

“ENDING DEATH, NOT ENDING LIFE”

Understanding Positive Attitudes toward
Assisted Dying in the UK



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The front cover image of Heather was provided by her daughter Victoria.

(Please note, some identities have been changed at the request of participants to protect their identity).

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Foreword

My name is David Minns. I am dying of blood cancer, and I want the choice of an assisted death. The assisted dying debate too often focusses on the views of politicians or doctors but stories like mine and the ones you will read in this report should be at the heart of any discussion about how we cater to the needs of dying people.



I first saw the harm done by the current law in 2021 when my daughter Katie died an excruciating death from sarcoma at the age of just 46. As she lay dying in agony, I contemplated stepping in to end her suffering. I am horrified that the law forced me into a situation in which I considered killing my own daughter just to end her pain. On the day that Katie was told her own cancer was terminal, I was diagnosed with multiple myeloma and amyloidosis. My cancer knows no cure, and while I have tried all I can to stop or slow its progression, after careful consideration I have decided to stop all treatment. Chemotherapy is no longer working, and the side effects are debilitating. My amyloidosis, caused by the cancer, means my vital organs are slowly being damaged. As things stand, dying quickly of a heart attack is my best-case scenario as I am terrified of a slow and painful death.

The impact of Katie's death was the catalyst that spurred me into campaigning for assisted dying to be brought into law as a choice for terminally ill people, knowing all the while that I would not likely benefit from any change. Every year thousands of terminally ill people die in unrelieved pain, despite the best efforts of medical professionals, while hundreds take their own lives in lieu of a safe and compassionate assisted dying law. I believe we must change the law so that dying people can have choice at the end of their lives, while having the comfort of knowing they have the option of assisted dying if they want it.

The findings of this research are a crucial piece of evidence in the assisted dying debate. I am grateful to the researchers for giving people like me a voice and increasing our understanding of what lies behind public demand for greater choice at the end of life.

David Minns, December 2022

Executive Summary

Even the best quality palliative care has its limits. According to the Office of Health Economics, each year 50,709 end-of-life patients will die experiencing some level of pain, whilst 5,928 will experience no relief from pain *at all* during their last three months of life. It is unsurprising then that up to 650 terminally ill individuals take their own lives each year, with up to 10 times as many making attempts to end their lives, often using traumatic, dangerous, and painful means. Proponents argue that assisted dying can allow terminally ill individuals to have choice and dignity at the end-of-life, yet it remains illegal in the UK.

This research has explored the reality of dying in the UK from the perspectives of people with terminal illness and their families. Eighteen individuals who are terminally ill, family members of those who experienced a bad death, and family members who helped take a loved one abroad for an assisted death, were interviewed. This research aimed to understand *why people hold positive attitudes toward assisted dying*.

Assisted dying allows quality at the end-of life

The current blanket ban on assisted dying denies choice and leads to suffering, rather than emphasising *quality of life* at the end-of-life. The findings indicate that terminally ill individuals want a ‘good death’; one that is pain-free, that they have control over, and enables them to retain their emotional wellbeing. For participants, the desire to end unmanageable pain and suffering and wanting a good quality of life at the end-of-life were key factors influencing positive attitudes toward assisted dying.

Assisted dying acts as a “safety-net”, allowing people to enjoy the remainder of their lives without having to worry about what their death could look like. It can provide reassurance that, *should palliative care not work*, there are other options available to them. Assisted dying was viewed as an additional tool which could be used by palliative care services. Under no circumstances was assisted dying perceived as a replacement to high quality palliative care. Ultimately, findings indicate that having the option of assisted dying available, for those that want it, can add to quality at the end-of-life.

Assisted dying allows people to fulfil their basic human needs at the end-of-life

According to Self-Determination Theory, all human behaviour is motivated by the pursuit of three universal human needs: Autonomy, Competence, and Relatedness. Assisted dying has been discussed previously as a product of loss (e.g., loss of dignity, control, and independence). This research has pivoted the discussion, demonstrating that assisted dying can **give**. It allows terminally ill individuals to secure their basic human needs when other means have become unavailable (often because of pain and suffering). Assisted dying *gives* terminally ill individuals control over the dying process (Autonomy), enables them to make end-of-life decisions and by dying how they wish to, this gives a sense of mastery over the dying process (Competence), and finally, they can have a minimally distressing death that they are happy to share with family and friends (Relatedness).

Assisted dying does not result from feelings of being a burden

Feelings of being a burden are, unfortunately, normal amongst people who are ill – whether that is a short-term, chronic, or life-limiting illness. However, past research has demonstrated that the sense of being a burden is among the *least* important and *least* frequently cited reasons for seeking an assisted death. The current findings support this, with participants indicating that unbearable pain, suffering, loss of dignity and autonomy were the most important reasons for desiring an assisted death. Feeling like a burden was *not* the driving factor behind the pursuit of an assisted death. Instead, the findings indicate that terminally ill individuals find continuing to live with pain, suffering, and a loss of dignity and autonomy to be a *burden on themselves*. Pursuing an assisted death was based on one's own desire to have relief from pain and suffering.

Assisted dying legislation will give more safeguards than current unregulated processes

Whilst participants strongly opposed the view that burdensomeness played a role in assisted dying, they did support the implementation of robust safeguards within future law changes in favour of assisted dying. Findings indicate that an assisted dying law, such as those outlined in Liam McArthur MSP's 'Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill', will give *more* safeguards and protection to vulnerable individuals than what is currently in place.

Currently, there is a blanket ban on all forms of assisted dying in the UK. This has caused such practices to become secretive and hidden. This leads to terminally ill individuals attempting to end their suffering alone, often using dangerous and traumatic methods, or family members being put in the situation where they are risking conviction trying to help their loved one die how they want to. As it stands, people who want help to end their deaths are not protected and systems which promote open dialogue with dying people about their worries and concerns are discouraged. It is not until the person has died and no longer has a voice that investigations begin. With safeguards embedded within assisted dying legislation, checks can be made at an early stage that the individual is mentally competent and is making the decision *for their own benefit*.

Conclusion

To conclude, **“the problem is dying badly, and the answer is dying well”**. With a law change in favour of assisted dying, for those who want it, assisted dying can provide quality of life at the end-of-life, enabling terminally ill individuals to have a safety-net should high quality palliative care not work for them. It allows them to have a sense of Autonomy and Competence over the dying process and gives them the opportunity to have a good death that they can share with their family, should they wish to. Ultimately, assisted dying is about giving terminally ill individuals choice at the very end of their lives.

1. Introduction

Assisted dying legislation: UK and abroad

Over 200 million people worldwide have access to a form of assisted dying, with the number of countries legalising assisted dying growing. Currently, assisted dying is legal in some form in the Netherlands, Belgium, Canada, Colombia, Luxembourg, New Zealand, Switzerland, Spain, Germany, Austria, all six states in Australia, and 11 states in the USA¹. Yet, in England, Wales, and Northern Ireland, it is a crime to encourage or assist suicide, with a maximum penalty of 14 years imprisonment^{2,3}. There is no specific crime for assisting a suicide in Scotland, although someone can be prosecuted under the banner of culpable homicide for helping an adult to die.

The debate surrounding assisted dying legislation is currently being considered in Scotland, England, and Wales. In Scotland, Liam McArthur MSP recently held a public consultation for the 'Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill'⁴. 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 proposal⁵. Following the results of the public consultation, Mr McArthur lodged a final proposal for cross-party support. The target of support from 18 MSPs, allowing the right to introduce the legislation to parliament, was reached within two hours of submission⁶.

A similar Private Members' Bill for the legalisation of assisted dying in England and Wales had its second reading in the House of Lords on 22nd October 2021 and was passed unopposed with most speakers in favour and strong cross-party support. However, due to a lack of time for full and fair debate, the Bill was unable to pass through all necessary stages before the parliamentary session ended. On 5th December 2022, MPs launched a new inquiry into assisted dying in England and Wales⁷.

