

“The problem was dying badly, and the answer was dying well”

Assisted Dying: A policy briefing

This briefing summarises research about assisted dying, conducted by Dr Jaimee Mallion, Lauren Murphy and colleagues, between January and May 2022. Interviews were conducted with eighteen people who had experience of terminal illness, were family members of those who had experienced a ‘bad death’ or had travelled abroad for an assisted death¹.

According to new data by the Office for National Statistics², people in the UK with severe and potentially terminal illnesses are more than twice as likely to take their own lives than the general population. Currently, one person every eight days travels to Switzerland from the UK to end their life.³

Despite this, assisted dying is currently prohibited in the UK, and those who assist a loved one to die are at risk of prosecution. This is despite substantial, continuing, and growing support for a change in the law, with 87% of the Scottish population supporting the option of assisted dying⁴. Recently, Liam McArthur MSP led a consultation for a change in the law⁵, enabling mentally competent adults, who are terminally ill to be able to request assistance to end their life. This received the highest number of responses for a consultation on a Members Bill in the Scottish Parliament to date, with a clear majority of respondents (76%), many of whom had first-hand experience of a loved one suffering a “bad death,” fully supportive of the proposal⁶.

This policy briefing identifies and summarises relevant literature, expanding on this with the addition of findings from a qualitative research project (conducted by the authors), concluding that a law change in favour of assisted dying should be supported, on the basis that it **enables terminally ill individuals to attain their basic human needs of autonomy, competence, and relatedness, and experience a good quality death.**

These conclusions are supported by three key research findings:

- 1) Assisted dying gives quality to the end-of-life
- 2) Assisted dying allows people to secure their basic human needs
- 3) Assisted dying does *not* result from the sense of being a burden

This briefing is based on research currently in preparation for publication, which was conducted at London South Bank University, in collaboration with Dignity in Dying Scotland.

¹ Some participants have requested to remain anonymous, to adhere to their wishes their names have been changed.

² Office for National Statistics. (2022). *Suicides among people diagnosed with severe health conditions, England: 2017 to 2020*. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplewithseverehealthconditionsengland/2017to2020>

³ Dignity in Dying. (2017). *The true cost: How the UK outsources death to Dignitas*. https://cdn.dignityindying.org.uk/wp-content/uploads/Did_True_Cost_report_FINAL_WEB.pdf

⁴ Dignity in Dying. (2019). *Dignity in Dying Survey Scotland*. <https://yonderconsulting.com/poll-archive/Dignity-in-Dying-Scotland-poll-11-24-March-2019-Q1-Q2-tables-for-publication.pdf>

⁵ McArthur, L. (2021). *Assisted dying for terminally ill adults (Scotland) bill*. <https://www.parliament.scot/-/media/files/legislation/proposed-members-bills/assisted-dying-for-terminally-ill-adults-scotland-consultation-2021-final.pdf>

⁶ McArthur, L. (2022). *Proposed assisted dying for terminally ill adults (Scotland) bill: Summary of consultation responses*. <https://www.assisteddying.scot/wp-content/uploads/2022/09/Assisted-dying-consultation-summary-FINAL-DRAFT.pdf>

1. Assisted dying gives quality to the end of life

Regardless of whether there was universal access to the highest quality palliative care, approximately 6,400 people annually would still suffer intractable pain during the last three months of life⁷. As Jackson and colleagues⁸ explain, not only does the experience of pain result in direct suffering, but it also prevents individuals completing tasks important to them at the end-of-life (e.g., grieving for the loss of their own life, organising legal affairs, and saying goodbye to loved ones).

The ability to access assisted dying would add to the individual's quality of life by alleviating total pain (i.e., physical, psychological, social, and spiritual pain) and suffering, preventing a sense of hopelessness, and enabling people to retain a sense of self⁹. Consistent with this, participants we interviewed saw assisted dying as a "basic humanity" that "could actually improve current palliative care services" (Emma, experienced bad deaths of family members). The desire to end intractable pain and suffering was cited as the most important reason for seeking an assisted death, as Hilary explains:

"If palliative care can't help me, then I want to know that I can say, 'I've had enough of this intolerable pain or this enormous discomfort.' (Hilary, mum experienced a bad death).

