

Terminally Ill Adults (End of Life) Bill

Submission of Evidence by The Orders of St John Care Trust

The Orders of St John Care Trust (the 'Trust') is one of the UK's leading not-for-profit care providers. We operate across more than 70 locations, and our offering to older people includes specialised dementia services, intermediate or reablement care, respite, day care, and expert nursing. Our sole purpose is to provide the best possible care to those who live with us – some of the most vulnerable people in society.

We are a major provider of services to Local Authorities and the NHS.

On behalf of the Trust, we submit the below evidence to the **Public Bill Committee**, which should be considered specifically within the area of social care in which older people live in residential services (Care Homes).

This submission builds upon an earlier submission made to the Health and Social Care Committee's inquiry on Assisted Dying in 2023 (submitted as appendix 1), and in particular, a letter sent to all MPs in the week prior to the second reading of the Bill on 29 November 2024 (submitted as appendix 2).

Separate to this submission, the Trust has commissioned research which will pull together the real experiences of care homes in other jurisdictions, where Assisted Dying is already in place. We intend to draw on the outcomes of this research in a further submission to the Bill Committee as soon as it is available.

We are willing to have a more direct involvement with the Bill Committee, knowing that we will be able to add significant expertise and experience through the lens of a longstanding charitable provider.

In summary, we believe that the Bill as drafted is flawed, and the risks to older, vulnerable people, residing within social care environments are substantial.

We believe that any assumption by those drafting the final legislation that it is not intended for use by those living with conditions regarded as part of the ageing process, would be mistaken. Any legislation would be immediately tested and assumed to be accessible to such a cohort of people.

To that end we believe that in order to provide the necessary protections to such a vulnerable part of our society, the Bill must be explicit in its reference to older people living in residential services.

The Bill must take account of the current unfairness and instability at the heart of our social care system, and question whether such legislation can be introduced whilst such problems exist.

The Bill must recognise that an individual health/social care professional's ability to remove themselves from the process of Assisted Dying is so difficult, that specific exclusion of the care home sector should be a feature of the Bill. In any case, organisations, and sites, should be given the ability to exclude themselves from the act of an assisted death without prejudice to their approval as providers of services to the state.

The points below are aimed at helping the Bill Committee to better understand some of the specific points made in our letter to MP's (appendix 2).

1. Current state of Social Care Provision for Older People in Care Homes

It is widely accepted that the current social care system is unfair, inadequate, and in urgent need of reform.

Those in need of care, if funded by the state, face exceptional waiting times for help and inconsistent levels of care and support when they receive that help. Whilst the overall spend by government on social care is substantial, at an individual level, funding is grossly inadequate.

Those that fund their own care pay substantial sums, often saved for over a lifetime - including property wealth. These savings will have been set aside for retirement and to pass on to loved ones. Instead, they are used to fund the costs of their own residential care, and to substantially subsidise the state.

We see the real prospect that those that might fit the criteria for assisted dying under the Bill, but have no wish to accelerate their death, would feel an immediate dilemma between prolonging their own lives, and the future quality of life of their loved ones. For illustrative purposes, the six-month period stated within the current Bill would equate to between £25,000 and £40,000 of expense borne by an individual paying for their own residential care in the current system.

Failings in the system mean that older people who should not be in hospital are held there, causing a burden to the NHS, and Local Authorities face an ever-growing proportion of funding needed to support social care, without a proportionate increase in funding from central government.

As a result, we fear that whilst not spoken about explicitly, older people in social care as a whole are already viewed as a burden, and a problem without a solution. The use of terms such as 'bed blockers' illustrates this view. We believe that older people are already consciously or unconsciously the victims of discrimination in the way that the state serves them.

During the pandemic, we saw the appalling attempts at a widespread use of 'Do Not Attempt Resuscitation' arrangements for older people. This is a clear demonstration that an existing broken system places a lower value upon the lives of older people than of others.

To this end, we ask the Bill Committee to consider whether it is possible at all to achieve workable Assisted Dying legislation before this sector is substantially reformed.

