

Terminally Ill Adults (End of Life) Bill

Key considerations for the Adult Social Care Sector

28th November 2024

The National Care Forum

The National Care Forum (NCF) is the leading membership organisation for not-for-profit social care providers in England, bringing together over 175 of the UK's leading care and support organisations.

Our members offer thousands of services across the country, which are not-for-profit and always at the heart of community provision. Collectively, these organisations deliver more than £2.3 billion of social care support to more than 277,000 people and collectively employ more than 124,000 social care colleagues.

The NCF promotes collaboration, shares best practice, and advocates for positive change in the social care sector.

Our position on the legalisation of assisted dying

Our position is neutral – coming down on neither side of the assisted dying debate.

As the leading membership organisation for not-for-profit social care providers, the NCF has a broad membership. Our members provide a wide range of social care services to individuals in a range of settings including residential care, nursing care, home care, and community-based support. Our members also provide care to a range of demographics from older people with dementia to working age adults with learning disabilities and autistic people.

As expected with a broad membership base – providers have expressed a diversity of positions on assisted dying legislation. Our role as a trade membership body is to facilitate conversations, allow dialogue, help our membership understand the bill, and to help communicate questions and concerns to parliamentarians when they arise.

This briefing

This briefing has been developed to help elevate the voice of adult social care in the national discourse. To date, there seems to be a lack of engagement with the social care sector and little thought given to the practical considerations of this legislation on social care settings, providers and our workforce. Below are a number of considerations that need to be urgently addressed in relation to the Terminally Ill Adults (End of Life) Bill.

Absence of social care in the current thinking about the legislative framework: the proposed bill seems fairly silent on how social care fits into this proposed legislation and how the potential impacts of it might be managed in social care. Care and support service support some of the most vulnerable people in the country, some of whom may choose to exercise their right to die under the proposals. The bill views this primarily as an issue for health care providers; our members feel very concerned that the implications for social care seem absent in the debate.

Our members have made clear that there are many challenges that a change in the assisted dying law might pose for providers of care and support. These include significant governance considerations, as well as significant practical challenges that will need careful consideration for those operating care and support services under any new law.

Offering our expertise of lived experience: providers of care and support services bring valuable lived experience to this debate which we believe is key to understanding how the legislation, safeguards and processes need to be crafted and how they can be implemented.

Amongst some of our members, concerns have been raised based on provider experience and expertise in supporting people who come to live with them for end-of-life care. These providers have reported that individuals who were expected to live for only a very few weeks or months have thrived and lived for much longer than expected due to the expert care and support they received. From their perspective, they are uncomfortable with introducing assisted dying legislation before undertaking the fundamental reforms and funding increases needed to improve adult social care and wider healthcare services.

While the safeguards in the bill are welcome, we need to ensure they also address these concerns that some of our members have. Part of this will be ensuring that there are relevant safeguards for adult social care settings. Wider than this piece of legislation, we must push for the reform needed to improve our health and social care services, including palliative care, so people are enabled to have a better quality of life for longer whilst also giving the widest range of options at the end of life depending on their circumstances. Assisted dying may be one of those if the legislation passes. Much of the concern around the legislation from some of our members is derived from the lived experience of the pandemic with the wholly inappropriate use of the Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) as one clear example.

The legacy of COVID-19 and DNACPR: During the COVID-19 crisis our members raised concerns that NHS colleagues were applying blanket “Do Not Attempt Resuscitation Orders” (DNACPRs) on people with learning disabilities and older people under their care, without involving the individuals or families or taking into account each person’s individual circumstances. The pandemic exposed the deep biases present in the health system and highlighted the deep-seated and damaging *discrimination* people with a learning disability and autistic people face when trying to access medical care. The lessons from the pandemic need to be learned and if the legislation is to be safely implemented, we must also tackle the deep-seated biases that continue to exist in our health system.

The bill is clearly conscious of the importance of safeguards for people with mental health problems and disabilities and protection against coercion. Nevertheless, our members regularly observe that we live in a society that can be prone to broader ageism and discrimination against those with disabilities. Our members are concerned that some of the people they support may sadly already see themselves as a burden. This can be financial, or just because they are now reliant on those who once relied on them. The concern is that this makes them vulnerable to deciding for this reason alone, or as a result of exploitation.

Key questions for the legislation:

- How is the legislation proposing to tackle and address the deep-seated biases that often underpin medical decision making?
- What particular protections are in place to avoid disproportionate impacts on minority communities, people with learning disabilities, and those without advocates in the system?
- How is the interface between social care and health being considered? Particularly in cases where people who draw from care and support are admitted to clinical settings/engage with the healthcare system?

The role of care providers: There is a lack of clarity around the role of social care providers in the proposed assisted dying process. As organisations that support some of the most vulnerable people in the country, the role of the social care provider is as important as the role of the health care provider in this proposed legislation and yet it seems absent from the bill and the debate.

The focus on clinicians and the lack of reference to social care providers has concerned our members.

Key questions:

- What is the **exact** role the legislation envisages for care providers in the assisted dying process?
- What consideration has been given to the ability to opt out of this legislation as a care provider organisation?

Impact on social care settings and the wider community that lives there

Accommodation-based social care services are often communities in their own right. Often people have lived in settings for a number of years, with evolving relationships, friendships and companionship.

It is not clear that the bill has thought through the implications and consequences of those settings becoming places where people opt to their right to die. After all, social care settings are one of the places where people die, thinking especially of older people and the hard work that goes into helping people die in their preferred place of choice, which is usually not hospital.

