ASSISTED DYING DEVELOPING THE DEBATE

Exploring the issue of assisted dying and its legislation in the UK

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JOSEPH ROWNTREE FOUNDATION

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Before you read this report

Before Shaping Our Lives published this report we shared the contents with some of our members. Some found it upsetting and we thought we should mention this. It is not our intention to cause any distress by publishing these report findings, but we do recognise that for some people the themes may be difficult to read about. We sincerely hope that you find this report offers a sensitive insight despite this.

THE AUTHORS

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Peter Beresford OBE is Emeritus Professor of Social Policy at Brunel University London and Professor of Citizen Participation at the University of Essex. He is a long term user/survivor of mental health services and Co-Chair of Shaping Our Lives, the independent UK disabled people's and service users' organisation and network. He has a longstanding interest in issues of participation as a researcher, writer, campaigner, educator and service user. He is author of *A Straight Talking Guide to Being a Mental Health Service User* (PCCS Books, 2010) and his latest book is *All Our Welfare: Towards Participatory Social Policy* (Policy Press, 2016).

Tina Coldham first started using mental health services in 1990, and is still a practising depressive! She became a user activist through setting up self-help groups, and also being part of a local successful campaigning user group. This led to wider regional, national and international involvement. Tina is a member of the National Institute for Health Research (NIHR) Involve Advisory Group and Executive Group; Chair of the Social Care Institute for Excellence's (SCIE) Co-Production Network and a SCIE trustee; Honorary Visiting Fellow in the Dept of Social Policy and Social Work at the University of York; An associate at the Centre for Citizenship and Community at the University of Central Lancashire; and has stepped down as Chair of the National Survivor User Network (NSUN) having led this from the project planning stage to independence.

The research on which this report is based was initiated and guided by Peter and conducted by Sarah and Tina.

SUMMARY

The aim of this small, exploratory research study was to bring together people with outwardly opposing views about assisted dying to see if there was any common ground between them which could provide the basis for more helpful discussion and policy development.

MUCH OF THE DEBATE IN THE MEDIA IS SIMPLIFIED AND DOES NOT ACCOUNT FOR THE WIDER SOCIAL CONTEXT

So far debate about assisted dying, particularly in the media, has been highly polarised and it was this that led to the setting up of this project. Its findings reinforce this view that, to date, the debate on legalising assisted dying for terminally ill people with fewer than six months to live has been polarised and lacking in full discussion of the complexities and practicalities. As such there has not been much room for those with outwardly opposing positions to explore common ground. Much of the debate in the media is simplified and does not account for the wider social context. The majority of participants from both sides of the debate felt that this research project offered a valuable opportunity to explore common ground, particularly in relation to the complexities and practicalities of assisted dying.

A change in the law was seen as a social and political issue and there appears to be a willingness to discuss the prevailing social context and societal values, with a key theme being the concept of being 'a burden' on family and society. The adequacy of social and palliative care provision for terminally ill people emerged as a common theme and there was recognition that the debate on legalising assisted dying was taking place in an 'unequal society.' Despite disagreement about the extent to which detailed processes and safeguards should be included in assisted dying legislation, respondents agreed that the practical aspects of assisted dying and the processes and safeguards would need to be carefully considered and planned. Older people emerged as being a group needing particular thought and attention, whose circumstances and relationships may make them vulnerable, especially if they are terminally ill. Several areas of common ground emerged when respondents discussed the ethical and 'existential' aspects of death and dying, including the psychological aspects of pain, suffering, death and dying for individuals and loved ones, understanding the 'good death' and the 'bad death' and the role of compassion and values in the debate on legalising assisted dying.

These points of commonality offer a tentative basis for further, potentially constructive discussions on the possible legalisation and potential implementation of assisted dying in the UK. All participants had a wish to find the best way forward with compassion for people who are terminally ill, regardless of being for or against legalising assisted dying.

INTRODUCTION

In 1985, the year that the Voluntary Euthanasia Society (renamed Dignity In Dying in 2006) celebrated its 50th anniversary, a researcher reported that '"Right to Die" campaigners have not exactly found Britain a fertile ground for their message' (Bell, 1985). Subsequent history has suggested that conclusion was mistaken. The issues of the right to die and assisted dying have gained massively in profile and political priority.

They have become the subject of innumerable discussions and media headlines, sometimes typified as generating more heat than light. The issue of assisted dying and its legalisation in the UK is thus an important one and it understandably raises strong views. The aim of the project was to gain the views of people who have shown a particular interest in the issue of assisted dying and to explore if there are any points of commonality between those who support and those who are critical of assisted dying. The approach taken was one of neutrality, which made it possible for people with different points of view to offer those safely, confidentially and anonymously, unless they desired otherwise.

PARTICIPANTS INCLUDED PEOPLE FROM PALLIATIVE CARE BACKGROUNDS, DISABLED PEOPLE, WITH OTHERS BEING FROM ORGANISATIONS CONCERNED WITH THE CARE AND SUPPORT OF OLDER PEOPLE

The aim of this small but unique consultation was to examine opposing viewpoints on legalising assisted dying in order to explore the possibility of finding common ground, or shared understandings, between those engaged in this discussion from outwardly conflicting positions. In proposing this project we did not assume that such common ground between opposing views was actually desirable or achievable. We took the view that if we found there was little room for consensus building, it would be a significant finding in itself. However, we considered it to be equally helpful if we were able to identify any possible areas for developing shared or common views. Either outcome could provide a basis for further developing discussion and practical policy.

METHODOLOGY

The aim at this stage was to carry out a number of confidential, individual interviews with those who support and those who oppose assisted dying. The majority of interview participants were drawn from those who were involved with the Demos Commission on Assisted Dying (Demos, 2011), either as commissioners or as experts who gave evidence to the Commission. Other participants were invited because of their particular position on assisted dying.

The Demos report was the most detailed document supporting a change in the law to date. In 2012 the organisation Living and Dying Well produced a further report offering a critical analysis of the Demos Commission on Assisted Dying concluding that in its view it had not made a 'convincing case for changing the law' (Living and Dying Well, 2012).

PARTICIPANTS IN BOTH GROUPS INCLUDED PEOPLE FROM PALLIATIVE CARE BACKGROUNDS WITH OTHERS BEING FROM ORGANISATIONS CONCERNED WITH THE CARE AND SUPPORT OF OLDER PEOPLE

We identified and invited a total of twenty participants comprised of ten people supporting legalising assisted dying and ten who opposed legalising assisted dying. A total of fourteen participants finally agreed to take part, with seven who opposed legalising assisted dying and seven who supported legalising assisted dying. One person who supported legalising assisted dying replied to the invitation to indicate that they thought the project had no point and so would not participate. The remaining five invited people did not reply despite follow up invitations. Participants in both groups included people from palliative care backgrounds, with others being from organisations concerned with the care and support of older people, a disabled person and individuals from academic, social work and policy backgrounds.

