Terminally ill adults (end of life bill) - The implications for palliative care

Summary of the discussion held at the RSM on Wednesday 26 February 2025

On February 26th 2025 the Royal Society of Medicine's Palliative Care Section hosted a 'Moral Maze' style discussion focused on the Terminally Ill Adults (End of Life) Bill and implications of assisted dying for those involved in palliative care in the UK. Chaired by Michael Buerk of BBC Radio4's Moral Maze, the aim of the discussion between eight panellists and eight witnesses over the course of two hours was to delve deeper into issues, hear from different voices and generate new thinking. This document summarises the key points and themes raised by the experts in the room who represented a balance and range of views, and were speaking as individuals, not representatives. It also highlights some questions that were considered to still require exploration.

Everyone recognised both that this is a complex topic and that the Terminally Ill Adults (End of Life) Bill (referred to as the 'Bill' for brevity) had prompted worthwhile and greatly needed discussions across the country about preparing for death and dying well. This synopsis does not represent the views of the RSM who remain neutral in all the clinical discussions and debates they host. We hope that this summary including pending questions will be of interest and help to those who are involved in all end-of-life issues. We are very grateful to the participants for their time, and those who took part are as follows:

Name	Role
Professor Nancy Preston	Professor of Supportive and Palliative Care
Mrs Victoria Ali	Clinical Team Lead Nurse, and PhD candidate
Mr Toby Porter	Chief Executive Officer, Hospice UK
Dr Mary Hodgson	Director of Inclusion and Social Innovation and Visiting Associate
Dr Amir Simon Hannan MBE	General Practitioner
Professor Matthew Hotopf CBE	Executive Dean and Professor of General Hospital Psychiatry
Mrs Glyn Berry	Social Worker and Co-chair of the Association of Palliative Care Social Workers
Professor Suzanne Ost	Professor of Law
Dr Jamilla Hussain	Consultant in Palliative Medicine and Senior Research Fellow
Dr Rachel Clarke	Palliative Care Consultant
Mr Mark Jarman-Howe	Chief Executive Officer, St Helena Hospice
Professor David Oliver	Consultant in Geriatrics and General Internal Medicine
Professor Richard Huxtable	Professor of Medical Ethics and Law
Ms Michele King	Social Work, Welfare and Safeguarding Lead
Professor Katherine Sleeman	Professor of Palliative Care and Honorary Consultant in Palliative Medicine
Dr Graham Winyard CBE	Former Medical Director NHS Executive, and Board Member, My Death My Decision

Limited opportunities for open discussions on assisted dying in palliative care

Clinicians most closely involved with dying were claimed to be the most concerned about a change in the law. Some conversations around assisted dying have been polarised and the grey areas where potential concerns may arise were felt by some to have not been thoroughly explored within palliative care. Some clinicians report that simply engaging in discussion or research about assisted dying is perceived as an endorsement of the practice.

Many felt it to be crucial to create a culture within palliative care where open discussion is encouraged and accepted.

Practical considerations for palliative care professionals – involvement and integration

It was reported that the role of nurses has been overlooked in the literature, debates and research. UK nurses report requests to hasten death from patients near the end of life when the person is suffering, and sometimes this suffering can cause the nurse to suffer themselves. Alongside this a concern was expressed about our willingness to interrogate palliative care practice. In one recent study, nurses have expressed uncertainty about whether the interventions they regularly perform may inadvertently hasten death but reported feeling the discussion can be stifled by doctors.

Doctors' involvement in assisted dying includes assessing patients, prescribing medication, and being present at the time of death. Findings from the Netherlands, US, and Switzerland indicated most doctors are not opposed to a change in the law, but also that only a minority of doctors are willing to be actively involved in assisted dying. Swiss doctors were described as not being proactive in helping people to navigate assisted dying, which creates a risk that the medical community's stance on it could impact access. GPs, palliative care and geriatrics were claimed to tend to be against legalisation.

Assisted dying deaths were described as not “normal” deaths, ones which could be isolating for the healthcare professional involved and requiring an adjustment to the abruptness of death. It was claimed that assisted dying contradicts the core values of many healthcare professionals. If enacted, it was suggested that debriefing and amended workload allocations may be required to give physical or emotional space to talk about death and explore concerns.

