

**REPORT TO THE COMMISSION ON
ASSISTED DYING: DEMOS RESEARCH WITH
VULNERABLE GROUPS**

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SECTION ONE: EXECUTIVE SUMMARY

The purpose of this research was to consult with members of groups that are frequently considered to be at risk from a change in the law on assisted dying. The groups that Demos sought to conduct research with included:

- Adults with terminal illnesses
- Adults with learning disabilities
- Adults with physical impairments
- Young people with terminal illnesses
- Older people

In the event we were unable to set up a session with young people with terminal illnesses. We consulted with organisations that provide services to young people with life limiting illnesses and they decided that it would not be appropriate for them to approach young people to take part in this research. Instead, we conducted interviews with two groups of young people aged 16-18 who were running drama and media workshops with service users at a London hospice.

During the research we conducted eight focus groups. Two of these were with adults with terminal illnesses at a hospice in South London, and two were with young people who were taking part in creative workshops at the hospice. We also ran two focus groups with disabled people, one in Preston, and one in Solihull. We also conducted one focus group with older people living in sheltered accommodation, and one specifically with adults with learning disabilities.

In addition to the focus groups, we also publicised the research via internet forums for people with terminal or critical illnesses and received twelve responses from individuals who wished to take part. We received nine submissions by email from this group, and

conducted two phone interviews and one face-to-face interview. The majority of the people who made contact with us through the online forums had motor neurone disease.

Themes explored in the research

A topic guide was developed for the focus groups and interviews to allow the same issues to be explored with each group. In each discussion we elicited people's views on the following subjects:

- The current law on assisted dying in the UK
- Attitudes to the legalisation of assisted dying in the UK (including assisted suicide and voluntary euthanasia)
- The identity of the person being assisted to die as a consideration
- The identity of the person providing assistance as a consideration
- Potential risks that assisted dying might pose to individuals or society
- Safeguards that might be required in a legal regime for assisted dying

The main findings from this research are summarised here; detailed findings are summarised in section two, and full reports on each focus group or interview are provided in section three.

Research findings

During the course of our research it became apparent that people's opinions were very strongly influenced by their own experience. Although not true in every case, we noted in particular that people who had seen a loved one die in distressing circumstances were more likely to support some form of legalisation of assisted dying. We also found that in the focus groups with disabled adults there were more people who were cautious about the legalisation of

assisted dying, or who rejected this on principle, although there was still considerable diversity of opinion in these groups.

We used the research sessions as an opportunity to ask people about the detail of any potential new legislation around assisted dying: who – if anyone - should be eligible for assistance in ending their lives and how eligibility might be defined. Among the people we spoke to who felt that assisted dying should be a legal option, most thought that eligibility should be limited to people with terminal illnesses or to those experiencing unbearable suffering for other (mainly physical) reasons. There was a clear strand of opinion that individuals who were suffering from significant physical pain should be able to choose an assisted death, but a large number of people commented that for people who were terminally ill, good palliative care would always be a preferable option. Some people were concerned that if assisted dying were to be legalised it might become the default response to a negative prognosis or sudden disabling accident, preventing patients and doctors from exploring alternative solutions.

On the question of whether people who were experiencing suffering as a result of serious disabilities should be able to choose an assisted death, there was a notable split in responses between the disabled groups and non-disabled groups. Many of the adults with physical impairments would be concerned about assisted dying being an available option for people who become disabled due to illness or accident and particularly if they had experienced this change very recently. There was a clear concern that disabled people might choose an assisted death as a result of inadequate social support, or because they felt that their lives were not valued by the rest of society. People in the other focus groups who were non-disabled were more likely to think that people who experienced a very negative change in their quality of life as a result of becoming seriously disabled should be able to choose an assisted death if they wanted to, although again, a range of opinions were represented on this issue.

The focus groups also provided us with a chance to consult people on what they felt might be an appropriate framework of safeguards

around assisted dying. During the research we asked the focus groups who might be responsible for making decisions about whether or not a person was eligible to choose assisted death. Options that the participants discussed included a GP or specialist consultant doctor, a legal tribunal, a panel of doctors, family members, social workers or a combination of these. People tended not to feel particularly strongly about this, although some people felt that the family definitely should be consulted, while a smaller group were more concerned that a person's family should not be able to influence whether or not a person was able to access an assisted death.