As part of the recruitment process, invited people received a letter explaining the project aims and scope, with assurances of neutrality, anonymity and confidentiality. Informed consent was sought. Potential participants were able to ask for further details and clarifications about the project and were given the option to see the interview schedule in advance.

Interviews lasted from thirty to ninety minutes, with most being about sixty minutes. They were conducted either face-to-face, on the telephone or via Skype, according to participant preference. Interviews were recorded and detailed notes were taken, these were then coded and thematically analysed. All participants were given the option to withdraw at any time. All participants approved the final report for publication.

THE INTERVIEWS WERE SEMI-STRUCTURED AND INCLUDED THE FOLLOWING QUESTIONS:

1. What terminology do you prefer for the subject?
2. Why do you prefer this terminology?
3. Can I ask you exactly what assisted dying means to you?
4. Why are you interested in the subject?
5. What is you view on assisted dying?
6. Do you have a public position on assisted dying?
7. Do you have particular concerns about the applicability of assisted dying to any particular people or groups?
8. What do you see as the problems in relation to this policy?
9. Do you feel the problems are insurmountable?
10. How do you see the practicalities of assisted dying?
11. What are the practicalities of informed consent and choice?
12. What is the role of alternatives like end of life, palliative or hospice care?
13. What are the main issues for moving from the principles to practical policy?
14. Why do you think assisted dying is so important now in our society in relation to other issues?
15. Is there any instance where you would take a different view to your prevailing one?
16. Are there any changes (in law or other) that you would nonetheless like to see?
17. Can you see any points of commonality with those who (support/ oppose as appropriate) assisted dying?
18. Is there anything else you would like to add?

TO ENSURE NEUTRALITY AND REDUCE THE INFLUENCE OF PRECONCEPTION, THE INTERVIEWS WERE CONDUCTED BY RESEARCHERS WITH LITTLE KNOWLEDGE OF THE SUBJECT AREA

In order to ensure neutrality and reduce the influence of preconception, the interviews were conducted by two experienced researchers with little knowledge of the subject area. They deliberately avoided immersing themselves in the topic beforehand and their degree of prior exposure to the debate was that of an ordinary member of the public.

TERMINOLOGY

During the participant recruitment process and interviews it became evident that several people did not perceive their position as clearly ‘pro’ or ‘anti’ assisted dying. Some people who chose to participate in the research reported that although they held particular views, the issue was too complex for them to take an extremely polarised position.

However, there were distinct divisions over whether or not it was right to change the law to enable assisted dying for people with a terminal illness who have been given fewer than six months to live. This is discussed in more detail in the report.

For the purposes of this report we will use terms like ‘opposing a change in the law’ or ‘supporting a change in the law’ to distinguish between participant viewpoints when discussing the key common themes, with the acknowledgement that, at times, this may not be a clear distinction.

Participants had mixed views on terminology, and this is discussed in more detail. However, for the purposes of this report we will use the term ‘assisted dying’ as this is the term used in the original research proposal.

FINDINGS

INFLUENCE OF PERSONAL EXPERIENCE

Overall, the majority of respondents from both sides of the debate spoke about the personal experience that had influenced their thinking on assisted dying.

Several people who supported a change in the law to enable assisted dying for people with a terminal illness who have been given fewer than six months to live said that this is something they would want for themselves. One person had considered assisted dying in the context of having been diagnosed with a potentially terminal illness from which he subsequently recovered, while another had attempted to include assisted dying in an advance directive with her GP.

Almost all of the respondents cited experience of personal distress at witnessing the end of life and death of relatives or friends, sometimes referring to the context of the available clinical and legal options. Those from both clinical and non-clinical backgrounds generously shared their personal and emotional perspectives on death and dying.

THE MAJORITY OF RESPONDENTS FROM BOTH SIDES OF THE DEBATE SPOKE ABOUT THE PERSONAL EXPERIENCE THAT HAD INFLUENCED THEIR THINKING ON ASSISTED DYING DYING

Of the total of fourteen respondents, five were or had been practicing clinicians (doctors or nurses) in palliative care. Four of these clinicians referred to their professional experience of the physical and psychological suffering (and in one case, suicide) of their patients when explaining why they supported a change in the law on assisted dying.[1] They reported patients having wanted to have conversations about assisted dying, which they felt could not be accommodated by palliative care practitioners in the clinical environment. Two described their unease at situations where they were repeatedly asked by a patient who was in the final stages of terminal illness if they could help end that patient's life, but were unable to do so. One spoke of their 'sense of failure' when a palliative care patient committed suicide.

A former palliative care clinician who did not support a change in the law spoke about the clinical practicalities of assisted dying and the need to accept the 'messy' physical reality of death and dying, whether assisted or not. A non-clinical palliative care practitioner also spoke about the influence of professional experiences of the complex emotional, social and physical reality of death and dying.

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[1] As we were advised by one participant, palliative care clinicians tend not to favour assisted dying. The proportion who did was over-represented in our consultation, but we were not seeking to reflect the preferences of any group or constituency, but rather to include people who strongly supported or were opposed to assisted dying.

THE QUALITY AND TONE OF DEBATE

Several respondents from both sides of the debate on legalising assisted dying for people with a terminal illness with fewer than six months to live said they actively supported the research project as an opportunity to have a broader, informed and potentially more constructive debate. They recommended this discussion should include more of the contextual, social, safeguarding, decision-making aspects of assisted dying and, as one participant said 'what medicine can and can't do' in terms of death and dying. One participant who supported a change in the law said 'the level of heat in the debate obscures some of the light', while an opponent described the debate as a 'ding dong'. An opponent of a change in the law called for 'a meeting of minds' and 'more careful, point by point discussion, with some resolution of many points that have been raised.'

PARTICIPANTS ON BOTH SIDES FELT THAT, TO DATE, THE QUALITY OF DEBATE HAD BEEN COMPROMISED OR STIFLED BY EXTREME POLARIZATION, EMOTIONALISM AND MEDIA MISREPRESENTATION

Participants on both sides felt that, to date, the quality of debate had been compromised or stifled by extreme polarization, emotionalism and media misrepresentation or over-simplification. This was felt to make constructive discussion and the exploration of common ground problematic. In addition, being neutral, undecided or questioning about a change in the law was thought to be difficult in this situation, with one participant feeling their opinion had been badly misrepresented in a major national newspaper. Therefore, the research project was welcomed by some as a place to begin to have a mediated, non-polarised discussion about assisted dying.

