



Compassion in Dying response to

Law Commission: Adult Social Care Consultation

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Law Commission: Adult Social Care Consultation

Compassion in Dying

Compassion in Dying is a charity that focuses on research, education and advice on all aspects of the end-of-life process (for adults). Our charitable objectives are to conduct research and to provide advice, information and guidance to all those affected by the end of life; including patients, carers and health professionals.

Compassion in Dying's response specifically focuses on those aspects of social care that are most relevant to adults at the end of life. Adults at the end of life have specific practical, medical and emotional needs, and trajectories of decline can differ on an individual basis. Planning and delivering effective care for this group of people requires detailed thinking which falls beyond the scope of this consultation document and is covered elsewhere¹.

Compassion in Dying welcomes the Law Commission's attempt to create a coherent statutory framework for adult social care. Clearly, any change to the organisation of adult social care should involve input from service users, health care professionals and third sector organisations as well as those working in the social care field. Compassion in Dying also encourages the proposed changes to statute as a means of tackling the existing postcode lottery in terms of the availability and offer of care and support services across the country.

Response to consultation

We have focussed on two sections of the consultation document:

- Part 3: Statutory principles
- Part 5: Carers' assessments

Part 3: Statutory principles

Provisional Proposal 3-1: A future adult social care statute should include a statement of principles.

Compassion in Dying agrees with the approach taken in the consultation paper that there is a strong case for including statutory principles in the proposed adult social care statute. Such an approach would allow for a clear statement of the fundamental principles underpinning adult social care legislation, and provide a useful foundation and focus for those decision-makers and practitioners affected by the legislation. Making the principles part of statute, rather than simply part of the accompanying guidance emphasises their fundamental importance. The statutory principles in the Mental Capacity Act (2005) provide a useful example.

¹ Department of Health (2008) *End of Life Care Strategy* DH

Question 3-1: There should be a principle which provides that decision-makers must maximise the choice and control of service users.

Compassion in Dying agrees that there should be a principle about maximising service users' choice and control. Service users should be appropriately empowered to make their own social and health care decisions. Enabling this must be embedded in decision-makers' and practitioners' work.

Compassion in Dying suggests that the accompanying guidance to the proposed statute be tailored to the specific needs of different client groups serviced by adult social care services around choice and control.

Question 3-2: There should be a principle based on person-centred planning.

Service users must be at the heart of planning and decision-making. In theory, this would enable service users and carers to plan their futures effectively.

Case study – Nicola and Alan¹

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.

Compassion in Dying notes that the principles and practice of person-centred planning were originally designed for people with learning, developmental and physical disabilities but believe that these principles apply to all service users, including those at the end of life.

Person-centred planning is already a core aim of end-of-life care, which is defined by the National Council for Palliative Care as²:

Help(ing) all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Furthermore, the End of Life Care Strategy¹ provides useful guidance to help plan end-of-life care for adults. The strategy states that:

¹ Wood N, (2009) *True Love Cruel Fate - A Tribute to my Partner who died of Motor Neurone Disease* Seven Arches Publishing, Peterborough

² National Council for Palliative Care (2006). Quoted in Department of Health (2008) *End of Life Care Strategy* DH

Individuals differ in many ways as they approach the end of life. No two people will have an identical end of life care pathway. For each individual many different factors will impact on their needs and preferences for care. These include:

- *The nature of the condition, or conditions, from which they are suffering and the different symptoms that they cause.*
- *Living arrangements, for example, whether they live alone or with others, the proximity of close family, in sheltered and extra care housing accommodation, in a care home etc.*
- *Social circumstances, e.g. poverty, refugee and asylum seeker status.*
- *Pre-existing vulnerabilities, such as mental health and learning disabilities.*

Question 3-3: Should there be a principle in our future adult social care statute which provides that a person’s needs should be viewed broadly?

Compassion in Dying’s view is that any principle concerned with person-centered planning should encompass viewing a person’s needs broadly. Therefore having a separate principle concerned with viewing a person’s needs broadly is probably not needed.

Question 3-4. There should be a principle based on the need to remove or reduce future need.