A second, and related issue was the question of, if the law was changed, which individuals or professions might be involved in providing people with practical assistance in the act of ending their lives. We wanted to know whether people felt that assistance should come from a health or social care professional, or from a close friend or family member. Again, there was a wide spread of opinion on this, with the debate focusing most closely on the potential psychological effect on the person who provided this assistance. Whilst one group of people felt that it might be appropriate for family members to be involved in giving assistance, most felt that a medical or other professional would also need to be present to protect against potential coercion.

We also discussed what sorts of safeguards might need to be in place in order to test for mental capacity or mental illness and the presence of external pressure. Many of the disabled people that we spoke to were concerned about the risk that value judgements about people's quality of life, particularly if they were disabled, might affect the advice they were given by medical and legal professionals. This view was communicated by one of the people we spoke to who had motor neurone disease, who felt that she had suffered from negative assumptions by those around her about her quality of life.

Mental capacity was another issue that divided the people we spoke to. The majority of focus group participants agreed that depression was a factor that needed to be identified and treated before an assisted death could be considered. However, a small subsection of

the people we spoke to felt that in some cases depression was as traumatic as physical distress, and as such could be seen as reasonable grounds for an assisted suicide. The issue of mental capacity was also highlighted by the focus group we ran with people with learning disabilities, which demonstrated the complexity of assisted dying as an issue and the difficulty for some people of grappling with these concepts.

Key points that emerged during the research

People were critical of the current law

The majority of the people we spoke to felt that there needed to be more clarity around the law. Some people felt that the current legal situation put too much power into the hands of the Director of Public Prosecutions, and was too reliant on the personality and values of the person filling the post.

The two main problems that people saw with the current situation were as follows. Firstly, that it is wealth-based: only those who can afford the fees and plane fare are able to travel to Dignitas for professional assistance. Secondly, while assisted suicide remains illegal, there can be no upfront safeguards in British law to assess a person's mental capacity before they travel to Switzerland. Several of the people we interviewed argued that the Swiss system has less stringent capacity tests than those that would be likely to be included in legislation in the UK. As such, people thought the current system fails in its duty to safeguard British citizens.

Assisted dying already takes place in the UK

Many of the respondents believed that euthanasia already frequently takes place in the UK, particularly in the end stages of life. They believed that the current situation – with euthanasia or assisted suicide conducted in secret - is impossible to regulate, and can concentrate too much power in the hands of the medical profession, while there is little support available to family members or doctors following the event of hastened deaths.

An emphasis on personal choice and autonomy

Many of the discussions that took place during the research focused on the importance of individuals retaining personal agency over their own lives and in many cases this was the main justification for people who supported the legalisation of assisted dying. The importance of choice and autonomy at the end of life were particularly a feature of discussions with hospice service users and older people. It was discussed that people respond differently to pain and suffering and have varying thresholds for discomfort; what might be right for one person would not be appropriate for another. However, out of all of the groups, we found that the disabled people who took part in the research were most cautious about the circumstances in which assisted dying might be a legitimate choice that could safely be made available to people.

Eligibility for assisted dying

In nearly all of the focus groups people were more comfortable with the choice of assisted dying being available to people with terminal illnesses than they were with people having this option if their suffering was caused by chronic conditions or physical impairments. However, there was also a strong strain of thought among some participants that eligibility for an assisted death should be determined by the level of the person's suffering rather than by the type of illness or condition a person had. This view was put forward particularly by participants in one of the focus groups with disabled people, and by some of the hospice service users. There was a very broad range of opinion on whether a person whose suffering was a result of very significant impairments, such as Tony Nicklinson, should be able to access an assisted death. As mentioned above, the disabled people we spoke to were most likely to be concerned about this option being available to people with significant impairments, or to oppose it entirely.

Assisted suicide versus voluntary euthanasia

Some people found the distinction between assisted suicide and voluntary euthanasia confusing and difficult to understand. In

particular, some of the adults with learning disabilities had difficulty with these concepts.

