of the car on my own. Before we made the decision on a suitable vehicle, the hospice occupational therapist recommended that we should go to an assessment centre, where we would be given advice on a suitable vehicle, or modifications to a vehicle. Incidentally, I had no idea that we should have had access to the social services' occupational therapists....

...The doctor came to assess Alan for the environmental control system. A visitor from the NHS had already been to see us and explained that, because Alan had MND, he could be 'fast-tracked', and for that same reason, we wouldn't have to pay for the equipment. Means-testing was not required. This was a first for us, and music to our ears. At the very first meeting for the system, we were told we had fallen upon one of the best kept secrets of the NHS. Why a secret, when people have such a real need for it?

...We were also put in touch with Crossroads, an organisation that supports carers at home. This organisation, with its own carers, was able to give far more support than we had previously been led to believe. When I was first advised of the organisation, I was told that their resources were under considerable pressure.

....As a result, I had not pursued it before. But now we learned that, given the nature of MND, and its effect on the main carer, we would be considered a priority, and the carers were able to assist in personal care. As a result, I had the help of a Crossroads carer support worker for a few hours during the Saturday and the Sunday of the last two weekends of Alan's life.

By making more extensive use of information technology (such as the Internet) for providing information to the public, Government will help to ensure that people are adequately informed and can act more proactively to have their care needs met. However information and advice cannot be exclusively provided over the internet or through 'technology'. For some people traditional methods of information dissemination are more accessible – so information must be available in a variety of formats.

Taking the ideas at the heart of this consultation forward, it will be vital that people have a clear understanding of what counts as social care, and what counts as health care, particularly given the proposed plans around insurance. It is also very important for people to know what they can expect. In relation to the planned reform of the care and support system,

people currently receiving social care support and related benefits will need clear information about what will change for them once the changes set out in the consultation come into effect.

It is also particularly important that people are made aware of their right to have their needs assessed. Local authorities have a duty to inform people, and their carers, of their entitlement to a needs assessment. These assessments are vital given the fact that people want the option of meeting someone face-to-face to discuss their care and support needs and how to get the services they want.

More specifically, for people who have appointed a Lasting Power of Attorney to act for them once they have lost capacity, there needs to be clear information about what decisions around social care an attorney will be able to make for them with regards to social care provision and payment.

Finally, Compassion in Dying welcomes the reference to the important role for third sector organisations in providing information and advice to the public. Compassion in Dying is planning to develop its role in providing information and advice by setting up a dedicated information and advice service to provide up-to-date and reliable information about rights at the end of life, advice about care and treatment options and free documents such as a Guide to Rights at the End of Life and Advance Decision documents.

- On personalised care and support:

Compassion in Dying welcomes the proposed reforms aimed at pushing forward the more personalised approach to service provision.

People increasingly want to have their say about the care they would like to receive at the end of life. A survey commissioned by Dignity in Dying showed that 65% of people think they would be more likely to have a dignified death if they could discuss and record their wishes around care and treatment at the end of their lives. 67% of people say that an End-of-Life Care Plan is a good idea, yet 40% of people have never discussed their wishes for care and treatment at the end of their lives with anyone⁸. Government's End of Life Care Strategy also attaches great importance to ensuring that people's individual needs, preferences and wishes are respected when approaching the end of life.

Compassion in Dying supports the idea of personal budgets, which will enable people to make their own decisions about what form of care and support they would like to receive. Within the system of personal budgets, it is crucial that people get all the support they need to make decisions in relation to their care and support. However, not everyone will want a personalised budget – some people will not be comfortable with personalised budgets.

Local authorities must act on their responsibility to help people get the right care and support. In addition, there will need to be education and training on the concept of personal budgets for all staff involved in providing care. In this context, health and social care professionals need to be aware of the existence of End-of-Life Care Plans so that they can be taken into account in discussions about personal budgets. These kinds of conversations with people who are nearing the end of life require a specific set of communication skills. It is vital that the workforce as a whole receives the necessary training and education to this end.

- On fair funding:

Compassion in Dying calls on Government to investigate the possibility of paying for social care for individuals who are at the very end of their life, with a one year prognosis at most. Social care in the final stage of life should be fully state-funded, as is the case for social care at the beginning of life. People who are dying find themselves at the most vulnerable stage in their lives. We want all people to have a good and dignified death. Full state funding for this final stage would have the much needed effect of increasing care service provision and would allow for more people to receive the care they want at the end of their life. Therefore we ask the Government to consider fully funding social care for dying people.

Any chosen funding system will need to be fair, affordable, clear and predictable.

In this respect, the new standardised system for conducting individual care needs assessments is expected to lead to greater fairness and predictability, and move us away from the current postcode lottery in services. Under the new system, people will be informed of the level of care and support they can expect, wherever they live in England, so that people know in advance what kind of care and support services they can expect in any given locality in England.