It was highlighted that having the option of an assisted death added quality at the end of life, with assisted dying seen as "reassuring" and a "safety-net" (Norma, who has terminal cancer). Assisted dying enables individuals to enjoy the remainder of their lives to the full, knowing that if the pain was unbearable there were still options available.

"I can sit back and say, 'I can really enjoy my life, what's left of it now', and I don't have to worry about it anymore, because assisted dying is just ... it's a nice, gentle, dignified, hopeful way to go." (Alex, who has terminal cancer).

The option of an assisted death reduces concerns about the future, helping individuals to live in the present. Participants explain that this can help them to come to terms with dying:

"I think not everyone that wants an assisted death will actually act it out in the end, but it may help them on the journey of dealing with their terminal illness." (Louise, whose father-in-law experienced a bad death from MND).

By enabling assisted dying, this could improve the end-of-life experience, particularly for those experiencing intractable suffering.

Under no circumstances did participants believe that assisted dying would replace palliative care, but assisted dying was perceived as an additional tool that could *improve* current practices.

2. Assisted dying allows people to secure their basic human needs

As demonstrated above, assisted dying is primarily motivated by the desire to alleviate pain and suffering⁹. To develop a deeper understanding, the current research explored additional factors which can lead some individuals to seek an assisted death.

⁷ Dignity in Dying. (2017). *Last Resort: The hidden truth about how dying people take their own lives in the UK*. <https://www.dignityindying.org.uk/wp-content/uploads/Last-Resort-Dignity-in-Dying-Oct-2021.pdf>

⁸ Jackson, V. A., & Leiter, R. E. (2021). Ethical considerations in effective pain management at the end of life. *UpToDate*. <https://www.uptodate.com/contents/ethical-considerations-in-effective-pain-management-at-the-end-of-life>

⁹ Hendry, M., Pasterfield, D., Lewis, R., Carter, B., Hodgson, D., & Wilkinson, C. (2013). Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying. *Palliative medicine*, 27(1), 13-26. <https://doi.org/10.1177/0269216312463623>

According to Self-Determination Theory¹⁰, there are three basic human needs: *competence* (mastery over activities), *autonomy* (sense of control and independence), and *relatedness* (feeling securely connected to others). Fulfilling all needs is fundamental for psychological well-being.

When an individual is terminally ill, it becomes challenging to achieve these. Take *competence*, as illnesses progress and pain and/or physical functioning worsens, individuals become less able to maintain activities they previously mastered (e.g., work/hobbies¹¹). Factors such as accessibility, pain, and embarrassment (e.g., fungating cancers) can reduce one's ability to spend time with others, negatively impacting on the basic human need of *relatedness*¹². Finally, a loss of independence, choice, and dignity, prevents a sense of *autonomy*¹³.

When we consider assisted dying, we often assume that it is the product of loss: a loss of function, loss of ability, loss of independence. However, our research has demonstrated that assisted dying can also **give**; give a sense of competence, relatedness, and autonomy. Critically, *these basic human needs are valued as much during the dying process as they are in life.*

Consistent with past research⁹, our participants want to have control over their life and the right to choose how they experience death: giving a sense of *autonomy*.

“I’m not scared of death. What I’m scared of is not being able to control it and not being able to do it in the way that I want to do it” (Sarah, who has experienced life-limiting conditions).

Participants highlighted that being able to make end-of-life decisions allows them to gain a sense of mastery over the dying process: fulfilling the basic human need of *competence*. Regarding *relatedness*, participants discussed how having an assisted death allows them to have their family with them during death, in a way which is peaceful and minimally distressing to all involved.

“What a nice thing to do, to choose your time, have your family round... had a big meal, they’ve all said their goodbyes, you have a wee drink, and you go to sleep, how fabulous is that?” (Norma, who has terminal cancer).

By enabling assisted dying, this could allow the attainment of basic human needs, leading to improved psychological well-being at the end-of-life.

