

A national review of choice in end of life care - consultation paper and response form

Why the review of choice in end of life care has been launched

Almost half a million people die in England each year. However, significant numbers of people do not currently have proper opportunities for their choices about how, when and where they receive end of life care to be identified, discussed or met.

That is why the Government has set up a review of choices in end of life care – to help shape its national choice offer. The review is being undertaken by an independent programme board, chaired by Claire Henry, the Chief Executive of the National Council for Palliative Care. The information gathered will outline the kinds of choices that people would like to be able to make at the end of life and information about the funding, systems and processes that would be needed to enable choices to be acted upon.

The review focuses on end of life care for adults aged 18 and over, and within the current legal framework. Therefore, it does not focus on assisted dying or anything that would involve changes to mental capacity legislation.

The programme board is due to present its findings and advice to Government in February 2015.

The diagram below shares examples of what surveys and research show can be important to people at the end of life and therefore indicates the types of choices you may wish to consider; however, please do not feel restricted by these.



We want to hear from you

To ensure the review is as comprehensive as possible, it is vitally important that we hear from a really wide range of people about the choices that are important to them at the end of life, what they would mean in practice and whether and how they could be made a reality.

Whether you're a member of the public or someone who has a professional interest, perhaps through your work within health, social care or housing, we want to hear from you. We're interested in any aspect of choice in end of life care and support which falls within the scope of this work – so it needs to be related to care of people aged 18 and over and within the current legal framework. This work is not about assisted dying or anything that would involve changes to mental capacity legislation.

We want you to tell us:

a) What a 'national choice offer' for end of life care should consist of

We are therefore inviting views on what a 'national choice offer' could and should include in order to meet people's needs and wishes. We want to hear from you about the kinds of choices people should be able to make at the end of their life given that resources, such as funding, are finite and there is inevitably the need to prioritise.

b) How a 'national choice offer' for end of life care could be achieved

For any 'choice offer' to be meaningful it also needs to be realistic, effective and consistent. We are therefore inviting views on the things that would need to happen to ensure that any 'national choice offer' is achievable. To help us understand this we want to hear from you about:

- The extent to which people **currently** have choices at the end of life and examples of good practice, where people have been able to make choices at the end of life and how these choices have made a difference to their experience and quality of care and support.
- What would need to be in place for people to be able to make informed choices about their care and support at the end of life and be confident they will be acted upon? Some examples may include:

For people who are nearing the end of their life and those close to them:

- o An understanding of the current situation and what the future may hold
- o A meaningful and helpful assessment of the care and support needed now and that may be needed in the future
- o An understanding of sources of support and care available and how to access them
- o An opportunity to express and record wishes for care and support and who they would like to be involved in decisions
- o Confidence that this information can be easily updated and will be available to the right people at the right time
- o For support and care to be available when it is needed, including at night and over weekends
- o For the people who provide support and care to be trained, skilled and supported

For professionals who provide care and support:

- o Adequate funding and staffing levels
- o Access to training and support
- o Effective systems for accessing accurate and up to date information about people's wishes and preferences
- How we would know if a 'national choice offer' improved people's experience of care at the end of life. For example, how we might be able to measure and evaluate the impact on the quality of care and support received.

You can respond by completing the form below and returning it by post or email. You can also respond to our online survey or in other ways if you would prefer. Please visit <http://www.ncpc.org.uk/ChoiceOffers> for more information. We would like to hear from you **by 30th September 2014**.

Thank you

Claire Henry, MBE
Chair of the Choice Review Board

Please complete this form and return it by 30th September 2014 using the contact details below.

Question 1: What kinds of choices should people be able to make at the end of their life? Please list them in priority order and describe what would need to be in place for them to be achieved.

Priority 1
Description
What would need to be in place for this to be achieved?

Priority 2
Description
What would need to be in place for this to be achieved?

Question 3: How would we know if a 'national choice offer' improved people's experience of care at the end of life? For example, how we might be able to measure and evaluate the impact on the quality of care and support received. Please share your answers below.

About you

If your responses are mainly based on your personal experience, i.e. not as someone who works in health or social care, but as someone who has or has cared for someone with a life-limiting condition or who has died, please answer the following questions.

How old are you?	Please select
Under 18	
18-24	
25-34	
35-44	
45-54	
55-64	
75-84	
85 and over	
Gender	
Female	
Male	
Is your gender identity the same as the gender you were assigned at birth?	Yes/No
Which of the following best describes how you think of yourself?	
Lesbian	
Bisexual	
Gay	
Heterosexual/Straight	