The principle of removing or reducing future need is essential to deliver a person-centred and cost-effective service. Removing or reducing future need means:

- Service users, in theory, would be managing themselves effectively and leading independent lives
- Service users would not be reusing particular services which would save money in the long-term.

Therefore Compassion in Dying would support a principle based on removing or reducing future need.

Question 3-5: Should there be a principle in our proposed adult social care statute based on the concept of independent living?

Compassion in Dying supports the principle of independent living as a means of providing those at the end-of-life with dignity and a place to live and/or die during the last stages of life, as well as in the broader sense (for disabled people and others not approaching the end of life).

We would support a large definition of what independent living means, based on individual circumstances. Levels of independence can be achieved across a number of settings (own home, care home, sheltered accommodation etc.). Any concept of independent living needs to take into account that changes in social and health circumstances could mean a move from one type of accommodation

¹ Department of Health (2008) *End of Life Care Strategy* DH

to another (sometimes with a view to a person returning to their original residence). This is stressed in the End of Life Care Strategy¹.

It is vital that the new statute and any accompanying guidance reflect the importance of independent living, but it may be that this could be achieved through the statutory principles covering choice and control and person-centred planning, rather than requiring an additional statutory principle.

Question 3-6: Should there be a principle in our proposed adult social care statute based on an assumption of home-based living?

Compassion in Dying does not support home-based living as a blanket assumption of preference, but does support it as an underlying principle.

Living the last phase of life at home is not always possible for individuals, carers and health and social care providers. 50% of people are not dying in their place of preference², and for many people this would mean dying at home. In 2007, Healthcare for London found that 57% of people would prefer to die at home, but that only 20% do³. However, *choosing* to die at home and the *process* of dying at home are different things, and the process is complex from all stakeholder perspectives⁴. Compassion in Dying's view is that living the end stage of life at home should be one of a series of options available for service users depending on a number of factors.

A consultation on the NHS Constitution and potential new patient rights included a question around a right to die at home⁵. The Government response to the consultation, published in March 2010 stated⁶:

For the choice to die at home, we will consult on more detailed proposals within the next Parliament. If the responses to that consultation are favourable, we will look to introduce this right as soon as possible.

With a new Government in power, it is unclear if further consultation on the creation of right to die at home will go ahead. However, the proposed statute should take the NHS constitution into account, as well as potential changes to it.

¹ Department of Health (2008) *End of Life Care Strategy* DH

² Dr Keri Thomas, National Clinical Lead, Palliative Care and the GSF Programme, NHS End of Life Programme at the Sixth Annual Conference on Palliative Care (September 2007)

³ Healthcare for London (2007) *A Framework for Action*

⁴ Gomes B and Higginson IJ (2006) Factors influencing death at home in terminally ill patients with cancer: a systematic review *BMJ* 332: 515-521

⁵ Department of Health (2009) *NHS Constitution: a consultation on new patient rights* DH

⁶ Department of Health (2010) *The NHS Constitution: Government response to consultation on new patient rights* DH

As with independent living, the option of home-based living is very important and Compassion in Dying's view is that this could be achieved through the statutory principles around choice and control and person-centred planning, rather than requiring an additional statutory principle.

Question 3-7: There should be a principle based on dignity in care.

One of the aims of the End of Life Care Strategy is to ensure that all people are treated with dignity and respect at the end of their lives. This covers all stakeholders and so it is logical for it to be enshrined in any adult social care reforms.

The principle of dignity in care is fundamental and should *provide a foundation on which all other elements of the statute are built*. Unless service users and carers are afforded dignity in the planning and delivery of appropriate social care, services will cease to deliver effective care.

We recognise the difficulties that the Law Commission has highlighted around defining dignity in care¹. However, the concept is so fundamental that Compassion in Dying's view is that it should be included as a statutory principle, as well as an over-arching standard. Accompanying guidance based on an examination of the concept of dignity and the practical delivery of dignity in care is needed.

Question 3-8: There should be a principle based on the need to safeguard adults at risk from abuse and neglect.

The consultation paper draws attention to the potential for tension between the principle around service users' choice and control, and a principle around safeguarding service users². Nevertheless, Compassion in Dying's view is that this tension could be addressed in a similar way to the Mental Capacity Act (2005), by having regard to the concept of *best interests*, and in particular, principle five of the Act, regarding decisions made on behalf of those without capacity which states³:

Before the act is done, or the decision made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Question 3-9: Should any one principle in adult social care be given primacy over all other principles?