As a consequence, people currently receiving social care support and related benefits will need clear information about what changes they can expect once the planned reforms of the care and support system, as set out in the consultation, come into effect.

Any chosen funding system must be clear and easy to use. It is crucial that people can find their way around the system easily and that they have a clear understanding of the different forms of care and support that are available to them.

In response to question 1a): Is there anything missing from this approach?

Compassion in Dying suggests adding *support for carers* as a separate point, rather than including it under the section on personalised care and support.

It is an acknowledged fact that informal carers make a huge contribution to the care and support system. Unpaid carers provide most of the care for older, disabled or terminally ill people. There are more than half a million carers of terminally ill people in the UK. Nationally it is estimated that unpaid carers save the economy an average of £10,000 per carer – a total of almost £60 billion per year. 625,000 carers experience physical or mental ill health as a direct consequence of caring, while one in five carers is forced to give up work because of their caring responsibilities⁹.

It is vital to provide carers with the support they need in order to enable them to fulfil their role to the maximum. The Government has made a number of commitments to carers in the Carers' Strategy. Government must now act on these commitments and make them a reality.

As pointed out in the End of Life Care Strategy, carers are central to the team that cares for somebody at the end of life and they should be treated as a part of the health and social care team in terms of communication. As a consequence, they need to be involved in discussions about the care and treatment of the person they are caring for right from the start. Compassion in Dying attaches great importance to informing carers about their entitlements as a carer (such as benefits, respite breaks and other support). As highlighted in the End of Life Care Strategy, local authorities have a duty to inform carers of their right to

have their needs assessed. However, whilst it is vital that health and social care staff communicate well with carers and involve them in decision making, they must also recognise that carers are not health professionals. Before anything else they are the partner, family member or close friend of the patient. Health professionals must recognise this crucial aspect of the carer-patient relationship and treat carers with sensitivity, compassion and support.

Case study - Susan and Michael¹⁰:

Susan's husband got admitted to hospital after suffering a series of strokes. After he got out of hospital, Susan wasn't offered any form of support in caring for him. There was no place available at the hospice and Susan was told to contact some nursing homes herself to check the availability. Susan preferred to care for her husband at home but she felt limited in the care she could provide. She hardly received any information about her husband's condition and specific needs. Her husband could no longer communicate and Susan was very worried that he did not get adequate pain relief and was unable to express his pain or discomfort. Susan asked about pain relief at 3 different occasions but her requests were ignored. She was also worried about her husband losing the ability to eat or drink. She never got the opportunity to discuss her concerns and nothing was done to inform or reassure her. Susan's husband eventually died from dehydration and starvation. Susan is still determined to find out whether her husband had adequate pain relief at the end and didn't have to suffer any unnecessary pain.

Compassion in Dying also supports calls for carers to be better rewarded. Anyone providing more than 35 hours of care per week, regardless of age, should receive a carer's benefit in recognition of their caring role. Carers should also be better protected under law, so they cannot be discriminated against because of their caring responsibilities.

Consultation question 2:

We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

- a) Do you agree?
- b) What would this look like in practice?
- c) What are the barriers to making this happen?

Compassion in Dying response:

On the 3 core elements of the National Care Service:

1) On joined-up working:

Compassion in Dying supports an integrated approach towards care. In order to enable a system of personalised care, the different services that a person needs must work together smoothly. Better joined-up working between health, housing and social care services would make a huge difference to the quality of care that is currently provided. A joined-up system will also make it easier for people to find their way around the system. Under the current system, people find it particularly difficult to understand where the boundary lies between NHS care and social care and what kind of conditions qualify for each. This issue can be addressed by creating a new care and support system which joins up the different elements

of care and support that are available to people. As far as the integration of the disability benefits and care and supports systems is concerned, it is essential to make sure that people who rely on disability benefits will continue to receive an equivalent level of support and protection under the new care and support system.

In the context of end-of-life care, the End of Life Care Strategy suggests that Primary Care Trusts consider the work from the Marie Curie Cancer Care Delivering Choice Programme (which works in partnership with the NHS, social care and various agencies to develop patient focused 24-hour service models that service local needs and have an impact on the whole patient pathway). The findings from the ongoing research that The King's Fund is undertaking with this Programme has demonstrated the importance of partnership working across health and social care providers¹¹.

Any future strategy aimed at improving joined-up working will need to highlight the importance of education and training for staff to this end. In developing a strategy in order to address this issue, the experiences of patients and carers will also need to be taken into account.