Reasons for desiring an assisted death

New data by the Office for National Statistics⁸ found that 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. Research has suggested that dying people in the UK have ended, or attempted to end, their lives using a range of highly distressing, undignified, and violent

¹ World Federation Right to Die Societies. (2022). *World Map*. <https://wfrtds.org/worldmap/>

² Suicide Act (1961). *Section 2*. [https://www.legislation.gov.uk/ukpga/Eliz2/9-10/60/section/2/1991-02-01#:~:text=2%20Criminal%20liability%20for%20complicity%20in%20another's%20suicide.&text=\(1\)A%20person%20who%20aids,term%20not%20exceeding%20fourteen%20years.](https://www.legislation.gov.uk/ukpga/Eliz2/9-10/60/section/2/1991-02-01#:~:text=2%20Criminal%20liability%20for%20complicity%20in%20another's%20suicide.&text=(1)A%20person%20who%20aids,term%20not%20exceeding%20fourteen%20years.)

³ Criminal Justice Act [Northern Ireland] (1966). <https://www.legislation.gov.uk/apni/1966/20/contents>

⁴ 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>

⁵ 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>

⁶ McArthur, L. (2022). *McArthur wins right to introduce Assisted Dying Bill in Scottish Parliament*.

https://www.liammcarthur.org.uk/mcarthur_wins_right_to_introduce_assisted_dying_bill_in_scottish_parliament

⁷ UK Parliament Committees. (2023). *Assisted dying/assisted suicide inquiry*. <https://committees.parliament.uk/work/6906/assisted-dyingassisted-suicide/>

⁸ 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/suicidesamongpeoplewithseverehealthconditionengland/2017to2020>

means⁹. Not only can these be painful and distressing for the individual, but they are highly distressing for loved ones, first responders, or anyone else who may find the person who has ended their life.

Proponents for assisted dying argue that when death is inevitable, terminally ill individuals should have the right to control how and when they die. They suggest assisted dying is compassionate and prevents unnecessary pain and suffering, should palliative care not work¹⁰. Comparatively, opponents to assisted dying argue that high quality palliative care can relieve pain adequately in nearly all terminally ill individuals¹¹. Yet, the Office of Health Economics examined unrelieved pain across the UK, finding that even if everyone received the highest quality of palliative care, 50,709 end-of-life patients would experience some level of pain, whilst 5,928 would experience no relief from pain *at all* during their last three months of life¹². This suggests that palliative care, whilst beneficial to most, does have its limits.

Whilst experiencing intractable pain is often cited as a leading cause for desiring an assisted death, research has suggested that amongst those with manageable pain, the side effects of medication can equally be unbearable¹³. In addition, past research has identified that experiencing a poor quality of life, at the end of life, can lead to the desire for an assisted death¹⁴. Among some terminally ill individuals, their illness can have serious effects on their ability to function, which can lead to a loss of dignity, meaning, and sense of self, whilst reliance on others increases¹⁵.

Critically, opponents have suggested that the sense of 'being a burden' can lead some to pursue an assisted death. This argument warrants discussion, given that the sense of 'being a burden' is common amongst terminally ill individuals, due to their increased dependence on others to meet their physical and emotional needs¹⁶. Despite this, being a burden has been found to be among the least important reasons cited for seeking an assisted death, with factors including unbearable pain, suffering, loss of dignity and autonomy amongst the most important¹⁷. The need for choice, control and autonomy during the dying process are frequently cited as factors increasing the desire for an assisted death. These are synonymous with Self-Determination Theory, the idea that all human behaviour is intrinsically motivated by three innate and universal human needs (Autonomy, Competence, and Relatedness)¹⁸.

⁹ Dignity in Dying. (2021). *Last resort: The hidden truth about how dying people take their own lives in the UK*. <https://www.dignityindying.org.uk/news/hundreds-of-terminally-ill-brits-take-their-own-lives-in-uk-each-year-latest-estimates-suggest/>

¹⁰ Friends at the End. (2022). *Assisted dying*. <https://fate.scot/assisted-dying/>

¹¹ Care Not Killing. (2022). *FAQs*. <https://www.carenotkilling.org.uk/about/faqs/>

¹² Zamora, B., Cookson, G., & Garau, M. (2019). *Unrelieved pain in palliative care in England*. Office of Health Economics. <https://www.ohc.org/publications/unrelieved-pain-palliative-care-england>

¹³ Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Vissers, K. C., & Van Weel, C. (2011). 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying. *Journal of medical ethics*, 37(12), 727-734. <https://doi.org/10.1136/jme.2011.045492>

¹⁴ 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>

¹⁵ 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>

¹⁶ 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.

¹⁷ 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>

¹⁸ 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>

Yet, to date, there has been a lack of research directly exploring the influence of self-determination on attitudes toward assisted dying.

The Current Research

The current research aims to explore why terminally ill individuals in the UK desire an assisted death. Eighteen individuals who are terminally ill, family members of those who experienced a bad death, and family members who helped take a loved one abroad for an assisted death, were interviewed. Findings from this report aim to answer three key questions:

- (1) What role does assisted dying play in having quality at the end of life?
- (2) What role does the pursuit of basic human needs play in assisted dying?
- (3) How does social context and the sense of being a burden affect attitudes toward assisted dying?

2. Methodology

Two independent researchers from London South Bank University conducted 18 in-depth qualitative interviews. Dr Jaimee Mallion and Lauren Murphy from the Division of Psychology at London South Bank University (LSBU) interviewed people from three affected groups:

- People living with a terminal illness or life-limiting disability
- People whose loved one experienced a 'bad death'
- People who took their loved one for an assisted death in Switzerland

Ethical approval for this research was given by the LSBU School of Applied Sciences ethics committee. Interviews were drawn from a pool of people who had contacted Dignity in Dying interested in sharing their experiences. Dignity in Dying directly approached these individuals about the research. If they were interested, they were asked to contact the researchers. Interviews lasted from one to two hours. They were transcribed verbatim and examined using thematic analysis.

All quotes in this report are taken directly from the interviews. For clarity and concision, some quotes may be abridged. All interviewees gave full consent for the contents of their interviews to be used in this report and some provided images of themselves and/or their loved ones that they wished to share in the report.

Interviewees were asked whether they wanted to be identifiable. For some the fear of prosecution and disclosure of very sensitive information meant they preferred to be anonymous. In cases where the interviewee has asked to remain anonymous, a pseudonym has been applied. Where the interviewees real name is stated, full consent was given.

3. What role does assisted dying play in having quality of life at the end of life?

The World Health Organisation¹⁹ defines Quality of Life (QoL) as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. QoL is a multidimensional construct and incorporates five domains including physical, social, emotional, material, and developmental wellbeing²⁰. Simply put, QoL is an individualised and personal concept – how we experience life is informed by our desire to achieve, and our experience of fulfilling, the five domains. This means that to enhance QoL, we must also take an individualised approach.

The concept of QoL becomes more complicated when we begin to consider QoL at the end-of-life. *How can we ensure QoL when that life is ending?* For most terminally ill patients, having quality at the end-of-life is more important than simply prolonging the length, or quantity, of life²¹. Indeed, factors related to improved quality of death in terminally ill patients are synonymous with those reported as enhancing QoL. These factors include relieving pain, having autonomy, control, and dignity, and support from family and friends²². As such, to ensure quality at the end-of-life, we must also consider the quality of death itself.

The Institute of Medicine²³ defined a ‘good death’ as one that is “free from avoidable distress and suffering for patients, family, and caregivers, in general accord with the patient’s and family’s wishes, and reasonably consistent with clinical, cultural, and ethical standards.” The World Health Organisation²⁴ highlighted that a good death included relief from pain, in such that the patient could physically and emotionally achieve their goals before death. Supporting this, a recent review identified that the three key factors enhancing the experience of a “good death” are: pain-free status, having control over the dying process, and retaining emotional wellbeing²⁵. This review also found that assisted dying was a treatment preference enabling a good death.