Several respondents from both sides of the debate felt that it could be possible to find some common ground. This was particularly in regard to engaging with the social complexities, ambiguities, safeguards and processes needed, where an extremely polarised debate on assisted dying would not help. One participant said that because of the nature of the topic the debate 'needs to be complicated' but at present it felt too 'medicalised' while another who was against a change in the law said that the 'how' questions had not been sufficiently considered.

Points being made in the debate about decision-making processes, safeguarding and broader social issues such as quality of care and support for people who are identified as terminally ill (including those who are older or disabled) by those who did not take a polarised position, were nonetheless felt to be presented or understood as 'slippery slope' arguments. As such, some respondents from both sides of the argument felt that the dynamic of the debate determined that potential areas for constructive discussion were at risk of being dismissed as extreme. One respondent who supported a change in the law said while it was 'impossible to eliminate risk', the potential 'unintended consequences' should be considered.

Three respondents who gave evidence to the Demos Commission on Assisted Dying reported dissatisfaction with the report recommendations, which they felt had not adequately accounted for or addressed the broader social complexities and full ethical implications of a change in the law.

Several of those who supported the proposed change in the law mentioned the role of clinical professional representative organisations in the debate, suggesting that this collective public position may inhibit individual clinicians and health professionals from asserting their own perspective on assisted dying. Similarly, three respondents who supported a change in the law cited the collective influence of 'religious lobbies', again raising the issue of 'collective' or 'associational' positions that may not represent what individuals themselves feel about assisted dying.

SEVERAL RESPONDENTS THOUGHT THAT THE FOCUS OF THE DEBATE ON LEGAL AND CLINICAL ISSUES RESULTED IN THE DISCUSSION BEING ISOLATED FROM THE WIDER AND COMPLEX SOCIAL CONTEXT IN WHICH LEGAL ASSISTED DYING WOULD TAKE PLACE

Several respondents thought that the focus of the debate on legal and clinical issues resulted in the discussion being isolated from the wider and complex social context in which legal assisted dying would take place. One respondent who identified as supporting a change in the law, while being very concerned about the social context, said that, 'I wish we were having the debate in the context of what informs the view of whether life is worth living or not'.

KEY THEMES

A thematic analysis of interview notes resulted in the identification of eight key themes from across the discussions:

1. **INDIVIDUAL** – the individual person with a terminal illness.
2. **RELATIONAL** – the context of relationships with family and friends.
3. **SOCIETAL** – the broader societal context.
4. **EXISTENTIAL** – aspects of human existence, suffering, death and dying.
5. **ETHICAL** – ethical considerations about assisted dying.
6. **LEGAL** – assisted dying in the context of existing law and legislation.
7. **PRACTICAL** – the processes and final act of assisted dying.
8. **CLINICAL** – the medical, practitioner and pharmacological aspects of assisted dying.

INDIVIDUAL

Participants from both sides of the debate said that there will always be a small number of individuals with terminal illnesses who will have an independent, settled and determined wish to end their lives at a time and place of their choosing, but because of their terminal illness, will need some assistance to obtain the means to do so. However, they were divided over how the state should respond to the wishes of those individuals. Three of those who opposed a change in the law expressed concern about the legalisation of assisted dying being influenced by individualistic consumer culture tied in with social and economic inequality.

RESPONDENTS WHO HAD EXPERIENCE OF WORKING IN A PALLIATIVE CARE CONTEXT SAID THAT IT WAS CURRENTLY DIFFICULT FOR PEOPLE WITH TERMINAL ILLNESS TO TALK TO STAFF ABOUT ASSISTED DYING

Most respondents from both sides of the debate who had experience of working in a palliative care context said that it was currently difficult for people with terminal illness to talk to staff about assisted dying, even in terms of getting information about what is and is not legally possible. Those who supported a change in the law felt that patients with terminal illness should have 'permission to have a conversation' with clinicians about death and assisted dying. One proponent from a palliative care background said that death and dying is a conversation with patients where 'nothing's ever said' and the discussion circles around 'what's not going to happen, rather than what is.' Those supporting a change in the law felt that having the option to choose assisted dying could provide reassurance and reduce psychological suffering during the dying process, even if the individual does not ultimately choose the option or die before they have the chance to. Being able to talk openly about death and assisted dying was felt to be an important aspect of individual choice and control.

For those who supported a change in the law, and for those who were cautious about it, assisted dying was seen as something that the individual must choose for themselves independently, without coercion from family, medical staff or through local palliative care policies determined by funding pressures. Three participants who supported a change in the law emphasised that terminally ill individuals should never be offered assisted dying, but should have the option to request it. They felt this was an important distinction for the exercise of choice.

It was acknowledged that it would be very challenging to determine and separate the effects of 'undue influence' from family or from the internal feelings of the individual, for example their own feelings of self-worth or perception of being 'a burden' on their family or on society. Feelings of 'being a burden' or having a 'sense of worthlessness' was felt by some on both sides of the debate to relate strongly to the ethical issues of equal access to good social and palliative care and support and quality of life. Two participants who supported a change in the law thought that 'self-sacrifice' was an autonomous individual decision and that this more challenging aspect of decision-making needed to be engaged with.

Four of those who opposed a change in the law reported that they took their position because they were not satisfied with how the current proposals addressed situational complexities, safeguards and decision-making processes for individuals. One concern cited by several who opposed legal changes focused on the risk that decision-making processes may not be flexible, sensitive or supportive enough to engage with individual cases, particularly those involving complex family relationships, fluctuating mental capacity or where the person wants to change their mind. One of these respondents mentioned the risk of assisted dying processes being absorbed into medicalised 'administrative procedure' that has not historically supported 'common sense and talking to people' and accommodated contextual and relational complexities in decision-making. A number of respondents on both sides who spoke about planning and decision-making said that the process and support should be responsive to individual circumstances.

SEVERAL RESPONDENTS FROM BOTH SIDES RECOGNISED THE POTENTIAL EFFECTS OF DETERIORATING MENTAL HEALTH ON DECISION-MAKING FOR SOMEONE WITH A TERMINAL ILLNESS

One respondent who was cautious about a change in the law because of concerns about its implementation asked the question 'how can we be satisfied that individual capacity has been adequately tested?' This question was reflected in the responses of five other participants, two of whom supported a change in the law. Two respondents who questioned a change in the law questioned the adequacy of the current provisions within the Mental Health Act 2005 for assessing capacity in the context of assisted dying, particularly for fluctuating capacity and capacity for autonomous decision-making in the context of abusive relationships.