Practical considerations for palliative care/ Health care professionals - training

Many recognised there is a lack of training on the concept of assisted dying within palliative care. It was suggested that open conversations about our current approach to potentially ethically challenging deaths could be the first step in identifying training and support needs, and that it would be essential to tackle public misperceptions about palliative care.

Most end-of-life conversations are not with specialists, but with GPs, district nurses, hospital teams etc. If the bill is passed, it was proposed that training for everyone involved in dying would be necessary, with an additional focus on trust, integrity, fairness, and decision-making for those directly involved in assisted dying.

Resource Issues

The Bill was described as highlighting gaps in palliative care, emphasising the need for more funding. While additional government money was noted as being already allocated, it was claimed more would be needed to ensure equitable access. Genuine end of life choices would rely on a well-funded palliative care sector, and some considered it would be a failure if assisted death were chosen due to fear of inadequate care.

Concerns about the NHS and the quality of medical and social care were described as widely valid, but improvements may take decades. It was observed that delaying legislation in the hope that the health system will eventually be fixed would not help those wanting an assisted death now

The current Bill requires doctors to remain with a patient until they die which was observed would require a significant additional resource. It was discussed that if assisted dying is fully state funded, there is a symbolic risk of sending the wrong message to society when hospice care is not. Alternatively, a private or partially government-funded assisted dying model could raise concerns about equity of access for those without financial means. Other country's funding solutions were referenced where some doctors may not charge for their services (Australia) or offer discounts, or people receive financial support from right to die organisations and charities (Switzerland).

Implications for the Hospice Sector

Participants were reminded that unlike MPs / individual physicians who are invited to act in line with their personal views, that it is essentially the opposite for hospice charities. Governing Boards of Trustees and Leadership Teams are required by law and regulation to always act in the best interest of the charity, and explicitly to put to one side their personal interests and opinions. Some believed that determining best interest of a charity in dealing with any change in the law would be an immensely complicated task for hospices. There would be a myriad of considerations – duty of care to patients, community opinion, as well as potentially significant practical implications on workforce and finance.

Choice, power, individualism and community

Recent community research by St. Christopher's Hospice looking at public views on assisted dying was shared, indicating a considered pro-social approach that was compassionate, not polarised. People's views on the proposed legislation were shaped by their lived reality. Those with lived experience of inequalities, and those with negative or inequitable healthcare experiences expressed more concerns, but this didn't always mean they were opposed. Power imbalances between health and social care institutions and the community was felt to underly negative dying experiences. It was reported that framing assisted dying within healthcare could further impact those with lived experience e.g. disabilities.

For some marginalised groups assisted dying was described as a luxury worry, they are far more concerned about their basic needs being met. Another report was shared of conversations with 98 people from ethnic minorities in Bradford, none of them had heard about the Bill. It was suggested that communities need to be more involved and engaged in addressing the issues the Bill raised, and that patients and carers are some of the most underutilised resources the NHS has.

It was reported that there has been no equality impact assessment as it's a private member's Bill, so it needs statutory guidance if safeguards are to be effective.

End of Life conversations and Death literacy

Some described death being as much a social event as a clinical one. Many agreed that conversations about death and dying well and advance care planning, need to be undertaken much earlier and need to be culturally appropriate. A campaign was suggested to educate the public on ‘death literacy’ and clinicians on overmedicalisation of death and individualised care.

It was shared that clinical teams have experienced resistance from patients and families when they try to de-medicalise death, talk openly about end-of-life care and initiate treatment escalation discussions including resuscitation. Some people were described as highly resistant to referrals for specialist palliative care services, and some believe that palliative care is already a form of assisted dying.

It was reported that positive experiences of assisted dying in other countries have been described by families where they were well supported, respect shown to the patient and the uncertainty of the timing of loss removed. Yet it can still be a taboo subject, and some choose to keep their decision secret from people, which can complicate bereavement. Suggestions were made that assisted dying conversations would need to be normalised in the UK so they are not limited by fear and taboo.

Trust

A national survey from last year was referenced in which one in three people from ethnic minority groups reported they don't trust healthcare professionals to provide high quality palliative and end of life care. One in five people from ethnic minority groups believed palliative care means giving people drugs to end their lives.

The value of continuity of care with healthcare professionals was described, less transactional interactions, and a proactive approach to support individuals by addressing the gaps they may have experienced. Technology could enhance this continuity as well as facilitate access to information and clearer communication between multidisciplinary teams, and across services.