Consistent with this, the current report found that the desire to end unmanageable pain and suffering, in turn supporting attainment of a good death, was cited as the most important reason for seeking an assisted death:

“He just had a terrible painful slow death, and he did end up with the kind of locked in situation... he was in pain despite the palliative care and he was in distress...” (Louise: father-in-law experienced bad death from Motor Neurone Disease [MND])

¹⁹ World Health Organisation. (2022). *WHOQOL: Measuring Quality of Life*. <https://www.who.int/tools/whoqol>

²⁰ Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in developmental disabilities, 16*(1), 51-74. [https://doi.org/10.1016/0891-4222\(94\)00028-8](https://doi.org/10.1016/0891-4222(94)00028-8)

²¹ Waller, A., Sanson-Fisher, R., Brown, S. D., Wall, L., & Walsh, J. (2018). Quality versus quantity in end-of-life choices of cancer patients and support persons: a discrete choice experiment. *Supportive Care in Cancer, 26*(10), 3593-3599. <https://doi.org/10.1007/s00520-018-4226-x>

²² Granda-Cameron, C., & Houldin, A. (2012). Concept analysis of good death in terminally ill patients. *American Journal of Hospice and Palliative Medicine*, *29*(8), 632-639. <https://doi.org/10.1177/1049909111434976>

²³ Institute of Medicine. (1997). *Approaching death: Improving care at the end of life*. National Academies Press. <https://doi.org/10.17226/5801>

²⁴ World Health Organisation. (1990). *Cancer pain relief and palliative care. WHO Technical Report Series 804*. <https://apps.who.int/iris/handle/10665/39524>

²⁵ Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): literature review and call for research and public dialogue. *The American Journal of Geriatric Psychiatry, 24*(4), 261-271. <https://doi.org/10.1016%2Fj.jagp.2016.01.135>

“My nan was in a tremendous amount of pain, she’d gone from being very independent, fun, active person, to couldn’t even lift her head up off the pillow. In those moments of awareness, she was so distressed it was painful to watch... she didn’t want to live the life that she found herself in, it was too painful.” (Chloe: mother and grandmother experienced ‘bad deaths’, husband has life-limiting condition)

“I’ve watched my grandparents, literally, fade to nothing in a lot of pain. I’ve watched so many people that I care about have a really, really horrendous ending and not an ending that, in any way, matches the person that they were. As I keep saying, I just don’t understand why we don’t have that choice [for an assisted death]. It just seems like a humane thing to do.” (Sarah: lives with disabilities, Grandparents experienced bad deaths)

“For such a dignified person, strong person, that level of indignity and suffering and pain and sickness and so on was intolerable, so futile in her mind as well. She would have wanted that dignified end with her family around her, as comfortable as she could have been made. There was no need for... it was cruel, it was cruel to extend that in the way that it went on, and it was testimony to her strength, of the person that she was, but that was so cruel and needless.” (Caroline: Aunt and Uncle experienced bad deaths)

“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)

“He’s railing in pain, it was just hideous, awful to see him suffer like that, so our memories will forever be of him having a terrible death instead of having the death we know he wanted which was him ending his life in a peaceful surrounding in a dignified way.” (Louise: father-in-law experienced bad death from MND)

What constitutes a ‘good death’ is highly personal, unique, and dynamic throughout the process of dying. End-of-life care should aim to alleviate ‘total pain’: physical, psychological, social, and spiritual pain and suffering. This prevents a sense of hopelessness and enables people to retain a sense of self²⁶. Alleviating total pain will differ from person to person, thus, to ensure a good death, this means listening to, and respecting, the rights and wishes of each terminally ill patient²⁷. As Amber (who is living with MND) explains:

“Everybody’s ‘cut-off point’ – if you like – is going to be slightly different as is what they consider an acceptable quality of life, given a terminal prognosis.”

²⁶ 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>

²⁷ Krikorian, A., Maldonado, C., & Pastrana, T. (2020). Patient's perspectives on the notion of a good death: A systematic review of the literature. *Journal of pain and symptom management*, 59(1), 152-164. <https://doi.org/10.1016/j.jpainsymman.2019.07.033>

Assisted dying has been suggested as a means of having a dignified and pain-free death, enabling autonomy, choice, and control over the dying process²⁸. Research has found that knowing the option of an assisted death is available enhances one's ability to tolerate both the illness itself and the uncertainty of the future²⁹. For instance, Georges et al.³⁰ interviewed 87 relatives of terminally ill patients who had an assisted death, finding an assisted death contributed favourably to the quality at the end-of-life in 92% of patients.

Findings from the current study suggest that having the option of an assisted death could add quality to the end-of-life of terminally ill individuals. Participants indicated that assisted dying enables the terminally ill individual to enjoy the remainder of their lives to the full, knowing that if the pain was unbearable there were still options available. Assisted dying was seen as **“reassuring”** and a **“safety-net”** (Norma: living with terminal cancer), alleviating worries and concerns about declining health.

“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: living with terminal cancer, mother experienced bad death)

“You’re going to die, its whether or not you die in pain, or whether or not you have the choice to live your life out not worrying about dying in pain’. That’s all assisted dying does.” (Shana: living with Multiple Sclerosis)

“I think an assisted death would feel like a safety net. If I can say – announce it – ‘I’ve really had enough. I’m in too much pain. I’m too limited in what I can do.’ I would be far more confident about carrying on longer if I knew that I could just say, ‘Right. I’ve passed it. Time’s up.’” (Amber: living with MND)

“Assisted dying’s just there as a last resort: as an insurance in case things get so tough, then they use it. And that’s, surely, what we want, and we should have in the UK.” (Angela: husband, Tom, experienced bad death from prostate cancer)

“I think assisted dying would be enabling for me, if I knew I’d got this safety-net of an assisted death if I wanted it, rather than fretting about what my death might be. That would be the benefit of it, I think a huge benefit, is the reassurance. It would be that reassurance that would bring a bit of calmness into my worries about the illness itself. I would think, ‘Well, at least that bit, I can, maybe, be in control of, even though I can’t control the fact that I’ve got this illness or what it’s progression ... how quickly it might progress or what it’s manifestations might be, but I could actually ... I’ve got some control’ and that would give me some comfort in the face of all that.” (Hilary: mum experienced a bad death)

²⁸ Rietjens, J. A., van der Heide, A., Onwuteaka-Philipsen, B. D., van der Maas, P. J., & van der Wal, G. (2006). Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. *Palliative Medicine, 20*(7), 685-692. <https://doi.org/10.1177/0269216306070241>

²⁹ Nissim, R., Gagliese, L., & Rodin, G. (2009). The desire for hastened death in individuals with advanced cancer: a longitudinal qualitative study. *Social science & medicine, 69*(2), 165-171. <https://doi.org/10.1016/j.socscimed.2009.04.021>

³⁰ Georges, J. J., Onwuteaka-Philipsen, B. D., Muller, M. T., Van Der Wal, G., Van Der Heide, A., & Van Der Maas, P. J. (2007). Relatives' perspective on the terminally ill patients who died after euthanasia or physician-assisted suicide: a retrospective cross-sectional interview study in the Netherlands. *Death studies, 31*(1), 1-15. <https://doi.org/10.1080/07481180600985041>

“The revelation that assisted dying existed and he might be able to take advantage of it, was like a light went on in his head and a weight was lifted from his shoulders. Because now, he no longer had to worry” (Lesley: accompanied her brother, who had MND, for an assisted death at Dignitas)

“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: father-in-law experienced a bad death from MND).

Past research has highlighted the similarities between the philosophies for palliative care and assisted dying; both are underpinned by the need for patient-centred and individualised care focusing on an individual’s right to die free from pain and with dignity³¹. Participants indicated that they saw assisted dying as a tool that **“could actually improve current palliative care services”** (Caroline: Aunt and Uncle experienced bad deaths). It’s important to note that *under no circumstances* did participants believe (or wish to see that) assisted dying would replace palliative care. Assisted dying was perceived as an additional tool, *for those that wanted it*, which could improve current practices and enable a good quality death:

“I feel it could actually improve palliative care, because that peace of mind of individuals knowing they have the choice and so on, then they could maximise the palliative care that’s available to them, to get them to the point where they feel that that’s then right. Nobody wants to talk about that kind of circle, that actually it could improve palliative services for everyone.” (Caroline: Aunt and Uncle experienced bad deaths)

“I am a really big, strong proponent and advocate for palliative care and better resourcing of palliative care and support for terminally ill people. I am a huge proponent, and my support for assisted dying does not conflict with that in my mind at all. I want both and I think dying people should have both, and they should be able to explore either or both options thoroughly, and one shouldn’t stop the other.” (Caroline: Aunt and Uncle experienced bad deaths)

“One of the opposition’s arguments is that this is almost deriding palliative care. And it absolutely isn’t... I think palliative care can be wonderful and it needs to be more available. It does need greater funding; it does need to be more mainstream for everyone – on offer for everyone. But it simply does not work for everyone.” (Hilary: mum experienced a bad death)

“Palliative care is wonderful; it works for a lot of people but it doesn’t work for everybody and that’s the problem. When you see people screaming out and the nurses trying because they can’t give you any more sedation or pain relief, it’s every four hours and they can’t do any more.” (Norma: living with terminal cancer)

³¹ Granda-Cameron, C., & Houldin, A. (2012). Concept analysis of good death in terminally ill patients. *American Journal of Hospice and Palliative Medicine*, 29(8), 632-639. <https://doi.org/10.1177/1049909111434976>

“As a family we have lost loved ones before and I think palliative care worked to an extent, much better than it worked for my mum so we are not saying that palliative care doesn’t work because it does, of course it does, but there are times when palliative care isn’t enough and in this instance that’s the case.” (Tom: accompanied his mother, who had Multiple Sclerosis [MS], for an assisted death at Dignitas)

The concept of assisted dying as compassionate and a basic human right has been reiterated time and time again throughout the literature^{32,33}. This was echoed by participants who highlighted that assisted dying should be viewed as a **“basic humanity”** (Caroline: Aunt and Uncle experienced bad deaths) that ensures people have quality at the end of their lives.