Case study – Nicola and Alan¹²:

At last, the support seemed to be falling into place, although we were still waiting for the shower chair, and for ceiling hoists to be fitted. Now that Alan had been accepted for continuing care, all the papers for these aids had to be passed from the social services to the NHS – two different budgets! He died before either were fitted. I am not sure that they were even ordered.

2) On more choice and offering a wider range of services in care and support:

One of the key aims of the End of Life Care Strategy is to ensure that services provided to people approaching the end of their lives are, as far as is possible, responsive to their needs and preferences. To achieve this aim it is essential that those responsible for providing care are aware of the needs and preferences of each individual. People need to be given the opportunity to consider what care they wish to receive, based on the best available information and what services are available. During the development of the Strategy many people have identified the lack of open discussion between health and social care staff and those approaching the end of life and those who care for them, as one of the main obstacles to giving people more choice about the type of care they would like to receive. Rectifying this represents a major challenge but is crucial in order to achieve more personalised care and support. It is necessary for all staff to possess the appropriate skills to have conversations with people in order to identify their needs and wishes in terms of care and support.

Compassion in Dying supports the idea of personal budgets, whilst acknowledging that they will not be right for everyone receiving social care (as discussed in the section on personalised care and support). Local authorities must act on their responsibility to help people get the right care and support. In addition, there will need to be education and training on the concept of personal budgets for all staff involved in providing care, and on End-of-Life Care Plans, so that they can be taken into account in discussions about personal budgets.

As pointed out in the Green Paper, commissioners will want to engage with people who use care and support and with user-led organisations, which can play a useful role in helping local authorities and providers of services to understand what people want and need from

services. Compassion in Dying agrees that it is essential to involve the people who use care and support services.

Compassion in Dying would also like to reinforce that personalised care and support services should not lead to a postcode lottery across the country and is pleased to note that the Green Paper aims to address this issue.

3) On high quality:

Compassion in Dying welcomes a stronger focus on rights and entitlements for people under the new National Care Service (in contrast to the End of Life Care Strategy whose provisions are merely recommendations and do not give people rights as such). It is important for people to know what their rights are and to have ways of enforcing them. For example, the right to a needs assessment, both for people who need care and for carers, is a very strong instrument for people to ensure that they get the care and support that is right for them.

Compassion in Dying agrees that the development of the workforce is at the heart of achieving high quality care and support for all. We welcome the recently published strategy on the future of the care and support workforce by the Department of Health¹³. In providing care for terminally ill people, health and social care staff must have the necessary skills to openly talk to people about their needs and wishes for their care at the end of life. However, during the development of the End of Life Care Strategy many people have identified the lack of open discussion between health and social care staff and those approaching the end of life and those who care for them, as one of the key barriers to the delivery of good end-of-life care. This represents a major challenge. A cultural shift in attitude and behaviour related to end-of-life care must be achieved within the health and social care workforce.

The Green Paper rightly devotes attention to defining “high quality” care. In order to improve quality, it is indeed crucial to know which care and support services work best. Compassion in Dying strongly agrees that it is vital to take users’ experiences into account in order to help ensure that the right care and support services are available to people. This should include working with users, user-led organisations and the third sector.

Over the last few years, the NHS has rightly invested in engaging people in the design and delivery of services. Using patient feedback to drive service improvement now forms a key plank of the policies to transform the NHS. The future National Care Service must do the same and provide opportunities for the views of users to be heard. Local Involvement Networks (LINKs), which are being introduced around the country to help strengthen the system that enables communities to influence local health and care services, could play an important role in this respect. Through these networks, people get the chance to say what they think about local health and social care services. The networks then feed back to services what people have said so that things can be improved.

In the context of patient and public involvement, the experiences with Patient Advice and Liaison Services (PALS) can also offer interesting insights in providing information, liaising with service providers and working to improve service provision.

In the context of ensuring high quality care and support, Compassion in Dying welcomes the recently issued guidance setting out a simpler, joined-up approach to dealing with complaints in health and social care. This will aim to make sure that the whole system responds quickly, flexibly and fairly to concerns and complaints.

Case study – Nicola and Alan¹⁴:

When I contacted the vehicle assessment centre, I was told there was a long waiting list. I can't remember how long but it was too long for us, given the rate of progression of the disease. So Alan and I made our own assessment and found a company that could supply what we considered we would need. The company brought a vehicle to the house, to give us a demonstration, and this enabled us to make our final decision. That was it, decision made. We were fortunate that we were able to afford to do this. I was beginning to learn that assessment was another word for delay or, worse, not happening at all. How could this make life bearable for a person suffering from a cruel terminal illness? How could it make them feel less of a burden?