2. Fundamental differences in personal/professional relationships, in older peoples' social care

Relationships within residential care for older people are both professional and intimate. Carers, Care Leaders, and Service Managers are all competent health and social care professionals, but they are also friends and confidantes of those that live within social care services. The relationships are familial in the sense of contact for hours each day and the extension of support to ordinary, everyday issues outside the scope of normal healthcare professionals.

Our employees deliver loving care and build relationships in a way that residents come to depend upon and take comfort from. Such relationships are key to excellent care provision, and these important relationships enhance and prolong lives by providing a sense of purpose and of place to older people.

In such a setting, it renders the ability for an individual to refuse to partake (Section 23 – No obligation to provide assistance), as useless.

In an environment such as a care home, there is no way in which a professional could be fully 'separated' from Assisted Dying, should a resident that they work with closely seek to enquire about or make a request.

Imagine a scenario where an individual living in social care is at the point where they will be provided with the approved substance to bring about their death: In a care home, this is likely to be in their own room, which will be in close proximity to many other older people who live within that setting. It will be commonplace and understandable that the magnitude of the event will mean that the

individual will wish to have company and comfort up to and immediately before/during the period in which the substance is taken.

A request for the company of a care professional will create a substantial moral dilemma for that person, profoundly so if they are individually opposed to Assisted Dying. Even where they are not, it will mean that they will intimately witness the death of someone with whom they have a strong bond; with that death having come about through facilitation, rather than naturally.

The scenario is made worse by the prospect of an assisted death not resulting in a quick nor painless death. There are examples from other jurisdictions of significant complications leading to painful deaths and deeply traumatic experiences for loved ones. Social care professionals should not be exposed to the risk of such experiences.

To this end, we ask the Bill Committee to consider the unworkable nature of individual exclusion from the processes of Assisted Dying for social care professionals.

Consequently, specific exclusion of the care home sector should be a feature of the Bill. In any case, organisations, and sites, should be given the ability to exclude themselves from the act of an assisted death.

We have copied below the key bullet points from our letter to MP's (appendix two) for ease of review as part of this submission:

- Many residents move into our homes for end-of-life care, expected to live for only a very few weeks. Determining prognosis of an individual's condition and judging how long they have left to live is inevitably difficult and prone to error. We regularly see that when a sense of self-worth, place, and belonging are restored, the therapeutic value can be greater than all medicine. Loving care can vastly improve quality of, and length of life, and change individual outlooks. Many of our residents 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. This makes them vulnerable to deciding for the 'wrong' reason, or as a result of exploitation.
- The above point is amplified hugely by the fact that all parties acknowledge that the social care system is in crisis. Our sector is unreformed and inherently unfair, with those responsible for funding their own care paying more, and too often exhausting almost all the savings they have built up over a lifetime. It is without question that a proportion of people in this group will consider an application for an assisted death to protect the prospects of their loved ones, and not because they wish to die.
- We can foresee a time when it is our employees who find themselves providing information or documentation in cases where a request has been made by someone who lives with us. This would place a huge emotional 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.
- We cannot be drawn into giving advice (whether this be formally to medical professionals or informally to residents or their families) as this would open us to all sorts of legal challenges as well as emotional ones, and direct conflicts of interest.
- We have concerns about the potential for incremental extension of eligibility criteria once legalised. Where access to assisted dying is already permitted, there are clear examples where countries have subsequently widened their qualifying criteria. There is no basis on which to assume the UK would be any different.
- We are concerned for those around the periphery of the process, especially our employees in an organisation with a Christian ethos, who may be expected to play a part (albeit in the background) within the process.
- Many of the charitable providers of social care in the UK are sponsored by, or have their origins in, religious faiths of one type or another. Such organisations derive their values and operational principles from the faith body 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. A change in the law may lead in some cases, to the disassociation between sponsor and day-to-day charity, which would serve to destabilise and bring about substantial costs in an already fragile sector.

APPENDIX 1

(2023) Response to Assisted Dying Inquiry submitted by the Trustee Board of The Orders of St John Care Trust

The Orders of St John Care Trust (the 'Trust') is one of the UK's leading not-for-profit care providers. We are a Christian charity who offer care to all faiths and none. We operate across over 60 locations and our offering to older people includes specialised dementia services, intermediate or reablement care, respite, day care and expert nursing. Our sole purpose is to provide the best possible care to those who live with us – some of the most vulnerable people in society.