“I just don’t understand why we don’t have that choice [for an assisted death]. It just seems like a humane thing to do... “I’ve seen people in so much pain and just horrific stuff happening. And I’m like, ‘Well, that doesn’t *have* to be the case: very easily doesn’t have to be the case. We’re not asking for anything other than dignity.’” (Sarah: lives with disabilities, Grandparents experienced bad deaths)

“I feel very strongly that, as a society, we’ve come a long way in certain aspects of individual rights, but not for the rights for dying people, that has seemed to have been left very far behind, and I find that incredible, given that it’s the one certainty in life, that we’re all going to die... On a humanity basis, I just cannot see any capacity where at any point it’s right to force people to suffer, futilely, completely against their wishes, I just cannot see that being something that I could ever justify in my mind.” (Caroline: Aunt and Uncle experienced bad deaths)

“After having an awful two weeks in hospital, where he had to dehydrate and starve, really: that was the only way to accelerate the end. So it was completely unacceptable and it reinforced my belief about the need to have a more humane end and a more compassionate end. And I had said to many people, ‘You would treat a dog better than this.’” (Angela: husband, Tom, experienced bad death from prostate cancer)

“I feel assisted dying is one of the last human rights to take to the streets about.” (Gerald: living with MND)

In summary, participants explained that assisted dying could add quality at the end of life, allowing them to focus on enjoying the remainder of their life without having to worry about the prospect of a painful death. Assisted dying was never seen as a replacement for palliative care; rather participants saw it as an additional tool that could be used by palliative care services, for individuals that wanted it. Assisted dying was perceived as a humane and caring resource, particularly for those who would continue to experience intractable pain and suffering despite exemplary palliative care.

³² Feigin, S., Owens, R. G., & Goodyear-Smith, F. (2019). Helping a loved one die: the act of assisted dying in New Zealand. *Mortality*, 24(1), 95-110.

³³ Reichstein, A. (2019). A dignified death for all: how a relational conceptualisation of dignity strengthens the case for legalising assisted dying in England and Wales. *Human Rights Law Review*, 19(4), 733-751. https://ueaeprints.uea.ac.uk/id/eprint/71770/1/Accepted_Manuscript.pdf

Victoria's mum experienced intractable pain and suffering at the end of her life, despite receiving palliative care. She asked for help to die, the risk of prosecution stopped Victoria and her sisters from being able to fulfil their mum's request.

"Our mum Heather was diagnosed with Oesophageal cancer on 6th March 2020 and passed away 10 weeks later on 14th May. In between those dates, Scotland went into Lockdown, meaning our mum couldn't see her extended family or her friends. She was a fighter all her life, always fighting for other people's rights. She definitely did not want to die a cruel and horrific death but that's precisely what happened.

Heather went from sleeping most of the day to receiving end-of-life medication on Sunday 10th May. From then on it got very scary for her, myself, and my two sisters. We had all moved in to look after her. She was unable to go into the Hospice due to covid rules of only two named visitors; she did not want to choose two of us and never see the other one or her six Grandchildren again.

She asked on a number of occasions for us to help her end her life and also told doctors that she was scared and wanted to end her life. We discussed putting a pillow over her face but knew we would be arrested. Imagine having to think of doing that. The next four days were horrific for her and us. We should have been spending quality time as a family but instead, we were her nurses and watched her die in the most inhumane and cruel way. For the last 12 hours, brown foam was coming from her mouth constantly and we had to catch it using bedding that we cut up.

Had assisted dying been legal in Scotland we could have said goodbye in a peaceful and controlled way on her terms. She believed in assisted dying, and so did we. Had that been an option when palliative care did not work for her, then it would have been so different at the end.

We will continue to fight until terminally ill people have the choice to die a dignified and humane death in memory of our mum."



Image: Victoria and her sisters, with their mother Heather

Alex has Stage 3 Ovarian Cancer. After watching her mother die from Pancreatic Cancer, she is now having to consider her own death.

"During the Covid pandemic, Mum fell at home and couldn't get back up. She managed to press her alarm bell and get an ambulance. They took her to hospital, and she remained there for 18 days before they discovered her fractured hip and pancreatic cancer. She'd been adamant for 18 years that she didn't want to go to a care home, and she didn't want any lifesaving treatment. She was a very strong-minded lady. I'd also been diagnosed with a rare low grade serous ovarian cancer two years earlier and had a big operation to remove it, but it was stage 3 which is advanced. I was expecting to go back into hospital for another major surgery to repair two complex incisional hernias from the previous surgery. I wasn't able to visit her which was horrible for her and made me feel guilty and to compound this the hospital were keen to discharge her so someone else could have her bed. She'd not wanted to be kept alive even then and frequently told me she was "past her sell-by date". She couldn't be discharged back to her home with her neighbours as there was no social care available in the town, so we had to find her a care home. They were lovely people, but she hated not being in her own home having her favourite food. She couldn't be as private or as self-sufficient. She just wanted to no longer be alive.

I tried to explain to her that it wasn't legally possible to have euthanasia even though she so badly wanted it. She carried on living for well over a year in the care home but wanting her life to be over all the time. She hated the idea of selling her home to pay for her care; it meant everything to her that she'd saved so hard so she could give her children the proceeds from her house when her life was over. She watched the dream dissolve with each week she was in care. On the visits I made she'd ask why the doctor couldn't give her an overdose as she'd talked to a palliative health team when first admitted and she thought this was an option. She asked me to do what I could to change the law and we spoke openly about the fact that I don't want to go through what my cancer may have in store for me either. She would have helped me if she could, but I couldn't help her. In her last weeks she was on morphine and desperate to die. She'd ask me how much longer she had to be here. She had no dignity or pleasure in being alive. She remained polite and grateful for everything that was done for her, but she was also very unhappy that she couldn't simply end it. She had a strong faith she'd meet Dad and her family again. It was such a relief to know she was no longer suffering when she finally died this year.

I really want the law to change so people like mum don't have to go through the same process. And I don't want to deteriorate slowly either. I want to know I can die when I've had enough pain. I don't want to spend my last month's planning my suicide and I do not want to go abroad to do this legally. Enjoying what time, I have left and knowing I've got a way to leave this life without leaving a mess for my husband or medics if I'm unsuccessful is so important to me. It would be such a relief to know this was possible. We get prosecuted if we put animals through this torture. We should have at least the same rights as animals."

4. What role does the pursuit of basic human needs play in assisted dying?

Theorists have long argued that all human behaviour is motivated by the pursuit of innate and basic human needs, which are necessary for psychological growth and well-being (see, Maslow's Hierarchy of Needs³⁴ and the Good Lives Model³⁵ as examples). However, there has been little research to date exploring how basic human needs influences the desire for an assisted death. This is despite theorists suggesting that individuals at the end-of-life experience many needs across physical, psychological, social, and existential domains. Whilst freedom from pain is identified as the most important need, higher order emotional and existential needs follow closely in order of importance³⁶.

Self-Determination Theory (SDT)³⁷ suggests that all human behaviour is intrinsically motivated by three innate and universal human needs: Autonomy, Competence, and Relatedness. *Autonomy* refers to a sense of ownership over one's behaviour and/or goals. *Competence* means having mastery over one's activities. *Relatedness* refers to the feeling of being securely connected to others. An individual's well-being is directly influenced by their ability to attain each of these universal human needs (i.e., the more an individual secures their basic human needs, the better their well-being). However, conditions outside the control of the individual (e.g., terminal illness) can impact on their ability to achieve these innate human needs.