In the focus groups with disabled adults in Solihull and Preston, the groups' initial reactions tended to be that they were more comfortable with the idea of assisted suicide than they were with voluntary euthanasia, as it enables the individual who wishes to die to remain in control. However, people also raised the challenge that assisted suicide might pose to disabled people who might not have the physical capacity to end their own life. Ultimately, most of the people who were in favour of legalising assisted dying did not think that there was an important difference between the two practices and that a person experiencing extreme suffering should be able to choose the method that best met their needs.

Concerns about the risks posed to people with disabilities

Some of the people with physical impairments that we spoke to felt worried about the effect that legalising assisted dying might have on social attitudes to disabled people generally. They also highlighted the particular dangers posed by allowing people who had suddenly become profoundly incapacitated as a result of illness or accident to consider the option of assisted suicide; the participants noted that it can take several years for people to become adjusted to life with a disability. One person cited the case of Daniel James as an example of the risk that a person might be allowed to die without exploring all of the options that could be available for living a full and fulfilling life. The majority of the discussion here tended to be focused on the importance of quality of social support and access to adequate supportive services for people with significant impairments.

SECTION TWO: DETAILED SUMMARIES OF EACH FOCUS GROUP AND SET OF INTERVIEWS

Focus groups at a hospice in South London, 23 – 24 June 2011

Demos researchers spent two days with hospice service users at a hospice and in total interviewed 12 people who had a progressive incurable illness. We also interviewed young people who were taking part in group work with the service users. The young people were all A-level students at a performing arts school. The group we spoke to on the 23rd were drama students and the group on the 24th were media studies students.

On the first day we ran a large focus group with service users and the drama students, followed by two smaller focus groups with the young people. We also conducted individual and small group interviews with service users. On the second day we did a large focus group with service users and the media studies students, followed by one smaller focus group with the young people. We also conducted a number of individual interviews with service users.

For the purposes of this thematic report we have split the respondents into two groups. The first part of the report from the hospice concentrates on the conversations we had with service users. The second part concentrates on the conversations that we had with the young people. A full transcript of the sessions can be found at the end of this document.

2.1 - Interviews and focus groups with hospice service users

The current law in the UK

The major theme that emerged during our discussions about the legal status of assisted dying with hospice service users was that of individual choice: most people felt that, at least in some circumstances, an individual should be able to make the choice to have an assisted death. One female service user who had a progressive neurological condition that had caused significant physical impairment and made it difficult for her to speak, said: 'I feel strongly that people should have self-determination; they should have the right to control what happens to them in the course of their lives.' This sentiment was echoed by a male service user: 'If I got to a stage where I couldn't manage myself, then I would want to pass on. I wouldn't want my grandson and everyone around the bed, wondering...'

For some of those we spoke to, the current legal status of assisted suicide raised social justice issues, as professional assistance was available only to people who could afford to travel abroad to a Swiss suicide clinic. One male service user said

I personally think it should be legal. [...] The country doesn't stop people going abroad to be done, they don't stop husbands and wives taking their partner abroad to have this done abroad. So if the government allows you to do that, then they're halfway there aren't they?

Views on the legalisation of assisted dying

For many of the hospice users we spoke to, this belief in the importance of personal agency was expressed as a definite desire for the law to be changed. One female service user told us: 'I think the law should be changed so that people have got their own choice.' However, some people felt that suicide was a personal issue, and not something that should be the subject of legislation or medical involvement. A female service user who said she had not been brought up in the UK said: 'If someone doesn't want to live any longer, it should be up to that person. It's not something the medical profession should be involved in.'

In several cases the individuals we spoke to believed that medical involvement in assisted dying was already prevalent, and that their loved ones had been assisted to die. According to these accounts, this had taken the form of involuntary euthanasia near to the end of life, rather than assisted suicide or voluntary euthanasia. These people were generally positive about the experiences they reported. One male service user told us:

At the end of my father's life, the Doctor had to give him injections every day. And I'm certain that at the end of his life; he helped him. And I couldn't say nothing, so I just said 'Thank you Doctor.'

Interviewer: And did you think that was a good thing?

I thought it was a blessing.