On behalf of the Trust, we submit the below evidence to the Inquiry, which relates primarily to our experience in the field of social care. For clarity, we are not expressing views on behalf of our residents.

We start from a position of agreement with the current law on this issue in England and Wales and our comments relate to the specific changes which would follow if the law permitted Assisted Dying as defined by the Parliamentary Office of Science and Technology briefing (i.e. Healthcare professionals would be actively involved in the provision or direct administration of lethal drugs, at the patient's request).

Providing healthcare professionals with an ability to accelerate the death of a person creates real challenges for our residents:

- Many residents move into our homes for End of Life care, expected to live for only a very few weeks. Determining prognosis of an individual's condition and judging how long they have left to live are inevitably difficult and prone to error. We regularly see that when a sense of self-worth, place, and belonging are restored, the therapeutic value can be greater than all medicine. Loving care can vastly improve quality of life and change individual outlooks.
- Whilst there would be strict eligibility criteria, there will be inevitable scope creep, and areas of poor or differing practice. Many of our residents 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. This makes them vulnerable to making a decision for the 'wrong' reason, or to exploitation.
- For those already living in care homes, a change in the law may unintentionally create a constant burden of deliberation, additional pressure through witnessing the choices of fellow residents to opt for assisted dying and potentially a stressful environment where residents perceive they are being continuously assessed about whether they qualify. A change in law may erode the trust placed in medical professionals by our residents.
- Many residents do not have capacity to make specific decisions in the last months of their lives. This is an area of acute concern.
- We can foresee a time when it is our colleagues who find themselves giving information/evidence /documentation in cases where a request has been made by someone who lives with us. This might place a huge emotional burden on colleagues who join the Trust largely to extend and enhance the lives of those in our care. The relationships formed by social care professionals are often entirely different to the ones formed by medical professionals whom residents may only see once or on occasion. We cannot be drawn into giving advice (whether this be formally to medical professionals or informally to residents or their families) as this would open us to all sorts of legal challenges as well as emotional ones, and direct conflicts of interest.
- We have concerns about the potential for incremental extension of eligibility criteria once legalised. Where access to Assisted Dying is already permitted, there are clear examples where countries have subsequently widened their qualifying criteria. There is no basis on which to assume the UK would be any different.
- Precedents elsewhere suggest that conscientious objection safeguards are primarily limited to individuals and not institutions. As a faith-based organisation, we would find ourselves unable to facilitate Assisted Dying. Any change to the law could place us and others like us in an irreconcilable position if the law were to require such facilitation from us. For care providers with large local-authority funded resident bases, the possible imposition of a contractual

obligation to facilitate Assisted Dying could pose an existential threat to the Trust and reduce the number of beds available for Local Authority purchasing. As a minimum, any proposals should allow both organisations and their staff members to claim exemption. In any event, we foresee that pressure would be exerted upon “dissenting clinicians” to refer residents requesting drugs to end their lives to a clinician who will assent.

- We are concerned for those around the periphery of the process, especially our staff in an organisation with a Christian ethos, who may be expected to play a part, albeit in the background, with the process without being able to opt out in any meaningful way.
- Finally, what impact would a change in law have on the value of the lives of older people, and might this have a consequential impact on the provision of services and care that give purpose to and quality of life? There is not yet enough research into the societal impacts of a change in legislation in jurisdictions where the law has already been changed. Our concern is that the value of the lives of older and disabled people will be diminished and this could adversely affect healthcare decision making in the longer-term, e.g. investment in palliative or end of life care services.