Take *Competence*, as illnesses progress and pain and/or physical functioning worsens, individuals become less able to maintain activities and roles they previously mastered (e.g., work/hobbies³⁸). Past research has indicated that being able to engage in these activities and roles are integral to one's sense of self and identity and give life a sense of meaning and purpose³⁹. Consistent with past research, participants indicated that initial losses of function, in the early stages of terminal illness, were managed by focusing on new interests or activities⁴⁰. However, as the terminal illness progressed, participants reported difficulty in engaging in activities or roles important to them. Difficulty securing the basic human need of *Competence*, alongside the loss of a sense of self, were key reasons for desiring an assisted death.

³⁴ Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, 50(4), 370–396. <https://doi.org/10.1037/h0054346>

³⁵ Ward, T., & Maruna, S. (2007). *Rehabilitation: Beyond the risk paradigm*. Routledge

³⁶ Leung, K. K., Tsai, J. S., Cheng, S. Y., Liu, W. J., Chiu, T. Y., Wu, C. H., & Chen, C. Y. (2010). Can a good death and quality of life be achieved for patients with terminal cancer in a palliative care unit? *Journal of palliative medicine*, 13(12), 1433–1438. <https://doi.org/10.1089/jpm.2010.0240>

³⁷ 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>

³⁸ Marie Curie. (2022a). *Work and terminal illness*. <https://www.mariecurie.org.uk/help/support/terminal-illness>

³⁹ 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>

⁴⁰ *ibid*

“I used to volunteer after I *had to* finish ‘work’ work, and it’s one of the things that I enjoy a lot. Come the time when I can’t do that anymore, that’s going to hit me hard. When I say there are tipping points: that’s a big tipping point psychologically: you can’t work anymore.” (Amber: living with MND)

“He was a singer/song writer, so he was often performing when he was well. It’s what drove him. He’d had to stop performing. Because his voice was getting weaker: he had to stop singing. Because he realised there was something going on with his hands: he couldn’t really play the guitar as well.” (Lesley: accompanied her brother, who had MND, for an assisted death at Dignitas)

“I used to enjoy cooking... it got to the point where my hand function is not good enough and so I’ve had to let go of that as well, and that’s another downward step.” (Amber: living with MND)

“Mum used to organise little street parties and things like that, obviously she couldn’t do that anymore. It...everything just stopped, everything literally just stopped, she just sat in a chair... It was as though everything that she was had been taken away.” (Chloe: mother and grandmother experienced ‘bad deaths’, husband has life-limiting condition)

“My plans changed radically, because I wanted to continue to work, I wanted to continue to be active as an artist and, as a psychotherapist, I thought, ‘Well, there’s no way I can carry on doing that’... I wanted to have a really active retirement and I can’t be as active as I want to be, I can’t do all the things down at the allotment that I’d like to be able to do, I was quite vigorous down there at one point and now I feel a bit pathetic.” (Alex: living with terminal cancer, mother experienced bad death)

“We all kind of accepted that his life was going to be in his house, in his home, he couldn’t really get out and about... His life very quickly became much smaller” (Louise: father-in-law experienced bad death from MND)

Factors such as accessibility, pain, and embarrassment (e.g., fungating cancers) can reduce one’s ability to spend time with others, negatively impacting on one’s ability to secure the basic human need of *Relatedness*⁴¹. In the next chapter, we will discuss the concept of ‘being a burden’ on family and the role this plays in attitudes towards assisted dying. Aside from this, past research has demonstrated that loneliness (often a product of loss of activities/roles discussed above) and dependency on others plays a role in considering an

⁴¹ 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>

assisted death⁴². Consistent with this, participants discussed how living with terminal illness can reduce contact with friends and family:

“You have no choices, you have no options, you have no ... like your network closes down, your experiences close down, your future outlook closes down, your interactions close down, so it could be a massive impact.” (Caroline: Aunt and Uncle experienced bad deaths)

“She was paralysed down one side, she lost contact with all of her friends, there was only one, one person who used to come and visit her, and that was somebody from the church. All of the people that she used to go to dinner-dancing with, look after their children, just abandoned her. So, all her social life disappeared, she was, she was stuck in these four walls.” (Chloe: mother and grandmother experienced ‘bad deaths’, husband has life-limiting condition)

“The friends that I thought were close to me, a lot of them have evaporated. So, I’ve just got a small group of friends now and I don’t consider myself a big part of society anymore, whereas I think I did before I was ill.” (Alex: living with terminal cancer, mother experienced bad death)

“I didn’t really go out for over a year and then I was going to go to the pub on Sunday night, it was embarrassing. It takes about ten minutes to get to the bar and at one time I’d have been the first one at the bar and the last one to leave. Now, it’s a bit of a pain.” (Gerald: living with MND)

“It goes back to your self-esteem and sense of control if you start to lose things like bodily functions, you start to have a fungating carcinoma that smells, you know, a breast cancer that absolutely reeks, you don’t want to be around in the pub or with friends, at a dinner party or whatever it might be. So, there will be times when you start to get more and more marginalised and excluded and your world starts to narrow down, you may not be so mobile, you may not want to go out in a wheelchair.” (Stephen: living with disabilities)

Individuals with terminal illness often report experiencing a loss of independence and choice, preventing attainment of the basic human need of *Autonomy*⁴³. According to Rodríguez-Prat and colleagues⁴⁴, the desire for dignity and the basic human need of Autonomy are interrelated factors in an end-of-life scenario. Specifically, dignity incorporates the capability to make choices over one’s own behaviour, environment, and treatment (i.e., need for autonomy), in combination with one’s perception of self-worth, well-being, and self-respect (i.e., emotional responses to autonomy). Findings from Rodríguez-Prat and colleagues’ systematic review suggest that the experience of reduced functionality and autonomy in

⁴² Georges, J. J., Onwuteaka-Philipsen, B. D., Muller, M. T., Van Der Wal, G., Van Der Heide, A., & Van Der Maas, P. J. (2007). Relatives' perspective on the terminally ill patients who died after euthanasia or physician-assisted suicide: a retrospective cross-sectional interview study in the Netherlands. *Death studies*, 31(1), 1-15. <https://doi.org/10.1136/jme.2011.045492>

⁴³ Colburn, B. (2020). Autonomy, voluntariness and assisted dying. *Journal of Medical Ethics*, 46(5), 316-319. <https://doi.org/10.1136/medethics-2019-105720>

⁴⁴ Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, X., & Balaguer, A. (2016). Patient perspectives of dignity, autonomy and control at the end of life: systematic review and meta-ethnography. *PLoS one*, 11(3), e0151435. <https://doi.org/10.1371/journal.pone.0151435>

terminally ill patients leads to a loss of dignity, with a loss of dignity undermining their identity and self-esteem. The right to autonomy and dignity are frequently cited in the literature as motivating factors for assisted dying⁴⁵. This is consistent with findings from the current study, with participants discussing their loss of autonomy, choice, control, and dignity as primary reasons for pursuing an assisted death:

“He felt more like a thing than a human being” (Lesley: accompanied her brother, who had MND, for an assisted death at Dignitas)

“She was dying, and I remember thinking that it was very unfair that she was having to go through this because all her dignity had gone.” (Chloe: mother and grandmother experienced ‘bad deaths’, husband has life-limiting condition)

“It was so undignified, he had carers in, he’d got compacted poo and he had to be cleaned and turned over, he couldn’t move, it was just absolutely humiliating for him, and that’s what I think caused the distress and especially the absence of being able to communicate. And he knew all this was coming which is why he wanted to be able to go to Dignitas.” (Louise: father-in-law experienced bad death from MND)

“I’m my own person, always have been, always will be and to having to get him to help me is quite hard, it’s quite hard so yes, you do have to give that up a wee bit whether you want to or not, you don’t have a choice.” (Norma: living with terminal cancer)

“Having speech is very important but having some hand function is also very important. And I think it’s going to feel like imprisonment when I can look around me, see, hear, speak, but I can’t move.” (Amber: living with MND)

“To be honest, she was really independent, she was quite a hard patient and if you said words like commode, wheelchair, hospice, all these words, you didn’t want to mention any of those words around her because she was just so independent.” (Victoria: mother experienced a bad death from oesophageal cancer)

“I have got this bad illness and before that I could do anything and everything and now, I can’t do anything, and it is very embarrassing. You know, your life has stopped. You’re in charge of your life and then it’s all taken away.” (Gerald: living with MND)

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 Autonomy, Competence, and Relatedness. Considering the basic human need of *Autonomy*, participants wanted to have control over their own life and the right to choose how they experience death. 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*.