Some members are concerned that it is hard to model what a change in the law might mean for those communities. Some say it would unintentionally create a burden of constant deliberation, and a stressful environment where people perceive they are being continuously assessed about whether they qualify. Some are concerned about the pressure or distress this may put on people in the wider community. This speaks to the tension between individual rights and the potential impact they may have on congregate communities of people.

While we recognise that the legislation has been deliberately crafted in a narrow way to avoid eligibility expanding, some of our members are still concerned that this cannot 100% be mitigated against and worry that any expansion would leave communities under intense pressure, particularly with an unreformed health social care system, and the need to improve palliative care.

Key questions

- What is the **exact** role the legislation envisages for social care setting in the assisted dying process?
- What consideration has been given to the ability to opt out of this legislation applying to you as an individual care setting?

Impact on the social care workforce, in care settings and in the community

The role of the care workforce: Beyond the provider organisation level concerns, some providers have raised concerns for their workforce, some of whom may be clinicians as well as skilled care workers, who may be expected to play a part within the process. The bill seems silent on the potential role of our workforce as it focusses on clinician and health care professionals

Some members have raised that they can foresee a time when the social care workforce is required to provide information, or documentation in cases where a request has been made by someone who lives with us. This would place an emotional and operational burden on employees who join the profession to add quality to the lives of those within our care. The relationships formed by social care professionals are entirely different to the ones formed by medical professionals whom residents may only see occasionally.

On a further practical note, one particular concern raised by some providers and the ASC workforce is that they may be drawn into giving formal/informal advice on ending a life. This may well cause difficult of legal challenges as well as emotional ones, and direct conflicts of interest.

The diversity of the social care workforce, especially thinking about those working in homecare/ community settings, makes it even more vital that the bill considers the impact on the wider social care workforce, not just clinicians and health professionals

Key questions:

- What is the **exact** role the legislation envisages for the social care workforce in the assisted dying process?
- What consideration has been given to the ability to opt out of this legislation applying to you as an individual care worker
- And what about clinicians in social care?
- Does the legislation set out strict boundaries on who does/doesn't advise on an end-of-life decision?

Ability to opt out on basis of faith/ belief both as a care provider organisation, as a care service and as a care worker

Conscientious objection: Some charitable providers and not for profit providers of social care in the UK are sponsored by, or have their origins in, religious faiths of one type or another (most notably Christianity). As a not-for-profit trade association, our membership includes several such organisations. These organisations derive their values and operational principles from the

faith that they are aligned to, giving confidence to those that live and work within them, whether they share the same faith, any faith, or none.

There seems to be little consideration of this within the draft bill, perhaps because it is much more a characteristic of the care and support sector, especially the not-for-profit care and support sector, than the NHS. Many of our members have grown out of community activism, from a desire to make a change to people living in local communities, in terms of good access to care, support housing and companionship – a small proportion of these have come out of faith activism in communities.

Some members have registered concern that the draft bill does not recognise this and that this has very real-world implications for their ability to comply with the bill as currently drafted, both in terms of service provision and in terms of expectations on their staff. These providers have raised anxieties that the bill would result in the closure of valuable services if those organisations were not able to honour assisted dying wishes that don't align with their ethos and values. Other pieces of legislation have had to grapple with this concern, both for organisations and individual workers.

Key question:

- How will the right to “opt out” be enshrined in the law for providers, services and individual workers?
- What legal protections are in place for providers who do not wish to contribute to in the process of assisted dying?
- What legal protections are in place for social care workers who do not wish to contribute to the process of assisted dying?

Understanding how this bill applies to people with dementia

It is not clear from the scope of the bill how, if at all, this applies to people with dementia. We note the protections around mental capacity and safeguards around mental ill health and disability, but it seems less clear how this works for those at the early stages of dementia, with fluctuating capacity. Given that dementia is the leading cause of death in the UK ([Dementia UK](#)), it seems important to clarify.

Legislative Creep: Some members have highlighted a concern around the potential for incremental extension of eligibility criteria once assisted dying is legalised. Care providers working with working age adults with a learning disability, autistic people, those with severe mental health conditions, and older age adults with dementia have particularly raised concerns. Providers have outlined that they would like to see clear legislative safeguards that protects against the expansion of eligibility criteria to individuals at higher risk of exploitation.

We note the safeguards around mental health, disability and coercion and welcome these. We also note the power for the SoS to create a code/ codes of practice and the Five Year Review

Key question:

- Are these enough? Will these legislative safeguards protect against the expansion of eligibility criteria once assisted dying is legalised?

Coalition of Frontline Care for People Nearing the End of Life

The Coalition of Frontline Care (CFC) for People Nearing the End of Life is a partnership of leading organisations from across health and social care, united by a desire to promote best practice in care for older people in their final years of life in all settings, by empowering the three million-strong frontline workforce. Together we represent most of the health and social care workforce who care for most people in their last years of life and the leading provider of End of Life Care (EOLC) training for frontline staff, The Gold Standards Framework (GSF) Charity.

The National Care Forum is an active member of the coalition alongside partners such as the Homecare Association, Community Hospitals Association, The Associated Retirement Community Operators, Care England and the British Geriatrics Society.

The Coalition has produced a vital report entitled '[End of Life Care is Everyone's Business](#)'. It shines a spotlight on the importance of improving the consistency and availability of high quality of end of life care for all who need it in our country. There is a striking need to improve the provision of end-of-life care for the many thousands that need it each year, and to improve safeguards for the most vulnerable regardless of the decision the house takes on assisted dying legislation. The Coalition consists of independent separate organisations, so takes no single position itself, but some members have done so (see, for example, the [British Geriatric Society](#) position).

Get in touch

If you would like to discuss any of the points raised throughout this briefing further please do contact the NCF team.

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