The Trustees of The Orders of St John Care Trust, made up of:

Mark Everall - Chair

Millie Wentworth-Stanley, MA, LL.M – Deputy Chair

Richard Fitzalan Howard, Trustee

Graham Hutton, Trustee

Professor Jill Manthorpe, Trustee

Judy Wright, DStJ, Trustee

Richard Milligan-Manby, Trustee

Dr Anton Borg, Trustee

Anne de Bono FRCGP FRCP FFOM, Trustee

Tim Church, Trustee

James Macnamara, MStJ TD VR JP FCA, Trustee

James Kneller OLJ, Trustee

20 January 2023

APPENDIX 2

Text from a letter emailed to all MP's in the week prior to the second reading of the Bill on 29 November 2025

Terminally Ill Adults (End of Life) Bill

I write in advance of the second reading of the Terminally Ill Adults (End of Life) Bill in the House of Commons on 29 November.

The Orders of St John Care Trust is one of the UK's leading not-for-profit care providers. We are a Christian charity which offers care to all faiths and none. We operate across more than 70 locations and our offering to older people includes specialised dementia services, intermediate or reablement care, and end of life care and respite, day care, and expert nursing. Our sole purpose is to provide the best possible care to those who live with us – some of the most vulnerable people in society. Sixty percent of those we care for are funded by the state either via local authorities or the NHS.

The Bill is flawed, and the risks to older, vulnerable people, residing within social care environments are insurmountable.

Kim Leadbeater was kind enough to hear our concerns in person on 20 November, and from that we derive that older people living with dementia or living with conditions generally regarded as part of the ageing process, are not intended to be the focus of the Bill.

Regardless, our view is that in its current drafting, the Bill is not explicit in its reference to adult social care for older people and does not make adequate provision for the protections and exclusions required to protect individuals.

We hope that when deciding how to vote on 29 November, you will have regard to the insights of an experienced adult social care provider on the potentially adverse impact of the Bill on those living and working in the adult social care sector:

The Trustees and executive of The Orders of St John Care Trust have substantial concerns for the safety and wellbeing of those that live in social care environments for older people, most commonly care homes, and those professionals that work within the sector.

Providing healthcare professionals with an ability to accelerate the death of a person creates real challenges for our residents:

- Many residents move into our homes for end-of-life care, expected to live for only a very few weeks. Determining prognosis of an individual's condition and judging how long they have left to live are inevitably difficult and prone to error. We regularly see that when a sense of self-worth, place, and belonging are restored, the therapeutic value can be greater than all medicine. Loving care can vastly improve quality of, and length of life, and change individual outlooks. Many of our residents 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. This makes them vulnerable to deciding for the 'wrong' reason, or as a result of exploitation.
- The above point is amplified hugely by the fact that all parties acknowledge that the social care system is in crisis. Our sector is unreformed and inherently unfair, with those responsible for funding their own care paying more, and too often exhausting almost all the savings they have built up over a lifetime. It is without question that a proportion of people in this group will consider an application for an assisted death to protect the prospects of their loved ones, and not because they wish to die.
- We can foresee a time when it is our employees who find themselves providing information, or documentation in cases where a request has been made by someone who lives with us. This would place a huge emotional 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.
- We cannot be drawn into giving advice (whether this be formally to medical professionals or informally to residents or their families) as this would open us to all sorts of legal challenges as well as emotional ones, and direct conflicts of interest.

- We have concerns about the potential for incremental extension of eligibility criteria once legalised. Where access to assisted dying is already permitted, there are clear examples where countries have subsequently widened their qualifying criteria. There is no basis on which to assume the UK would be any different.
- We are concerned for those around the periphery of the process, especially our employees in an organisation with a Christian ethos, who may be expected to play a part (albeit in the background) within the process.
- Many of the charitable providers of social care in the UK are sponsored by, or have their origins in, religious faiths of one type or another. Such organisations derive their values and operational principles from the faith body 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. A change in the law may lead in some cases, to the disassociation between sponsor and day-to-day charity, which would serve to destabilise and bring about substantial costs in an already fragile sector.

Please consider what impact a change in law would have on the value of the lives of older people, and whether this might have a consequential adverse impact on the provision of services and care that give purpose to and quality of life?

There is not yet enough research into the societal impacts of a change in legislation in jurisdictions where the law has already been changed. Our concern is that the value of the lives of older people will be diminished, and this could adversely affect healthcare decision making in the longer-term, e.g. investment in palliative or end of life care services.