

Green Paper – Shaping the future of care together

Overview of key points

Introduction

Shaping the future of care together sets out a vision for a new care and support system. The Green Paper highlights the challenges faced by the current system and the need for radical reform, to develop a National Care Service that is fair, simple and affordable for everyone.

Within the Green Paper, it sets out a number of consultation questions and asks everyone to provide their views about how they think Government can make this vision a reality and develop a care and support system fit for the 21st century.

This paper serves as an overview of Compassion in Dying's response to the consultation and highlights the key points we will make in our full response. Trustees are invited to submit their feedback and suggestions by the 18th September 2009.

Consultation questions and suggested responses

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:

Note: These questions will be answered within specific comments on the six planned elements of the National Care Service above.

- On prevention services:

CiD supports the suggested approach.

The examples given throughout the document show that what has been done so far focuses too much on older people. These initiatives need to be extended. (It will especially help people to receive care at home much longer, and we know that this is important to many terminally ill people.)

- On national assessment:

This is essential in order to ensure that people are supported fairly wherever they live. The need for national assessment has been highlighted in our guide *Your Rights at the End of Life* and in the DiD Charter. We will particularly emphasize the importance of a carers' needs assessment.

- On a joined-up service:

We full-heartedly support an integrated approach towards care at the end of life (and in general). In order to enable a system of personalised care, the different services that a person needs need to work together smoothly. Social care needs to link up with all the different services a person (and their family) receives towards the end of life. Social care needs to be integrated into the 'joined up working', 'good communication' and other elements of the End of Life Care strategy.

- On information and advice (p56):

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.

⇒ From CiD's experiences, what kind of information do people need? Include some case studies if possible.

Looking at the ideas set out in this consultation, going forward it will be vital that people have a clear understanding of what counts as social care, and what is health care, particularly given the proposed plans around insurance. People need to know what they can expect. There will also need to be clear information about what decisions around social care an attorney (via a Lasting Power of Attorney) can make for someone with regards to social care provision and payment.

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

- On personalised care and support:

We know that people want to have their say about their care at the end of life. CiD supports the idea of personal budgets. Stress the importance of end-of-life care plans. It is crucial that health and social care staff have the appropriate skills.

- On fair funding:

Any chosen funding system will need to be fair, predictable and straight forward.

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

Compassion in Dying suggests adding *support for carers* as a separate point. The role of carers should not be underestimated. We can refer to the points in the Carers' Strategy and the DiD Charter for our views on this particular issue.

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 what this would look like and potential barriers:

The services CiD provides/will provide are based around information and advice rather than direct provision of social care or health services. Therefore our answers to the consultation questions will focus more on our areas of strength and expertise, and we do not intend to give detailed answers around service delivery models.

However we could comment on existing models that those designing the national care service may want to consider for suitability as models. The most obvious example is the End of Life Care Strategy around sharing information, joined up working, communication and support for carers.

We will try to use case studies to illustrate some of the barriers to delivery of the national care service.

On the 3 core elements of the National Care Service:

1) On joined-up working:

- From the Green Paper: Joined-up working matters more for certain groups of people, for example those with long-term conditions (a chronic illness that can limit lifestyle, such as diabetes or Parkinson's disease) and people who have complex health and care needs. There are currently over 15 million people living with a long-term condition in England, and this number is set to rise. People with complex needs often need many different agencies to come together and support them. For this group, close working and good co-ordination are particularly vital. Initiatives exist at PCT and local authority level. Nonetheless, we know that there can be obstacles to partners working together – ranging from different financial cycles to differences in the way in which staff are trained. We need to tackle these obstacles nationally so that local services are freer to make their own choices about how they can improve joined-up working. We will develop a coherent strategy centred on patients, people who use care and support and their carers, to support local leaders in making sure that the services that are delivered are joined up.
- CiD comment: We agree that this is very important, especially for people who are terminally ill and who have complex needs. In developing a strategy in order to address this issue, the experiences of patients will need to be taken into account.

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

- From the Green Paper: We will need to offer a wide range of high-quality services for our diverse population, enabling everyone to live independently, well and with dignity. Commissioners will also 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.

However, organisations will not change unless the staff who are actually working with people to deliver care and support are in favour of the change. As people have more choice over the services they receive, and more control over how they live their lives, the role of the staff who work with them will also change.

The role of local authorities in building the market will require a different set of skills to those that were required when they tended to provide or commission the majority of services themselves.

- CiD comment: Reinforce the importance of choice (personal budgets!). Very important that people who use care and support services are involved. Crucial that staff has appropriate skills. Tailored services should not lead to a postcode lottery.

3) On high quality:

- From the Green Paper: Development of the workforce is at the heart of the Government's concern with high-quality care. The National Care Service will be underpinned by rights and entitlements, which support a high-quality service. The Department of Health recently published a strategy on the future of the care and

support workforce. In order to improve quality, we need to know which care and support services work best. We think we could do this by giving an independent organisation the role of providing advice to government on what works best and is best value for money in care and support. Listening to people's views plays an important part in making sure that services are of good quality and can help local authorities ensure that the right services are available. This can include working with users, user-led organisations and the third sector. Many local authorities are already doing this.

From autumn 2009, we will publish annual information on users' experience of social care in different local areas. This will form part of the new Comprehensive Area Assessment. This information will also be an important part of the separate assessment of adult social care carried out by the CQC.

Early in 2009, the Government issued new guidance setting out a simpler, joined-up approach to dealing with complaints in health and social care. This aims to make sure that the whole system responds quickly, flexibly and fairly to concerns and complaints.

- CiD comment: CiD is supportive of a stronger framework of rights and entitlements as proposed. Training for staff is at the heart of providing better quality services. We strongly support taking into account users' experiences and we welcome an adapted complaints system (see the guide on Rights at the End of Life).

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?

CiD comment: We are not in a position to take a stand on which funding option we prefer – this sort of funding issue is extremely contentious and 'political'. We can emphasize the principles that need to underpin any funding option (fair, simple, affordable, predictable, flexible....)

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

CiD comment: The most important factor is that any system needs to be predictable. People need to know what kind of care and support services they can expect in any given locality in England. We want a flexible system with services that are tailored to people's needs but without the side effect of a postcode lottery.