⁴⁵ Rodríguez-Prat, A., Balaguer, A., Booth, A., & Monforte-Royo, C. (2017). Understanding patients’ experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography. *BMJ open*, 7(9), e016659. <http://dx.doi.org/10.1136/bmjopen-2017-016659>

“Assisted dying is for *you* as a person. All your life you work, you do your best and when it comes to your death everybody else is in charge.” (Gerald: living with MND)

“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: lives with disabilities, Grandparents experienced bad deaths)

“If it was hopeless and there was no coming back from it, that overwhelming feeling of the futility of that and your only future is one of that intensity of suffering with no turnaround possible, I just think that would be a horrendous thing to deal with anyway, but to lose your agency, to lose any control in that, and that to be your set-in-stone fate regardless, I just don’t think that’s right... I just think that choices matter in that situation, you know, people who are facing that have already had so much autonomy removed, and if you get to a certain point and then say, “That’s enough.” I think that should be respected.” (Caroline: Aunt and Uncle experienced bad deaths)

“His assisted death was more about wanting to be in control: wanting to be in control all the way through his whole life.” (Lesley: accompanied her brother, who had MND, for an assisted death at Dignitas)

“There was a dramatic realisation of a loss of independence/control. I think the two are quite inter-twined and the discussions about Dignitas gave him back a hope or temporarily a sense of control which in the face of his loss of independence felt really good... This concept of having a sense of purpose is so tightly tied in with having independence and control, and so then all that is taken away from you and assisted dying is a way of reasserting your purpose, it’s to look for the only control that’s left to you, and that is to influence the way you die.” (Louise: father-in-law experienced bad death from MND)

Regarding *Relatedness*, participants discussed how having an assisted death would allow them to have their family with them during death, in a way which would be peaceful and minimally distressing to all involved. This is consistent with past research emphasising the importance of having family members present during death⁴⁶.

“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: living with terminal cancer)

“The gift of being able to say a meaningful goodbye and hold somebody’s hand as they die: it’s just wonderful. I can’t articulate it enough.” (Lesley: accompanied her brother, who had MND, for an assisted death at Dignitas)

⁴⁶ Sandham, M., Carey, M., Hedgecock, E., & Jarden, R. (2022). Nurses' experiences of supporting patients requesting voluntary assisted dying: A qualitative meta-synthesis. *Journal of advanced nursing*, 78(10), 3101-3115. <https://doi.org/10.1111/jan.15324>

In summary, participants described increased difficulty securing the basic human needs of Autonomy, Competence, and Relatedness when experiencing terminal illness. Specifically, the loss of control, dignity, and ability to engage in important activities, can prevent attainment of these. Yet, people value these basic human needs as much in death, as they do in life⁴⁷. Participants suggested that enabling the option of assisted dying could support the attainment of the basic human needs by allowing people to have control over the dying process (Autonomy), make end-of-life decisions (Competence), and have a minimally distressing death that they can share with family and friends (Relatedness). Participants emphasised that assisted dying would not be something that everyone wanted but should still be an option available for those who do. For those who do desire an assisted death, this could allow them to attain their basic human needs, leading to improved psychological well-being at the end-of-life.

Chloe's mum and nan both died from painful terminal illnesses. They both asked for help to die, but they weren't allowed to make this choice despite having the capacity to do so. Chloe faces the same difficult situation with her husband now.

"I watched both my mother and Nan go through long drawn out, agonising deaths. My mum went from being a gregarious, independent woman to being reliant on others for her basic needs. She was incontinent and immobile, yet she wasn't depressed, she just had no quality of life and was in constant pain. I saw my mum the day before she died but she passed away alone because I was caught in a traffic jam and couldn't get to her. I still have nightmares of what she went through. She shouldn't have had to go like that and alone.

My nan had a terminal illness just a few years after my mum's passing. I looked after her too, for six months before she was taken into hospital. She was in so much pain. The doctor informed us he could 'make her comfortable so she won't feel any more pain, but she won't get better'. We agreed and the next day my nan passed. I now know this as palliative sedation.

Both my mum and nan were capable of making up their own minds, choosing what suited them both before and after their diagnoses. Why were they not listened to when they asked for their lives to be ended? Why did they have to suffer for longer when they didn't need to? Why was my nan's doctor permitted to make her 'comfortable' but I, in 2022, would not be allowed to take a loved one to Dignitas?

I ask these questions far too frequently because I'm watching my beloved husband suffer through a life-limiting condition. We have had the conversations around assisted dying and I will do all I can to help him when he thinks the time is right. I don't care if I'm arrested and imprisoned but he does and this, I know, will stop him saying 'help me'. Instead, he will have to suffer, and I will have to watch and feel helpless. The law needs changing, safeguards need to be strong, but so do individual voices."

⁴⁷ 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>

5. How does social context affect attitudes toward assisted dying?

Above, we have considered individual motivations for an assisted death. Humans by their very nature, however, are social beings, so we cannot neglect to consider the impact of social contexts on attitudes toward assisted dying⁴⁸. Past research has indicated that experiencing feelings of being a burden are common among individuals with terminal illness⁴⁹. Theorists have argued that equating illness with being a burden has become ‘normalised’ and widespread as a consequence of medicalising the dying process. Prior to the medicalisation of death, the focus was on a caring narrative, whereby supporting an individual throughout their journey with death was perceived as a meaningful, and not burdensome, act⁵⁰. The argument that the sense of being a burden is a wider societal issue was supported by Tom, whose mother (who had MS) travelled to Dignitas for an assisted death:

“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”

A recent systematic mixed studies review, however, found the sense of being a burden to be among the *least* important and *least* frequently cited reasons for seeking an assisted death. Instead, unbearable pain, suffering, loss of dignity and autonomy, and a sense of hopelessness were the most important reasons⁵¹. This suggests that whilst feelings of burdensomeness are common in the terminally ill, it is not a strong motivating factor for directly seeking an assisted death. This was supported by our research; findings indicating that whilst some (not all) participants had experienced feelings of being a burden on others, this was *not* the driving factor behind their positive attitudes toward assisted dying. Conversely, participants indicated that continuing to live with the pain, suffering, loss of dignity and autonomy was perceived as a *burden on 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. That’s the only point at which the word ‘burden’ would ever come into my discussing this subject because John felt his life was a burden: he didn’t want it anymore; he wanted to be rid of it.” (Lesley: accompanied her brother, who had MND, for an assisted death at Dignitas)

“If I talk about my own death and having an assisted death, I’m absolutely thinking of myself, and how I want to end this short time I have on this planet, and I believe from what I’ve seen it could be done in a way that wasn’t too painful for my family and believe it could be done in a way that was actually quite helpful for my family, but my

⁴⁸ Rodríguez-Prat, A., & Monforte-Royo, C. (2023). Human Flourishing Until the End: The Core Values of Palliative Care. In Las Heras, M., Grau Grau, M., Rofcanin, Y. (Eds) *Human Flourishing*. Springer. https://doi.org/10.1007/978-3-031-09786-7_9

⁴⁹ 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.