Several respondents from both sides recognised the potential effects of deteriorating mental health on decision-making for someone with a terminal illness, and how mental health assessment for the individual in this context could be challenging. Two respondents, one from each side of the debate, said that for assessing capacity and mental health it was important for the individual to be personally known and understood by the doctor or care staff who were undertaking the assessments.

RELATIONAL

Overall, the majority of respondents spoke about aspects of assisted dying which concerned relationships, particularly those within families. Generally, it was felt that relationship dynamics and familial context were highly important but complex considerations for assisted dying. While some who supported a change in the law were optimistic about families, a number of those who did not support or were cautious about change, were concerned about issues of trust and abuse in families, with one respondent saying, 'families are not always nice' and that this needs to be accounted for in safeguards.

The majority of those who opposed a change in the law were concerned with the potential for forms of coercion by family members, something that was also acknowledged by some of those who were in favour of a change in the law. Four of those who were in favour spoke about relationships in the context of the individual being able to consider their family and friends as part of the decision to choose assisted dying. This was either in terms of an independent, autonomous decision about 'self-sacrifice' or wanting to 'spare' their loved ones the distress of witnessing their prolonged or acute suffering. This relational theme is also linked to the existential theme of memory.

THE MAJORITY OF THOSE WHO OPPOSED A CHANGE IN THE LAW WERE CONCERNED WITH THE POTENTIAL FOR FORMS OF COERCION BY FAMILY MEMBERS

Participants from both sides of the debate discussed the concept of 'being a burden'. This was mentioned in relation to decision-making in the context of individual relationship dynamics, particularly with families, and in the broader societal context. It was thought that it would be very difficult to assess the influence of 'feeling a burden' on family or friends on the decision to request assisted dying and that the feeling itself may be influenced by unique, individual internal and external factors.

For most respondents who opposed a change in the law, and two who supported it, possible influences on 'feeling a burden' included negative pressure from immediate family who may be motivated by material gain or who are unable to cope. Others from both sides of the debate thought that feelings of 'being a burden' were partly caused by inadequate provision of social care and support for terminally ill, older and disabled people and their carers. Two of those who opposed a change in the law noted the potential wider influence of 'being a burden' on society based on how willing that society is to support and value people who are terminally ill, old or disabled. Some respondents who supported a change in the law mentioned the possibility that an individual can 'feel a burden' due to 'internal pressures within themselves' which can contribute to psychological suffering. Along similar lines, an opponent of the proposed change talked about psychological suffering in situations where a terminally ill person loses their independence and 'can't bear to be cared for.'

Three of those who opposed a change in the law recommended that, should assisted dying become legal, skilled professionals must assess family and relationship dynamics in the decision-making process to detect coercion or undue influence. Most of the opponents to a change in the law were particularly concerned about older people with terminal illness and the nature of power and control in their inter-familial relationships, particularly that relating to money or material gain. They recommended that there should be robust safeguards in the process to identify and address issues of elder abuse and coercion.

For five of those opposed to a change in the law, discussion of relational issues extended to the effects of loneliness or lack of human connection and the decision to choose assisted dying, particularly for terminally ill older people. Those respondents were concerned about the effects of the general social marginalisation and isolation of older people, which may lead some to conclude that 'life is not worth living'.

SOCIETAL

All respondents spoke about the wider social context and societal factors involved with assisted dying and a change in the law. For most a change in the law was seen as a societal and political as well as legal decision. Some of the societal sub-themes cross-refer to the relational, individual as well as ethical themes.

RESPONDENTS WERE CONCERNED ABOUT THE EFFECTS OF THE GENERAL SOCIAL MARGINALISATION AND ISOLATION OF OLDER PEOPLE, WHICH MAY LEAD SOME TO CONCLUDE THAT 'LIFE IS NOT WORTH LIVING'

The majority of participants who opposed a change in the law expressed concern about the contemporary societal context in which the debate on assisted dying is taking place, including the reduction in public funding for health and welfare and the negative social value placed on people who are 'ill, disabled or old.' Several of these respondents cited the marginalised social position and quality of life of many older people as making them potentially 'vulnerable' to coercion, abuse or experiencing extreme loneliness. Other participants who opposed a change in the law spoke about the excessive social value currently accorded to a person's financial and economic activity and that society should be encouraging and supporting everyone to 'lead full lives'. Some felt that these factors could lead some terminally ill older, disabled or socially disadvantaged people to assess their lives and contributions negatively and to their feeling of being a social and economic 'burden'. One respondent who was hesitant about a change in the law felt that disabled people's perceptions on legalising assisted dying may relate to experiences of having lived with long term conditions and disability, with the associated struggle to live independently with the right support. Referring to this perspective on 'assisted living', they said, 'first we need to talk about how we look after people, then look at assisted suicide.'

Social attitudes to death and dying were also felt to influence the current discussion on legalising assisted dying, with one respondent asking 'how do we attune society to think about dying?' Most of those who supported a change in the law felt that individuals being able to choose the time and place of their death was part of 'social progress' and 'a form of civil liberty'. Four proponents of a change in the law felt that the general public was becoming more supportive of legalising assisted dying, with one mentioning the need for politically 'brave' leadership on the issue. Three opponents to the change in the law thought that the policy was being influenced by a culture of consumerism and individualism. Four opponents also referred to the problems society has with death and dying as well as 'disability and difference'. For two respondents this was characterised by fear, where people are 'phobic of disability, illness and death' and want to control death and dying.

> **QUESTIONS ABOUT THE ADEQUACY OF INVESTMENT IN SOCIAL AND PALLIATIVE CARE LED SOME OPPONENTS AND SEVERAL PROPONENTS TO EXPRESS CONCERN ABOUT THE PROPER FUNDING OF ASSISTED DYING**

A number of respondents from both sides of the debate spoke about the social value placed on, and investment in, paid and unpaid caring, with one respondent who supported a change in the law saying that 'no value is placed on looking after people who can't look after themselves.' Some opponents spoke about the context in which assisted dying is being considered where inadequate or underfunded social care and support, including that for terminally ill people, could affect quality of life and potentially the decision to request assisted dying – if it became available. Questions about the adequacy of investment in social and palliative care led some opponents and several proponents to express concern about the proper funding of assisted dying. Their focus was on the proper provision of supported, informed decision-making and safeguarding processes; equal access to the option of assisted dying; professional, social and clinical support for individuals and families. For one respondent who was hesitant about a change in the law, the key question on accessing assisted dying was, 'how do you make sure people can access it...but also understand and say why?'.