3. Assisted dying does not result from the sense of being a burden

Opponents often argue that vulnerable individuals are at risk of feeling pressurised into seeking an assisted death, because of being an emotional, physical, or financial burden on family/friends/wider society¹⁴. Past research has indicated that experiencing feelings of being a burden are common among individuals with terminal illness¹⁵. However, a recent systematic mixed studies review, found this to be among the least important and least frequently cited reasons for seeking an assisted death.

¹⁰ Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68–78. <https://doi.org/10.1037/0003-066X.55.1.68>

¹¹ Marie Curie. (2022a). *Work and terminal illness*. <https://www.mariecurie.org.uk/help/support/ Diagnosed/practical-emotional-support/about-work>

¹² Marie Curie. (2022b). “You’re the first person who’s sat on that sofa in 12 months: Experience of loneliness among people at the end of life and their carers in Northern Ireland”. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/experiences-of-loneliness-among-people-at-the-end-of-life-and-their-carers-in-northern-ireland.pdf>

¹³ Colburn, B. (2020). Autonomy, voluntariness and assisted dying. *Journal of Medical Ethics*, 46(5), 316-319. <https://doi.org/10.1136/medethics-2019-105720>

¹⁴ Not Dead Yet UK. (2022). *Why are you concerned about assisted suicide becoming legal?* <http://notdeadyetuk.org/faqs/>

¹⁵ McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007). Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative medicine*, 21(2), 115-128.

Instead, unbearable suffering, pain, loss of dignity and autonomy, and hopelessness were the most important reasons¹⁶. This suggests that whilst feelings of burdensomeness are common in the terminally ill, it is not a strong motivating factor for seeking an assisted death.

This was supported by our current research, with findings indicating that whilst some (not all) participants ‘felt like a burden’, they highlighted that burdensomeness was driven by societal expectations, rather than because of personal or familial reactions to caregiving. Indeed, family members of those who had an assisted death abroad indicated that they did not perceive them to be a burden:

“Society says they’re going to be a burden so then the person thinks they’re a burden... I didn’t think she was a burden” (Tom, whose mum travelled to Dignitas for an assisted death).

Importantly, feeling like a burden on others was not cited as a reason for wanting or pursuing an assisted death. Instead, participants perceived *continued living* to be a burden for themselves:

“‘I’m not tired of life; I’m tired of living with MND.’ And that was the burden: it was his burden. He wasn’t a burden on anybody else: it was a burden to him – life was a burden to him” (Lesley, whose brother travelled to Dignitas for an assisted death).

As Lesley went on to highlight, the NHS¹⁷ commitment to patient-centred care should be considered when discussing the ethical considerations regarding burdensomeness:

“‘Patient-centred’ and ‘burdensome’, in my opinion, don’t go together because it’s you that wants it and you’re driving the process, it doesn’t matter what anybody else says... it’s what you want that drives everything” (Lesley).

Participants did indicate support for safeguards surrounding assisted dying, as proposed in Liam McArthur MSP’s Bill. Indeed, participants emphasised that having transparent procedures in place surrounding assisted dying could *protect* vulnerable people from the current informal, unregulated, and unreported processes that take place at the end of life (e.g., withholding/withdrawing life-sustaining treatment and palliative sedation) or from terminally ill individuals having to resort to attempting suicide using dangerous, painful, and often unsuccessful means.

Conclusion

This briefing has summarised the relevant literature, incorporating findings from a new qualitative study exploring attitudes toward assisted dying in the UK. As highlighted above, assisted dying can: give quality to the end-of-life, relieve intractable pain and suffering, add to palliative care practices, and enable people to achieve the basic human needs of competence, relatedness, and autonomy throughout the dying process.

In the words of Lesley: **“The problem was dying badly, and the answer was dying well”.**

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¹⁶ Roest, B., Trappenburg, M., & Leget, C. (2019). The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review. *BMC Medical Ethics*, 20(1), 1-21. <https://doi.org/10.1186/s12910-019-0361-2>

¹⁷ NHS Education for Scotland. (2022). *Person centred care*. <https://www.nes.scot.nhs.uk/our-work/person-centred-care/>