⁵⁰ Rodríguez-Prat, A., & van Leeuwen, E. (2018). Assumptions and moral understanding of the wish to hasten death: a philosophical review of qualitative studies. *Medicine, Health Care and Philosophy*, 21(1), 63-75. <https://doi.org/10.1007/s11019-017-9785-y>

⁵¹ 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>

emotion process is how I want to end my time... it's about me and just wanting a more calm, practical time controlled and situation-controlled death. I know sometimes people say assisted dying will be good for the person and their family, but I focus on the person." (Louise: father-in-law experienced bad death from MND)

"God, I've never been a burden. I might be a pain in the arse but I'm not a burden. There are two things they always say, that people push for assisted dying to get money and others say it's because you're a burden. It's not. If they ever tried asking the individual what they want, I bet you nine times out of ten they would say can I just go now? 'I'm tired, I'm gone, that's it.'" (Gerald: living with MND)

"I never felt like I was a burden. They've [my parents] never wanted me to feel like that. They've always said, 'If [roles] were reversed, they know that I would be the first one there.'" (Sarah: lives with disabilities, Grandparents experienced bad deaths)

"I can't imagine anybody trying to push me into an assisted death, can you [laughs]? I'd tell them exactly what to do [laughs], even if I was feeling really rubbish, I would still tell them exactly what to do. No, it's the opposite, I'm not scared of dying, I'm scared of living badly in a desperate situation, and I think a lot of people probably are." (Alex: living with terminal cancer, mother experienced bad death)

Even for participants who had experienced feelings of being a burden, the decision to want an assisted death was not based on these emotions, but on their *own* desire to have relief from their pain and suffering:

"I think being a burden is when I was really ill there and I was a week in my bed... and [my husband] was having to clean up after me, he was having to run up and down the stairs looking after me. If I was lying in that bed forever now, let's say that was the way it was going to be, I would feel a burden. But [assisted dying] would be a conscious decision on my heart... I would be of sound mind, and it would be my decision, because lying there forever more and my husband having to go through that, but not only for him, equally it's selfish here, I wouldn't want to lie there like that, who'd want to lie there like that?" (Norma: living with terminal cancer)

Past research by De Korte-Verhoef and colleagues⁵² indicated that *some* family carers report experiencing emotional and physical burdens during end-of-life care, particularly during the last week of life. The emotional burden referred to the knowledge that their loved one was going to die, in combination with having to watch them suffer and experience pain. The findings indicated that three-quarters of carers did not find this 'burden' to be a problem. Indeed, family carers reported that supporting and caring for their relative was rewarding and perceived as the final symbol of love they could provide. There was *no* evidence of

⁵² De Korte-Verhoef, M. C., Pasman, H. R. W., Schweitzer, B. P., Francke, A. L., Onwuteaka-Philipsen, B. D., & Deliens, L. (2014). Burden for family carers at the end of life; a mixed-method study of the perspectives of family carers and GPs. *BMC palliative care*, 13(1), 1-9. <http://www.biomedcentral.com/1472-684X/13/16>

increased hospitalisation among patients of family carers experiencing heavy burdens than those with light burdens.

Supporting this, the findings from the current study suggest that family members found it distressing watching their relative suffer intractable pain at the end-of-life. It was also emotionally challenging to accept that their loved one was going to die. Importantly, family members of those who travelled to Dignitas for an assisted death highlighted that they did not perceive their relative to be a burden:

“For the last few days, he was in my husband’s hands and mine completely. And that felt like *such a privilege: such an honor*”. “John was never a burden to us. I would have done anything and everything to have kept him alive had he wanted to live longer.”

(Lesley: accompanied her brother, who had MND, for an assisted death at Dignitas)

“I don’t think *she* thought she was a burden, she was a pain in the arse, and she knew it [laugh] but that wasn’t because she had MS that was because she was Mum [laugh].” (Tom: accompanied his mother, who had MS, for an assisted death at Dignitas)

Thus far, participants have indicated that the sense of being a burden does not influence their attitudes towards, or desire for an assisted death. Supporting this, past research has indicated that some terminally ill individuals repress their decision for an assisted death, as the strong desire to protect their family from the emotional burden and pain associated with the death of themselves, takes precedence over their own desire to hasten their death⁵³. Consistent with this, Angela reported how her husband Tom delayed his journey to Dignitas, specifically to reduce the emotional burden on his family. However, the delay caused by trying to protect his family from the emotional pain of losing their father early meant he was no longer able to travel to Dignitas:

“With his daughters, in principle, they were very much in favour of [Tom] going to Switzerland. However, they thought it was too soon. They had lots of discussions, and they were trying to persuade Tom not to go yet. And this was very difficult for Tom. He adored his daughters and didn't want any conflict, but they were not in agreement for him to go so soon. His daughters felt it was too early and then, of course, we were too late because things [medically] suddenly accelerated.” (Angela: husband, Tom, experienced bad death from prostate cancer)

This is a common issue for terminally ill individuals in the UK who desire an assisted death. In order to make the journey to Switzerland for an assisted death, a certain level of health is required. However, this creates a difficult trade-off, whereby terminally ill individuals make the decision whether they travel before becoming too ill to do so, but in turn sacrificing

⁵³ Schroepfer, T. A. (2006). Mind frames towards dying and factors motivating their adoption by terminally ill elders. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61(3), S129-S139.

quality time that could be spent with loved ones⁵⁴. Should assisted dying become legalised in the UK, terminally ill individuals would not have to be faced with this heavy decision. Importantly, the NHS has a commitment to patient-centred care^{55,56}, whereby care should be personalised, co-ordinated and enabling; allowing individuals to make choices and manage their own health. As Lesley argues, this should be considered in any discussion surrounding the role of burdensomeness in assisted dying:

“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: accompanied her brother, who had MND, for an assisted death at Dignitas)

Whilst participants strongly opposed the view that burdensomeness played a role in assisted dying, they did indicate support for robust safeguards to be built into UK law changes. In the recent Liam McArthur Assisted Dying Bill, several safeguards have been proposed⁵⁷, including: two doctors independently confirming the individual has a terminal illness, is mentally competent, is making an informed decision without pressure or coercion, and is fully aware of palliative, hospice, and alternative end-of-life options. The terminally ill individual must sign a written request, which is witnessed and co-signed by both doctors, and be given a waiting period of 14 days to reflect on their decision. Whilst the life-ending medication is delivered to the individual by a registered Health Care Practitioner (HCP) who checks they remain mentally competent to make the decision, the individual must administer the life-ending medication themselves.

Participants believed that implementing an assisted dying law will give *more* safeguards and protection to vulnerable individuals than what is currently in place:

“What I am saying is that good, assisted dying legislation will actually make medical involvement in end of life more transparent, not less. I think it will put the control back in the ill person’s hands rather than the GP’s hands where they are mentally competent, so I see it as it’s going to help transparency, not hinder it.” (Louise: father-in-law experienced bad death from MND)

“The scrutiny that would come necessarily as part of these assisted dying proposals would actually have afforded more protection to those vulnerable people. They were vulnerable because there weren’t the safeguards that assisted dying will bring.” (Caroline: Aunt and Uncle experienced bad deaths)

“With people who oppose a change in the law, they are fearful that there aren’t really robust safeguards included in the bill. Well, at least there are *some*: at the minute,

⁵⁴ 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

⁵⁵ NHS Education for Scotland. (2022). *Person centred care*. <https://www.nes.scot.nhs.uk/our-work/person-centred-care/>

⁵⁶ NHS England. (2022). *Involving people in their own care*. <https://www.england.nhs.uk/ourwork/patient-participation/>

⁵⁷ 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>

there are none. And that's what's kind of scary: there's nothing. The only safeguard is that, after the event – after the person has died – somebody may get investigated for that. That's no safeguard now for the individual patient.” (Hilary: mum experienced a bad death)

Under the current law, there is a blanket ban on all assistance to ending life in the UK. Rather than this preventing assistance to end a life, it makes the practice secretive and hidden. This links back to the data from the Office for National Statistics⁵⁸ that we reported in the Introduction, whereby individuals with severe and potentially terminal health conditions are more than twice as likely to take their own life than the general population. Similarly, data from Dignity in Dying⁵⁹ found up to 650 terminally ill individuals take their own lives each year, with up to 10 times as many attempts. Currently, this leads to terminally ill individuals attempting to end their suffering alone, or family members being put in the situation where they are risking conviction trying to help their loved one have some control over their death.