...After three weeks of waiting, I made several attempts to speak to our social worker. She was rarely in the office, and appeared to be extremely stretched, so eventually I managed to speak to her line manager. I was desperate. My voice must have conveyed near-hysteria. Finally, some action! They would get us assessed for continuing care. This would put us in the system and mean that the NHS might pay or contribute to Alan's every increasing care needs. It was welcome action, but I did not know when the assessment would be made, nor did it recognise the urgency of my immediate need for help. No one seemed to have any real idea of the impact of this disease, and the need to be able to act quickly. I had to be desperate, to be begging for help, before anything happened. It was humiliating.

...Alan and I had these meetings and conversations many times over, with various professionals who came to see us over the forthcoming months. We told them about the physical and mental effects. The words always fell on sympathetic ears. They genuinely wanted to know how we were getting on, and what they could do to help. If I knew, I told them. For the most part however, it might as well have fallen on deaf ears. We needed the kind of support given to a lot of dying cancer patients who choose to die at home. We needed to know how to access nursing and carer support, together with the equipment required for the job. Sadly, for a long time, we did not receive this level of assistance, and by the time it started to happen it was too late.

...We were again assessed for continuing care, and it was awarded. But it was too late. I am sure the emotional effect on us both would not have been as great, had we received the right support earlier. Without someone to look after him, Alan would have died. The NHS finally recognised that his care was not simply personal care; it was a health need. He was totally reliant on others, like a baby....

Consultation question 3:

The Government is suggesting three ways in which the National Care Service could be funded in the future:

- Partnership – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.
- Insurance – As well as providing a quarter to a third of the cost of people's care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.
- Comprehensive – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

a) Which of these options do you prefer, and why?

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

a) Which of these options do you prefer, and why?

In relation to funding we would like to reiterate that any chosen funding system will need to be fair, affordable, clear and predictable.

In this respect, the new standardised system for conducting individual care needs assessments is expected to lead to greater fairness and predictability.

It is also very important for people to know what level of care and support they can expect. In relation to the planned reform of the care and support system, people currently receiving social care support and related benefits will need clear information about what will change for them once the reforms set out in the consultation come into effect.

Any chosen funding system must be clear and easy to use. It is crucial that people can find their way around the system easily and that they have a clear understanding of the different forms of care and support that are available to them.

In terms of resources, the Government must undertake all the necessary steps to make sure that the money it is spending on care and support is being used in the most effective way.

Compassion in Dying calls on Government to investigate the possibility of paying for social care for individuals who are at the end of their life, with a one year prognosis at most. Social care in the final stage of life should be fully state-funded, as is the case for social care at the beginning of life. People who are dying find themselves at the most vulnerable stage in their lives. We want all people to have a good and dignified death. Full state funding will have the much needed effect of increasing care service provision for people and will allow for more people to receive the care they want at the end of their life.

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

The Government is suggesting two approaches for the way in which money is raised and distributed around England:

1. A part-national, part-local system
2. A fully national system

Compassion in Dying attaches great importance to achieving high quality personalised care and support for all, wherever people live or whatever condition they are suffering from. Compassion in Dying supports a flexible care and support system with services that are tailored to people's needs and wishes. Local authorities should listen to what local people have to say about their local health and social care services and they should be able to respond to the needs and wishes of the local population in terms of care and support. Therefore, it is important for local authorities to have the flexibility to take into account local circumstances. However, this ability to respond to local needs should not result in a postcode lottery – the boundaries of what individuals can expect, wherever they live, must be clear. Any chosen approach must guarantee a system that is fair and predictable. As emphasised throughout the Green Paper, people need to know what kind of care and support services they can expect in any given locality in England.

Compassion in Dying, November 2009

¹ House of Commons Public Accounts Committee - End of Life Care, 14 May 2009, House of Commons, London, p5.

² HM Government (2009) The case for change – Why England needs a new care and support system: Engagement findings.

³ Department of Health (2008) End of Life Care Strategy.

⁴ Department of Health (2008) High Quality Care For All: NHS Next Stage Review Final Report.

⁵ Equality and Human Rights Commission (2009) From Safety Net to Springboard: A new approach to care and support for all based on equality and human rights.

⁶ Nicola Wood, True Love Cruel Fate - A Tribute to my Partner who died of Motor Neurone Disease, Seven Arches Publishing, Peterborough, 2009.

⁷ See endnote v.

⁸ ICM poll, commissioned by Dignity in Dying, May 2008.

⁹ Carers UK – <http://www.sovereign-publications.com/carersuk.htm> (last consulted on 28 September 2009).

¹⁰ Case study based on communication by Susan with Compassion in Dying.

¹¹ For more information on this research project, please visit:

http://www.kingsfund.org.uk/research/projects/choice_at_the_end_of_life/#tab3 (last consulted on 28 September 2009).

¹² See endnote 6.

¹³ Department of Health (2009) Shaping the Future of Care Together.

¹⁴ See endnote 6.