Also of concern to some of the opponents of assisted dying was the degree to which housing, social care and support services were 'empowering' and supportive for terminally ill people, their friends and families. Related to this were additional concerns about the potential for some staff to have negative attitudes towards terminally ill people who are older or disabled, or who are judgmental towards people who request assisted dying.

EXISTENTIAL

A number of respondents from both sides of the debate spoke about some of the 'existential' aspects of death and dying relating to human existence and psychological suffering. This was without explicit reference to spiritual or faith-related perspectives, although the theme may have relevance for this dimension of the debate. This was particularly in relation to suffering, pain, the pursuit of a 'good death.' One participant who supported the change in the law recommended that the 'experience of existential suffering' of the dying needed to be researched and more clearly understood.

The 'good' and 'bad death' was described in physical and psychological terms for both the individual themselves and for their family and friends. 'Good' and 'bad' death was cited by respondents who had backgrounds in palliative care as being of professional concern to clinical and social care practitioners.

THOSE PALLIATIVE CARE PRACTITIONERS WHO SUPPORTED A CHANGE IN THE LAW FELT THAT THIS WOULD ALLOW THEM TO EXTEND THEIR PROFESSIONAL CARING ROLE IN RELIEVING SUFFERING

Broadly for participants on both sides of the debate who mentioned it, the 'good death' was associated with minimal suffering through pain control and sedation; maximum dignity, control and autonomy through the exercise of choice about end of life arrangements (including place of death) and sensitive care and support from palliative care and hospice staff as well as family and friends; minimal exposure of family and friends to the prolonged physical suffering and psychological distress of the loved one. For those who supported a change in the law, the control aspect was extended to the exercise of individual autonomy and choice regarding time as well as place of death. The palliative care practitioners who supported a change in the law felt that this would allow them to extend their professional caring role in relieving suffering.

The 'bad death' was seen by respondents from both sides of the debate who mentioned the topic, as being characterised by unbearable existential, physical and psychological pain and distress; loss of autonomy and dignity; and loss of control over basic functions of everyday life. Psychological pain was associated with loss of dignity and autonomy as physical symptoms of terminal (particularly neurological) illness progressed, such as movement and the ability to communicate. For those who supported a change in the law, the psychological distress in terminal illness included the inability to take full control over the end of life by having the option to choose when their life would end. Those mentioning the topic who opposed or were cautious about a change in the law, mentioned concerns about the influence of loneliness, negative familial relationships and feeling lack of individual self-worth (particularly for older or disabled people) on the psychological aspects of the 'bad death'.

The extent to which the clinical and physical aspects of death and dying could be controlled in order to achieve a 'good death' was explored by number of respondents on both sides of the debate. There was some acknowledgement from respondents from both groups that pain in terminal illness could be fairly well controlled clinically and that highly skilled palliative care staff could provide support to both patient and loved ones to ensure a sense of dignity and control. However, two respondents who supported a change in the law felt that the dignity and control provided by palliative care were not sufficient in some circumstances. One respondent who worked in a hospice remarked that while the goal of palliative care was for the person 'not to die in pain and to have a dignified death', this was not always possible, while another said 'dying isn't dignified'. Another respondent from a palliative care background who supported a change in the law said that 'doctors can construct a "good death", but it might not be that way for the patient.' Two participants, one who opposed a change in the law and one who supported it, mentioned that birth plans could be analogous to death plans. However, like birth, it was recognised that death is a biological and a life event that cannot be fully controlled.

MOST CONCEDED THAT THE REALITY OF PHYSICAL DEATH WAS SOMETHING THAT COULD NOT BE CONTROLLED AND THAT A 'GOOD DEATH' COULD NOT BE GUARANTEED, EVEN IN THE CONTEXT OF ASSISTED DYING

Most of those who spoke about it conceded that the reality of physical death was something that could not be controlled and that a 'good death' could not be guaranteed, even in the context of assisted dying. One respondent who was against a change in the law said that people could not legislate against 'death and disease' being 'a bit mucky', or offer a clear choice of a 'quick and easy' death. Another opponent remarked that 'people die in pain and not every death is wonderful'.

A number of respondents on both sides who were familiar with medical perspectives spoke about the clinical problems associated with self-administering barbiturates in drinkable liquid form, which can cause vomiting and convulsions at time of death or unconsciousness before the fatal dose is fully taken (meaning that the individual would recover). They were clear that this would be distressing for both the individual and loved ones who were present, and for the respondents who support a change in the law, this method was not felt to be satisfactory.

For several of those who supported a change in the law, the emotional responses of loved ones and the 'legacy of memory' at time of death were felt to be important. For one person who supported a change in the law, memory was a form of 'after-life' and they wished to have control over their death to preserve good memories of their life. This related to the concept of the 'good death' and the immediate memory of the death of a loved one that family and friends were left with. There was a feeling that witnessing a 'bad death' could result in memories to overshadow those of the person in life, which was thought to be an additional aspect to the exercise of choice and control for the dying person. Here, three of the 'pro' respondents were concerned about loved ones witnessing the effects of barbiturates, as well as the physical end stage of terminal illness. The existential theme of 'memory' appears to be related to the ethical theme of 'compassion'.

ETHICAL

Nearly all participants expressed an ethical perspective on assisted dying, but no one referred to a personal position based on religious faith alone and only one person disclosed that their ethical position was influenced by religious beliefs. Given that some opposition to assisted dying has been based on religious beliefs, this could be seen as reflecting a gap in who we were able to talk to in this small scale project. Our aim, however, was a modest initial attempt to begin some discussion between people with opposing views, rather than to reflect or represent all the different perspectives within each point of view. The majority of ethical positions were framed as rational and secular. No one cited taking one's own life as being morally wrong and no one said that they would deny a person the choice to take their own life on principle. As one respondent who supported a change in the law said, 'there may be some commonality in values but a different manifestation of how those values would be applied'.

NO ONE CITED TAKING ONE'S OWN LIFE AS BEING MORALLY WRONG AND NO ONE SAID THAT THEY WOULD DENY A PERSON THE CHOICE TO TAKE THEIR OWN LIFE ON PRINCIPLE

Two participants from different sides of the debate both borrowed the language of the abortion debate to describe their ethical stance as 'pro-choice' in contrast to 'pro-life'. In addition, several proponents of legalising assisted dying referred to the analogies with abortion legislation and the surrounding ethical debate, although another respondent who remained cautious about a change in the law, mentioned the ethical issues on abortion and the termination of pregnancies where the foetus is 'impaired.'