Trust between professionals and patients was described as facilitated by responsible sharing and accountability through shared patient records, which empower patients and generates understanding. Also that access for families to health records after death helps engender trust. Social workers were observed as being able to help build trust with whole families, and that trust and access to information is just as achievable for minority groups, as demonstrated by some GPs.

In countries such as Switzerland and Canada, assisted dying is provided outside of mainstream healthcare system which was claimed to help maintain trust in healthcare professionals.

Coercion

Considerable discussion was held on the topic of coercion, with self-coercion, societal coercion and system coercion in relation to assisted dying all raised as important considerations. Reasons given were individual and internalised pressures, pressure exerted by societal norms or public opinion, and lack of resources including social care or poor housing.

Therefore, it was suggested that initial conversations with people who want an assisted death should include an assessment of coercion. There could be an early role for social workers who can assess the fuller quality of life picture including relationships, housing, welfare and social care responsibility. The point was made that assessments need to be done in real life not virtually, as coercion is difficult to spot and that social workers can also suggest advocates for those who lack sufficient knowledge or support.

Palliative care professionals were described as well-positioned to assess potential coercion and explore available palliative care support to address this. If a doctor or nurse were not allowed to bring up assisted dying, as stated in some laws elsewhere, this might limit open discussion in early stages. For more complex cases, some felt clarity is needed to understand how professionals will engage with clinical ethics support services.

It was observed that safeguards will not be 100 per cent and the balance and levels of safeguards were debated. Some believed we are overly focused on the issue of coercion surrounding assisted dying, especially when other countries aren't reporting evidence of it occurring.

Suicide and capacity

For some, the term 'assisted suicide' is thought to be more fitting, as the distinction between suicidality and a desire for a hastened death can be unclear. Suicidality can be driven by mental disorders, but a lot can be driven by intolerable social circumstances. If you look at desire for death in palliative care populations, a very high proportion of people who express a strong desire for death were described as changing their minds over the course of several weeks. Mental health is a continuum, and people fluctuate between different states of distress which influences how they view the world. Usually discussions about suicide are exploratory, less dominated by a binary decision and allow clinicians to “buy time” to allow the person alternative ways of seeing the future.

The Mental Capacity Act 2005 was described as outdated with variability and subjectivity in approaches to assessment of capacity, and to training. The Act was designed to put the person first and foremost, to assume capacity and the right to allow unwise decisions. It protects people’s right to refuse overzealous medical and social care. However, it was claimed to be flipped in assisted dying legislation, where you are using mental capacity to request something rather than turn it down. As a clinician you are using the mental capacity act to potentially deny someone something they want.

Proposed Model for Assisted Dying

If an assisted dying Bill were to be passed, it was suggested it could be led by an independent panel outside of the NHS to avoid embedding it in healthcare. The panel roles could include social workers and psychiatrists to review coercion and capacity, palliative care doctors and nurses to ensure palliative care options have been fully explored, a lawyer’s legal oversite and an ethicist to provide the proper framework for exploring justice, inequality and social responsibility. Methods to support families during and after the assisted dying process were described by some as key, as well as prospective reviews and clear oversight.

Recent amendments to the Bill include the addition of a panel. It was observed that it would be crucial to maintain a list of trained medical practitioners willing to participate.

The following questions were identified by the attendees as being outstanding areas for further consideration:

Q. *Could assisted dying be provided equitably outside the NHS?*

Q. *Is it practical to ask a doctor to remain with a patient given the variation in time people take to die?*

Q. *How will hospices be supported to determine their role if assisted dying is legalised?*

Q. *How could we empower communities to play a bigger role in making death a more social experience and an assisted dying law safe for them?*

Q. *How should we address public concerns about palliative care, such as beliefs that it hastens death, before implementing assisted dying in the UK?*

Q. *Will an assisted dying law impact trust in palliative care, and could this impact groups that are already underserved by palliative care?*

Q. *Is there a "level" of possible coercion acceptable for society when implementing an assisted dying bill?*

Q. *What tools could we use to more effectively assess capacity and the authenticity of wishes regarding assisted dying?*

Q. *How should we adequately identify palliative care professionals that want to be involved in assisted dying panels?*

End

Disclaimer

This document represents a summary of the discussions that took place between the chair, witness and participants. It does not represent the views of the RSM who remain neutral in all the clinical discussions and debates they host.