

Consultation Response Template

**“Prioritising need in the context of *Putting People First*:
A whole system approach to eligibility for social care”**

Please fill in and/or tick the appropriate response.

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Are you happy for your response to be passed to other UK Health Departments

Yes

Are you happy for your response to be published in a summary of responses?
Yes

- Are you responding:
- *as a member of the public*
 - *as a health or social care professional*
 - *on behalf of an organisation* x

If you are responding as a member of the public, please supply the following details:

Job title:

Interest in this consultation:

If you are responding as a health or social care professional, please supply the following details:

Job title:

Interest in this consultation:

If you are responding on behalf of an organisation, please supply the following details:

Name of Organisation: Compassion in Dying

Interest in this consultation: 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.

Consultation Response Template

Q.1: Do you think the guidance sufficiently integrates the application of eligibility criteria within the new policy context of personalisation, choice and control?

Yes

If not, what changes would you propose?

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

The proposed guidance reflects the importance of respecting individuals' needs and preferences for care by presenting a person-centred assessment process, involving both the person seeking support and the people around them. However, Compassion in Dying would like to see greater emphasis on 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. Carers should be made aware of their personal right to have their needs assessed as well as of their entitlements to benefits, quality breaks and other support.

Compassion in Dying welcomes the approach to the provision of high-quality information and advice as presented in the proposed guidance, irrespective of people's eligibility for public funding. High-quality information and advice is crucial in order to enable people to make informed choices about the care they wish to receive. Local councils have a responsibility to empower people who wish to approach them for help and support by making high-quality information and advice available in a simple and adequate manner.

The vision for a personalised approach to adult social care has significant implications for the workforce. As pointed out in the proposed guidance, health and social care professionals need to be sufficiently skilled in understanding people with a wide range of needs.

Specifically for terminally ill people, staff need to be aware of the existence and contents of End-of-Life Care Plans so that they can be taken into account. We know it is important to people to have their say about the care they would like to receive at the end of life. A recent survey 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 (ICM poll, commissioned by Dignity in Dying, May 2008). The Government's End of Life Care Strategy (launched in July 2008) attaches great importance to ensuring that people's individual needs, preferences and wishes are respected when approaching the end of life.

Health and social care professionals need to be fully informed of the implications of the End of Life Care Strategy and the Mental Capacity Act 2005 for their work. Conversations with people who are nearing the end of life also require a specific set of communication skills. It is vital that the workforce as a whole receives suitable training and education to this end.

Q.2: Do you think the guidance sufficiently outlines councils' responsibilities towards their wider community as well as those individuals with eligible needs?

Yes

If not, what changes would you propose?

Q.3: Do you think the guidance sufficiently explains the need for councils to implement preventative strategies as well as the benefits that such strategies can bring?

Yes

If not, what changes do you propose?

Compassion in Dying supports investment in prevention 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, six out of ten people spend their last days in hospital (House of Commons Public Accounts Committee - End of Life Care, 14 May 2009, House of Commons, London, p5).

If people feel very strongly about accessing prevention services in order to receive care and support at home at the end of their life, they can set out these wishes in an End-of-Life Care Plan. Health and social care staff should accommodate the wishes set out in the End-of-Life Care Plan as far as they possibly can (in line with the End of Life Care Strategy). At the time of the individual care assessment, the feasibility of accommodating a person's wishes will need to be examined.

Q.4: Given the emphasis upon access to universal and preventative services as set out in *Putting People First*, do you think there is still a need for a fourth criteria band (low)?

Yes / No (delete as appropriate)

Please give reasons for your answer.

No comment.

Q.5: Do you think the guidance sufficiently underlines the principles of fairness, consistency and transparency in the process for determining eligibility for social care?

Yes

If not, what changes would you propose?

Compassion in Dying welcomes the proposed approach, in that it enables people with similar needs within the same local authority area to receive a similar quality of outcome, according to the individual circumstances and aspirations of each individual.

In addition, 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 and would make an end to the existing postcode lottery. People should have the right to know what level of support and care they are entitled to in the different parts of the country. A portable assessment is essential in order to ensure that people are supported fairly wherever they live. In the mean time, Compassion in Dying welcomes the provisions for people who move from one council area to another, as set out in the proposed guidance.

Finally, Compassion in Dying attaches great importance to making sure that reassessments of individual needs take place on an ongoing basis.

Q.6: Do you think the guidance itself is sufficiently transparent and understandable for both health and social care professionals and people seeking support?

Yes

If not, what changes would you propose?

In this context, we would like to reinforce the importance of providing clear information to people who are currently eligible for social care support. They must be fully informed about what will change for them once the changes set out in the consultation document have come into effect.

Q.7: To what extent do you think the revised guidance will have a positive impact on equality? Is there anything else that you would like to see in the guidance to manage any adverse impact and to promote positive impact?

No comment.

Q.8: Do you have any comments about the costs and benefits (monetary or otherwise) that the revised guidance will involve? Do you foresee any impact on local authorities or people seeking support that we have not identified?

See answer to question 6.