A number of participants from both sides of the debate described their approach in terms of compassion and the relief of suffering, but with one respondent who opposed a change in the law calling for better explanations about the meanings of 'compassion'. One participant who opposed a change in the law spoke about 'compassionate pragmatism'. Another spoke of her concerns about theoretical 'armchair compassion', saying that the best people to comment were those with first-hand experience who had 'got their hands dirty' or clinicians who had tried to make very ill and distressed people 'feel whole again'.

Several participants from both sides mentioned the concept of equality, and this was applied to different aspects of the assisted dying debate. All participants who mentioned equality did so in the context of recognizing that the campaign to legalise assisted dying for terminally ill people with less than six months to live was taking place in an 'unequal society'. Respondents from both sides of the debate recognised the particular issues for older people, who were felt to be socially devalued and marginalised.

Almost all of those who opposed a change in the law were concerned that at present some people who are terminally ill may not have equal access to the palliative and social care to enable them to have 'equal access to quality of life', 'assisted living' or 'dignity in living'. This included access to hospice support in terms of geography and referral criteria according to type of terminal illness, as well as suitable housing. For many, this issue of inequality was linked to the concept of social 'equal value' in terms of disability, age, poverty and access to social, familial and state support.

AT PRESENT SOME PEOPLE WHO ARE TERMINALLY ILL MAY NOT HAVE EQUAL ACCESS TO THE PALLIATIVE AND SOCIAL CARE TO ENABLE THEM TO HAVE 'EQUAL ACCESS TO QUALITY OF LIFE', 'ASSISTED LIVING' OR 'DIGNITY IN LIVING'

Those who supported a change in the law also expressed concern about equality of access to the best care and support, and this extended to equality of access to assisted dying. Some of the concerns about equality were about disability and the physical capacity to self-administer the fatal dose of toxin, while other concerns lay with inequality based on wealth and access to assisted dying. For one respondent who was cautious about a change in the law, equal access to assisted dying was dependent on the safeguards and decision-making process. They felt there could be a risk of rejecting more complex cases involving problematic family relationships.

Several respondents who opposed a change in the law were concerned that the policy focus was on younger terminally ill people who have 'capacity, autonomy and support' – 'those who are easy', rather than older people in complex familial circumstances. One opponent of legislative change expressed concern over broader social inequality in policy-making, as he felt that the change to the law on assisted dying was more a 'law for the doing class than the done unto class'. Similarly, a respondent who was cautious about a change in the law suggested that the people who would be likely to benefit would not be older people or people with life-long impairments who are terminally ill, but rather 'those without that baggage'.

There was additional concern from two participants who were against a change in the law about the risk that public funding for NHS palliative care services could be diverted into assisted dying, instead of additional resources being found to support it. However, a respondent who supported a change in the law who expressed a similar concern cited evidence from the implementation of the Death with Dignity Act in Oregon that suggested that resources were not being diverted from palliative care.

LEGAL

Respondents from both sides of the debate called for greater accuracy in the use of terminology associated with assisted dying. Some felt that the debate and public understanding were not being helped by the inaccurate or inconsistent use of terms and definitions. Several of those who supported a change in the law felt it was particularly important to make the distinction between 'euthanasia', 'assisted suicide' and 'assisted dying'. Further to this, some of the respondents from both sides of the debate spoke about the accurate use of the term 'physician assisted suicide' in relation to proposed legal changes. One proponent used the term 'supported dying' while one respondent who was cautious about a change in the law referred to 'voluntary euthanasia'.

SOME FELT THAT THE DEBATE AND PUBLIC UNDERSTANDING WERE NOT BEING HELPED BY THE INACCURATE OR INCONSISTENT USE OF TERMS AND DEFINITIONS

More opponents spoke at length about the legal aspects of assisted dying than those who supported a change in the law. Opponents who spoke in detail about legal issues said that a new law was not needed and that existing legislation, Director of Public Prosecution policy on assisted dying and case law, including Ms B vs An NHS Hospital Trust ([2002] EWHC 429 [Fam]) (a right to withdraw from treatment case) were sufficient. One respondent who opposed a change in the law said that the legal presumption should be that 'we don't help people to end their life, but in extremity we might' while another said that, for avoiding prosecution in such circumstances, 'the law that exists is not dysfunctional.' However, a respondent who supported a change in the law drew on their personal experience to challenge the view that the current legal options are 'humane'. One opponent said Lord Pannick's amendments to Lord Falconer's Bill (HL Deb (2014-15) 07 Nov 2014 col. 1853) requiring that a judge assess each individual case for coercion or undue influence, still needs 'much ironing out', particularly with regard to the reliability of medical evidence and difficulties with assessing familial coercion. In addition several opponents felt that current legal options concerning right to refuse treatment, treatment withdrawal and 'do not resuscitate' (DNR) advance directives were sufficient. One said that a change in the law would set up a 'licensing system' and process for assisted dying and that he did not think 'it is safe to legislate for it'.

Many respondents who opposed a change in the law, and two who did not oppose it but had concerns, thought that the proposed 'legislation is too tidy' and that a 'tighter, safer Bill' was needed. The majority of concerns focused on the extent to which explicit safeguards were included in the proposed legislation, with one opponent saying they remain 'weak and too loose', with more emphasis on the technical and clinical aspects of assisted dying than on the complex social and psychological factors in safeguarding and decision-making processes. For one respondent this implied full engagement with 'the person and their circumstances' as well as the medical aspects of their terminal illness. In relation to this, several opponents expressed concern about assessing coercion and potentially abusive familial situations, particularly for older people with terminal illness. Four opponents suggested that the Mental Capacity Act (2005) and mental capacity assessments were not designed for complex decision-making in assisted dying. Another respondent who was against a change in the law talked about the risk of having 'no guidance on steps or safeguards' in the Bill and said that 'conditions are not safeguards.' However, several proponents thought that the detail on safeguards and processes could be decided following a change in the law.

PRACTICAL

Nearly all participants from both sides of the argument addressed the practicalities of assisted dying. Discussion focused on which discipline would oversee assisted dying; the informed decision-making process and safeguards; the clinical mechanics of assisted dying; and the location of assisted death. Participants were less clear about resourcing assisted dying, although most who mentioned funding said it should be publicly funded as part of the NHS.

Many respondents from both sides of the debate referred to the operation of existing systems in Oregon, Netherlands and Belgium. For proponents of a change in the law, the system in Oregon was seen as a possible model to use and also as providing a source of research evidence on assisted dying in practice.