“My mum used to say to me ‘why do you let me live, why do you let me live’, you know, and that’s heart breaking” (Chloe: mother and grandmother experienced ‘bad deaths’, husband has life-limiting condition)

“If it wasn’t legal, so be it, we would do it for each other. We just would. Probably that means that we end up in jail, then so be it. Because I wouldn’t let my [family member] suffer and the same with me.” (Sarah: lives with disabilities, Grandparents experienced bad deaths)

“My dad had asked [my partner] if he could get him drugs for my dad to end it when my dad wanted to... I would not ever think I’d consider my dad having to self-ethanise himself, I never thought I’d look into ordering drugs from the dark web, I never thought I’d put my job at risk and sometimes I feel like I’m in a soap opera, but this is mental.” (Joanne: father experienced a bad death)

“We reached out to Dignitas and had the first conversations and, you know it was request the paperwork and start the process and obviously it’s illegal and you can’t talk about it and it’s all secret squirrel and don’t tell your friends and don’t tell your family and certainly don’t tell anybody who could get you into trouble.” (Tom: accompanied his mother, who had MS, for an assisted death at Dignitas)

“She asked us to help her die and we were thinking, what do you do? Would you put a pillow over her face, would you give her tablets, what would you do? We were actually contemplating basically helping her, but we knew it was illegal” (Victoria: mother experienced a bad death from oesophageal cancer)

⁵⁸ 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/suicidesamongpeoplediagnosedwithseverehealthconditionsengland/2017to2020>

⁵⁹ Dignity in Dying. (2021). *Last resort: The hidden truth about how dying people take their own lives in the UK*. <https://www.dignityindying.org.uk/news/hundreds-of-terminally-ill-brits-take-their-own-lives-in-uk-each-year-latest-estimates-suggest/>

In conclusion, the findings are consistent with past research, suggesting that 'being a burden' on others is amongst the least important reasons for desiring an assisted death. Instead, the experience of pain and suffering is a burden on oneself. Participants emphasise the focus on patient-centred care in the UK, whereby the focus should be on the individual's needs, agency, and choice. By introducing legislation permitting assisted dying in the UK, participants perceive that there will be *more* safeguards. Current legislations mean some terminally ill individuals are opting to attempt suicide alone or travel abroad for an assisted death.

Tom planned an assisted death but couldn't make it to Switzerland in time. His wife Angela is passionate about changing the law, so people get the choice of how they want to die.

"My husband, Tom, didn't get the death he wanted or deserved.

In 2019 Tom was diagnosed with terminal cancer and made plans to go to Switzerland. However, a sudden deterioration meant, at the last minute, he was too ill to travel. The result was that he then had to endure a truly miserable, drawn-out death.

When he was admitted into hospital he was suffering with excruciating pain in his stomach and was unable to keep any food or drink down. While the pain was subsequently kept under control, more or less, his suffering and discomfort continued and was plain to see. There was nothing the hospital could do for him, and we then started a waiting game which was extremely distressing for him, me and all the family. All food and liquids were stopped to hasten death, but this took two weeks and during this time black liquid which collected in his stomach (and caused a lot of discomfort) had to be pumped out through his nose. Towards the end he had to keep this line constantly in his nose which he tried to rip out even when heavily sedated.

After this awful nightmarish experience, I became even more convinced of the necessity to change the law on assisted dying. I now campaign in his memory so that others would not have to share the same fate. I believe that anyone who is terminally ill and mentally competent should have the choice of an assisted death if that is what they want. I volunteer for Dignity in Dying's Southwest London's campaign group."



Image: Tom's wife Angela, campaigning for change.

Caroline is passionate about campaigning for change, here she tells us why.

“There are so many experiences that have shaped my passionate belief in the availability of a safeguarded choice of assisted dying, as a crucial part of a free life. I live with two chronic diseases (thankfully currently not life threatening). I live in fear that when my death comes from whatever cause, I will not have choice afforded to me and that feels both terrifying and wholly unjust. Like so many with disabilities, I fight to have my choices and rights recognised and respected. In my voluntary work, I find it empowering that patient voice, agency and consent are rightly now crucial in care and research and yet conversely patient rights and choices in dying, are denied. Like many, I’ve encountered many loved ones’ “bad deaths” despite all treatment and palliative options, and they have traumatised me and my family. I want to know when my death, or more of my loved ones’ deaths are inevitable, that I did everything in my ability to fight for choice in death, while I was able.

My uncle James lived with severe, progressive, and highly debilitating MS, all his adult life, having to spend most of it in specialist care homes. My Mum (his sister) was with him as much as she could, and I visited weekly after school. The ongoing loss of every function was palpable to him. He knew the debilitation would ultimately be terminal. He cried, regularly distressed in his pain, suffering and he felt hugely his loss of dignity in the ravages of latter stages, begging for it to be over. He asked my Mum to promise to help him when the time came, asking her to “put a pillow over his head” or whatever it would take to spare him. She was in turmoil, of course, helpless to be able to make any such promises. He came close to death several times in several gruesome episodes, but his body wouldn’t give in, no matter how broken, or what his will wanted. My Mum and our family were traumatised by watching him futilely suffer against his will and ultimately in the final throws, it came down to a conversation with the hospital doctor who could only offer absence of life sustaining intervention, and the consequential suffering, rather than any compassionate assistance option James wanted.

My Aunt Fiona, my Dad’s beloved sister (and my Mum’s best friend) was such a hugely important figure in our lives – so strong, stoic and full of life. She and my Dad were always of the belief that life and death was something to be faced pragmatically and in the hands of God. After supporting her husband through terminal Parkinson’s, she got the devastating diagnosis of aggressive ovarian cancer. She took every treatment option available to her and was determined to fight. She battled so bravely, and the treatment was so gruelling, but ultimately the news came that there was no other possibility but death. From that point, Fiona couldn’t maximise the end stages of her life because of the overwhelming fear of what she was facing in death. She was in constant terror. I wish I could say that her fears were unfounded, but I can’t. Her final weeks were horrific for her and all her still traumatised family. Such a strong, independent, fearless woman went through torture, despite every palliative provision. Fiona never wanted to end her life – that was the antithesis of her life-loving personality and her life beliefs. But in the end, she knew she wanted the choice to end her death should the horror or indignity become too much to bear. We will never know whether she would ultimately have taken the option of an assisted death if she were to have had it. But both she and my dad firmly changed their minds within that awful process, to the conclusion that choice in dying should have been available and that no compassionate human or God would have condemned her for that.

Those opposed to assisted dying should absolutely have their individual dying preferences respected and safeguarded, as well as the ability to change that choice if they wish. All I ask is that my individual choice, should I wish for a safeguarded assisted death come the end, is equally protected.”

6. Conclusion

In the words of Lesley, **“the problem is dying badly, and the answer is dying well”**. For terminally ill individuals experiencing intractable pain and suffering, assisted dying can be the answer – should that be what they want. The data has repeatedly shown that there will always be individuals who, despite excellent quality palliative care, die in pain⁶⁰. Findings from this report suggest that assisted dying could be another tool in the belt of palliative care but should *never* be perceived as a replacement to high quality palliative care.

Participants perceived assisted dying as a safety net; something which can allow them to continue to live without having to worry about the potential suffering they could experience during death. Assisted dying allows people to be reassured that should palliative care not work for them, there is still another option available. It allows them to enjoy the remainder of their life and to focus on what is important to them, placing the focus on *quality* over quantity of life.

Past research has discussed assisted dying as a product of loss, loss of dignity, independence, and control. This research has pivoted the discussion, showing that assisted dying can **give**; give a sense of Autonomy, Competence, and Relatedness. This enables terminally ill individuals to secure their basic human needs, which remain as valued and important throughout the dying process as they are during life.

Feelings of being a burden are common among anyone experiencing an illness (whether that be short-term, long-term or life-limiting). While we should be careful to not dismiss these feelings, they are not seen as a strong motivating factor for seeking an assisted death. Indeed, comprehensive reviews of the literature have found this to be among the least important and least frequently cited reasons for seeking an assisted death⁶¹. As our participants highlighted, the decision for an assisted death was based on their own experience of pain and suffering; continuing to live was perceived as a burden *on themselves*.

Participants indicated support for the implementation of robust safeguards in laws supportive of assisted dying. They highlighted that, as it stands, there are no safeguards – it is not until somebody has died, and they no longer have a voice, that there is an investigation. Implementing assisted dying allows checks to be made at an early stage that the individual is mentally competent and is making an informed decision *for their own benefit*.

Ultimately, based on the findings of the research, **this report supports the implementation of a law change in favour of assisted dying in the UK**. Consideration should be given to the safeguards put in place, as has been done with the Liam McArthur Bill.

To end, it is important to remember that **“assisted dying is about ending death, it is not about ending life”** (Caroline: Aunt and Uncle experienced bad deaths).

⁶⁰ Zamora, B., Cookson, G., & Garau, M. (2019). *Unrelieved pain in palliative care in England*. Office of Health Economics. <https://www.ohe.org/publications/unrelieved-pain-palliative-care-england>

⁶¹ 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>