Compassion in Dying believes that in terms of values, the principles around choice and control and dignity are fundamental. However, at this stage it is difficult to determine whether either could become the overriding principle in *legal* terms.

¹ The Law Commission Consultation Paper No 192, 3.47, pg 24

² The Law Commission Consultation Paper No 192, 3.50, pg 24

³ Mental Capacity Act (2005), Part 1, para 1(6)

Part 5: Carers' assessments

Provisional proposal 5-1: There should be a duty to undertake a carer's assessment in the future adult social care statute.

Carers make a huge contribution to the care and support system. 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 year¹. It is vital and *fair* to provide carers with the support they need in order to enable them to fulfill their role to the maximum.

Compassion in Dying supports that there should be a duty to undertake a carer's assessment in the statute. The consultation document points out the inadequacies of the current system, where the delivery of assessments to carers has been patchy. The fact that at present only carers who provide a substantial amount of care on a regular basis are assessed can lead to many carers not receiving the support they require.

Provisional proposal 5-2: The duty to assess a carer should apply to all carers who are providing or intend to provide care to another person, not just those providing a substantial amount of care on a regular basis.

Compassion in Dying supports this proposal as it covers all carers and would be much fairer than the current system.

Provisional proposal 5-3: The duty to assess a carer should not be triggered by the carer making a request, but should be triggered where a carer appears to have, or will have upon commencing the caring role, needs that could be met either by the provision of the carers' services or by the provision of services to the cared-for person.

The question does not appear to accurately reflect that both carers and social and health care professionals can trigger a request².

Where social and health care professionals can trigger an assessment they may need to be trained to identify carers and to spot when a carer might need an assessment and potential support. This is especially true in end-of-life care where it is acknowledged that not all stakeholders have the necessary skills to engage with the client group³. Compassion in Dying welcomes the discussion (based on research) in the consultation around carers' reluctance to request an assessment⁴.

One concern is around the suggestion that *a duty to assess based on appearance of need could be triggered in some circumstances where the carer*

¹ Carers UK, www.sovereign-publications.com/carersuk.htm.

² The Law Commission Consultation Paper No 192, 5.27, pg 45.

³ Department of Health (2008) *End of Life Care Strategy* DH

⁴ The Law Commission Consultation Paper No 192, 5.23, pg 44.

*does not actively consent*¹. This needs further clarification, with reference to the Mental Capacity Act (2005) and with further discussion around the best interests of the service user. Guidance for professionals, produced alongside the statute, would need to provide more detailed discussion of this issue.

Provisional proposal 5-4: A future adult social care statute provides that the following carers are not excluded from the definition of a carer for the purposes of a carer's assessment: 1) a previously unpaid carer who now receives payments for their services through direct payments received by the cared-for person; 2) a carer who is paid for some but not all care they provide; and 3) a carer where the local authority believes the caring relationship is not principally a commercial one.

Compassion in Dying supports that all types of carers should be entitled to an assessment. This should lead to more effective support for carers.

Question 5-1: The proposed adult social care statute should encourage a more unified assessment process for carers and cared-for people.

Compassion in Dying supports a proposed statute that would encourage a unified and holistic assessment of the needs of the carer and cared-for person. This approach seems likely, in the majority of cases, to make the assessment process easier and less disruptive for both the cared-for person and the carer, and to encourage joined-up services and support after assessment.

Case study - Susan and Michael²

Susan's husband was 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.

Question 5-2: Do you think the carers' assessment duty should be merged with the community care assessment duty in our proposed adult social care statute?

For the reasons outlined in the consultation paper³ Compassion in Dying agrees that a merged assessment duty may not be practicable, and in particular may not adequately recognise the specific role of a carer (and related needs and challenges). A statute that *encourages a unified* assessment seems preferable.

¹ The Law Commission Consultation Paper No 192, 5.26, pg 45

² Case study based on communication by Susan with Compassion in Dying

³ The Law Commission Consultation Paper No 192, 5.49-52, pgs 50-51