SEVERAL RESPONDENTS FROM BOTH SIDES OF THE DEBATE SAID THAT ASSISTED DYING SHOULD BE LOCATED 'OUTSIDE MEDICINE' BUT WITH CLINICIANS BEING INVOLVED WITH THE MEDICAL ASPECTS

In terms of the discipline to oversee assisted dying, several respondents from both sides of the debate said that assisted dying should be located 'outside medicine' (including palliative care), but with clinicians being involved with the medical aspects. Some respondents from both sides of the debate thought that assisted dying should be situated in judicial process.

The practicalities of safeguarding against coercion and undue influence were discussed by both opponents and proponents of a change in the law. For some of those who opposed or who were hesitant about a change in the law, safeguards were not just 'qualifying conditions' and they wanted to see 'sufficient, appropriate and genuine safeguards in the process' in any legislation on assisted dying. One respondent said that while he did not oppose assisted dying, he thought that changing the law could provide 'a powerful set of circumstances for exploitation', especially for older people who are terminally ill. Another respondent who took a similar position said that safeguarding should not be reduced to an administrative 'tick box' process and would require the type of skills usually associated with social work, particularly for the detection of coercion within a family situation. Respondents who spoke about safeguards against coercion also mentioned the need for advisers from multiple disciplines (particularly practitioners who are known to the individual) and the assessment of the history and dynamics of relationships to identify coercion.

One respondent who was hesitant about a change in the law said that mental capacity assessment for assisted dying should accommodate the 'context in which decisions are being made' and that the current provisions within the Mental Health Act 2005 may not be sufficient. Several respondents from both sides of the debate said that the assessment of mental capacity should not be carried out by a doctor alone and that fluctuating mental capacity and mental health must be addressed as part of a preferably multidisciplinary assessment process. Three respondents, two of whom supported a change in the law and one who was hesitant about it, discussed aspects of assessing mental health in situations of psychological distress and the challenge of assessing (what one of them called) 'suicidality' in the context of assisted dying.

MENTAL CAPACITY ASSESSMENT FOR ASSISTED DYING SHOULD ACCOMMODATE THE 'CONTEXT IN WHICH DECISIONS ARE BEING MADE'

The informed decision-making process was discussed by both those supporting and opposing a change in the law on assisted dying. Four proponents said that assisted dying would only ever be 'voluntary and requested' and would never be suggested or offered by clinicians in any context. In addition to safeguards and capacity, respondents who spoke about decision-making processes mentioned having sufficient information in order to make the decision (including the administration and effects of the fatal dose of drugs); enough time to consider their decision with access to professional support and with regular review points; social and psychological support for making their decision and, the open option to change their mind at any point in the process.

Participants from both sides of the debate discussed the practicalities of the final act of assisted dying. Proponents from a clinical background discussed toxicology and the death process, saying that oral doses of barbiturates (often with an antiemetic to prevent vomiting) were not ideal as death can involve convulsions and vomiting or the individual can lose consciousness before they have self-administered the fatal dose. Several said the most effective way would be to have an intravenous dose that is administered by the individual using a suitable mechanism. One proponent with a clinical background in palliative care spoke about the difficulties with obtaining barbiturates in the UK and the development and use of newer forms of fatal drugs for assisted dying. They also spoke about the practical issues of self-administration for people who do not have the physical means to do so easily. Another proponent said that NICE could have responsibility for assessing the drugs to be used in assisted dying.

Both supporters and opponents of a change in the law discussed the place where the person could end their life. Again, some respondents said that the location of an assisted death should be 'outside the health system', including outside of hospices and

NHS or private hospitals. Others felt the act of assisted death could take place in hospices or hospitals. There was a suggestion from one proponent that the place should be of the person's choosing, provided there was provision for the appropriate disposal of the body and assurances that no members of the public would be unwittingly exposed to the act. Another proponent said that there was an assumption that death would take place in people's own homes, but it might also take place in nursing homes, where she would be concerned about resources and staff skills. Several respondents from both sides of the debate mentioned the possibility of establishing places similar to Dignitas clinics, while recognising the importance of 'pleasant surroundings' and ensuring that there is equal access and equal quality standards for everyone choosing assisted dying. One proponent expressed concern that a two-tier system could emerge where 'the rich will continue to be able to exercise self-determination' and where for poorer people, 'families might end up having to do this stuff'.

CLINICAL

Most respondents spoke about some of the clinical challenges and issues for the medical profession and medical environments posed by assisted dying. A number of participants from both sides of the debate considered that assisted dying should 'have no place in medicine' or be located in medical institutions or culture.

PARTICIPANTS FROM BOTH SIDES OF THE DEBATE MENTIONED THE POTENTIAL CHALLENGE OF ASSESSING AND DETECTING CO-EXISTING, FLUCTUATING MENTAL HEALTH PROBLEMS OR FLUCTUATING MENTAL CAPACITY

Many of those who were against a change in the law questioned how accurately clinicians could determine that a terminally ill person has six month or less to live, as put forward in the proposed legal changes. Four of these respondents also mentioned the possibility of diagnostic errors. Three of those who supported a change in the law said that medical assessment of disease progression and prognosis was not exact and medical progress meant that there could be a possibility that, at any one time, a treatment could become available to prolong life or relieve pain. A few participants from both sides of the debate mentioned the potential challenge of assessing and detecting co-existing, fluctuating mental health problems or fluctuating mental capacity and how these would affect access to and decision-making processes in assisted dying.

Three respondents, two who supported and one who opposed a change in the law, mentioned the need for a better understanding and application of toxicology and the administration of fatal doses of drugs for terminally ill people. One of these respondents noted that because of the legal issues surrounding this topic, research and development and manufacture of toxins for the purposes of self-administration in assisted dying has not been forthcoming owing to the reluctance of pharmaceutical companies to engage in such research and development. Another participant who supported a change in the law cited lack of research as one of the reasons why the options were limited to barbiturates and why technology around intravenous dosing was not well developed. Some of those who opposed a change in the law talked about existing possibilities for terminally ill patients to take control through treatment refusal or withdrawal and through the use of advance directives, including 'do not resuscitate' (DNR) orders. Two participants who supported a change in the law spoke about the ambiguities of the existing practice of total sedation during the end stages of a terminally ill patient's life.

MANY PARTICIPANTS FROM BOTH SIDES OF THE DEBATE SPOKE ABOUT DIFFERENT IMPLICATIONS OF ASSISTED DYING FOR CLINICAL STAFF, INCLUDING PALLIATIVE CARE CONSULTANTS, DOCTORS, GPS AND NURSES

Most respondents discussed aspects of the debate relating to the clinical environment and medical practice surrounding assisted dying. Most of the discussion focused on palliative care and hospices, where the UK was considered to be a world leader. One respondent who was opposed to assisted dying expressed concern about the UK's reputation in this area if assisted dying was introduced. Most respondents from a clinical background in palliative care who supported a change in the law viewed assisted dying as the ultimate extension of palliative and end of life care, in the context of increasing patient choice. However, those participants with a palliative care background who opposed a change in the law said that assisted dying should not be located within palliative care or take place in hospices. Two respondents, one from each side of the debate, mentioned that hospices were places that were sometimes mistakenly seen as where people go to die or 'to be finished off', and so offering assisted dying in a hospice environment could reinforce these popular misperceptions. This led to several participants from both sides of the debate to suggest that, if a change in the law were to be enacted, assisted dying should take place 'outside medicine' and not within hospitals or hospices. However, others thought it would probably take place in a hospital setting. One participant who supported a change in the law had concerns that nursing homes may not be appropriate or have the staff skills or resources to be able to accommodate assisted dying.

Many participants from both sides of the debate spoke about different implications of assisted dying for clinical staff, including palliative care consultants, doctors, GPs and nurses. Most of the comments related to what some respondents termed 'physician assisted suicide', where a clinician supports a terminally patient to end their own life by providing the drugs and/or mechanisms to enable the patient to self-administer the fatal dose. There were divergent views among respondents who opposed a change in the law as to whether it is a doctor's role to support a terminally ill patient to end their life, with several participants from both sides mentioning issues about how this role may affect trust in doctors. However, two participants who supported a change in the law said that assisted dying should not be offered by doctors, but that they would have legal capacity to respond to requests for assisted dying, or to discuss it with terminally ill patients should they begin the conversation.

THERE WERE DIVERGENT VIEWS AMONG RESPONDENTS WHO OPPOSED A CHANGE IN THE LAW AS TO WHETHER IT IS A DOCTOR'S ROLE TO SUPPORT A TERMINALLY ILL PATIENT TO END THEIR LIFE

The theme of 'burden' re-emerged in discussions on the role of medical staff in assisted dying, with one respondent remarking that the responsibility may place a burden on them. The implication was that medical staff should have a choice, whether or not to assist the individual. Another respondent who supported the law spoke about the palliative care nurse perspective and the communication and dynamics between doctors and nurses in a palliative care multi-disciplinary team. She suggested that because of the length of time spent with terminally ill individuals and the nature of support given, palliative care nurses have valuable contributions to make but may not always have the confidence to do so.

CONCLUSION

EXPLORING COMMON GROUND

This small, exploratory research study suggests that, to date, the debate on legalising assisted dying for terminally ill people with fewer than six months to live has been polarised and lacking in full discussion of the complexities and practicalities. As such there has not been much room for those with outwardly opposing positions to explore any possible common ground. Much of the debate in the media is over-simplified and does not account for the wider social context. The majority of participants from both sides of the debate felt that this research project offered a valuable opportunity to explore common ground, particularly in relation to the complexities and practicalities of assisted dying.

Overall, the analysis of the interviews suggests that the following may present common areas of interest and concern that could form the basis for further discussion:

ALL PARTICIPANTS HAD A WISH TO FIND THE BEST WAY FORWARD WITH COMPASSION FOR PEOPLE WHO ARE TERMINALLY ILL, REGARDLESS OF BEING FOR OR AGAINST LEGALISING ASSISTED DYING

CONTEXTUAL SOCIETAL VALUES

A change in the law was seen as a social and political issue and there appears to be a willingness to discuss the prevailing social context and societal values. Common themes include:

- **The concept of 'being a burden' on society.**
- **The social value placed on those who are older, ill or disabled.**
- **The social value placed on social care and support work.**
- **Social attitudes to death and dying.**

SOCIAL AND PALLIATIVE CARE PROVISION

The inadequacy of social and palliative care provision for terminally ill people emerged as a common theme, with specific discussion on the following aspects:

- **The concept of 'being a burden' on family and society.**
- **The value placed on, investment in and equality of access to good quality social care and palliative care for terminally ill people.**
- **Issues of quality of life for terminally ill people, particularly those who are older or disabled.**

EQUALITY AND EQUITY

There was recognition that the debate on legalising assisted dying was taking place in an 'unequal society', with the following common themes emerging from the discussion:

- **Unequal social value placed on older, ill and disabled people.**
- **Economic inequality and access to social care, palliative care and assisted dying.**
- **Ensuring equal chances for good quality of life for terminally ill people.**
- **Ensuring equal access to assisted dying.**

PRACTICALITIES, PROCESSES AND SAFEGUARDS

Despite disagreement about the extent to which detailed processes and safeguards should be included in assisted dying legislation, respondents agreed that the practical aspects of assisted dying and the processes and safeguards needed would have to be carefully considered and planned. Common themes included the following:

- **The location of responsibility for assisted dying decision-making processes.**
- **How to resource and fund assisted dying.**
- **The location of the act of assisted dying.**
- **The method and means of self-administering a fatal dose.**
- **The role of medical professionals.**
- **The assessment of capacity and mental health, including in complex situations.**
- **Assessing coercion or abuse and relationship dynamics, including within families.**
- **The composition and role of multi-disciplinary teams in assessment and support.**
- **How to support fully informed, independent decision-making.**
- **Assessment and planning that is flexible and responsive to individual needs and unique circumstances.**

OLDER PEOPLE

Older people emerged as being a group needing particular thought and attention, whose circumstances and relationships may make them vulnerable, especially if they are terminally ill. Key common areas for further discussion were as follows:

- **The concept of 'being a burden' on family and society.**
- **Safeguarding issues concerning family and other relationships.**
- **Loneliness and social marginalisation.**
- **Equal chances for good quality of life.**
- **Equal access to good quality social care and palliative care.**

EXISTENTIAL AND ETHICAL ASPECTS OF DEATH AND DYING

Several areas of common ground emerged when respondents discussed the ethical and 'existential' aspects of death and dying, as follows:

- **The psychological aspects of pain, suffering, death and dying for individuals and loved ones.**
- **Understanding the 'good death' and the 'bad death'.**
- **Issues of individual control and dignity at the end of life.**
- **The role of compassion and values in the debate on legalising assisted dying.**

These points of commonality could offer a basis for further, potentially constructive discussions on the legalisation and possible implementation of assisted dying in the UK. All participants had a wish to find the best way forward with compassion for people who are terminally ill, regardless of being for or against legalising assisted dying.

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SHAPING OUR LIVES

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The aim of this exploratory research study, supported by the **Joseph Rowntree Foundation**, was to bring together people with opposing views about assisted dying to see if there was any common ground between them which could provide the basis for further discussion and policy development.

Shaping Our Lives
A National Network of Service Users and Disabled People

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