However, the interviews also highlighted the strain that end-of-life decision-making can have on relatives, and the importance of emotional support for those caring for relatives at the end of life, and subsequently coping with bereavement. A female service user commented: 'I can see the difficulty about giving people the choice. Because now, having buried my husband, I feel like an absolute murderer, in a way. He could have dragged on for another few days, but it was my decision, not to give him any more food or water.' She went on to comment on the subject of assisted dying: 'If it was legal you'd be able to have guide-rules. Whereas at the moment you just have people's opinions.'

Two service users said that they were opposed to assisted dying on religious grounds. A male service user who was opposed to assisted dying because of his Christian beliefs commented: 'You come into this world – you're born, and you should die the same way. You don't need any injections, or to go to a foreign country.'

Attitudes to assisted dying in the UK

Who, if anyone, should be able to request an assisted death?

When discussing the circumstances in which assisted dying might be an option, participants strongly emphasised the importance of enabling people to have a reasonable quality of life and of alleviating extreme suffering. Poor 'quality of life' was mentioned more frequently than terminal illness when participants discussed situations when assisted dying should be available. One male service user commented:

It should be about quality of life. If your quality of life's not that bad, then I think you should carry on. But if your quality of life is less than a... than you'd expect an animal to live through, then you shouldn't carry on.

Another told us:

I've got this cancer, and it was such a shock. And they can't cure me. But they're trying to give me a quality of life. Well, as you say, with these people, if they're not getting that quality of life, then perhaps that's the way to go.

On further discussion we found that when most people spoke about 'quality of life' and suffering, they were mostly referring to the situations of people with degenerative and terminal illnesses. One male service user commented: 'I wouldn't like to see a loved one suffering right to the end.' Another, discussing potential eligibility criteria for assisted dying, stipulated: 'Their life must be over – practically over. They're not going to be getting out of bed doing Irish Jigs.' One male service user explicitly differentiated between the terminally ill and other social groups: 'I don't think you should change the law [for everyone]. But I think that terminally ill people should be given the choice.' This opinion was also held by a female service user who emphasised the importance of a short life expectancy:

I'm back to this time-span thing. If it was only a matter of time, they should be assisted. But for anybody to do it, then no. It's a terrible responsibility. I don't think anyone can realise what it's like.

Among the service users that we spoke to who felt that people with degenerative or progressive conditions should also be eligible for an

assisted death was a woman who had a progressive neurological condition. She felt that, although she herself would not want an assisted death, the option should be there for those that might:

I can quite understand why someone would want to give up. Because I went through a stage of thinking that I wanted to commit suicide. [...] I can quite imagine that plenty of people would not be able to cope with the type of things that happen.

The same service user argued that assisted dying should not necessarily be limited to people with physical illnesses. She told us:

It's difficult to limit it to an illness, because there are other reasons why people don't want to prolong their life. In the case of motor neurone or multiple sclerosis, or any of those, it can be considered in a physical sense. But I think there can also be mental conditions...

Interviewer: For example, if someone had a psychological disorder?

Yes, if someone is very unhappy, and there's no way of getting out of it... If you give someone with a physical illness the right to die, then you have to give someone with a mental illness the same facility. [...] I don't think you ought to dismiss depression. I think sometimes it can be a very traumatic thing to have. And you can be in a condition where you just don't want to carry on. But it's a tricky area to decide.

Opinion on assisted suicide versus voluntary euthanasia

In general we found that among the hospice service users there was no clear preference between legalising assisted suicide and legalising voluntary euthanasia. However, some service users were concerned that the legalisation of assisted suicide on its own might be insufficient if a person was not physically able to end their own life. One service user said:

The trouble is when you most need help, when you most need it to happen and you can't carry on, then you're not in a position where you can do it yourself. If you've got a terminal illness, and it's progressive,

and you most need to end the thing, you're least capable of doing it yourself.

Some of those we spoke to were concerned that people are currently killing themselves or travelling to Switzerland earlier than they really needed to, because they are afraid of being physically unable to later on. This discussion also drew out concerns about the effect of assisting with a suicide on the person left behind. One male service user commented: 'I don't think you should give someone else the right to do it. I don't think that's fair on the other person. If you're going to do it, it should be down to you, and then no one's responsible.'

Influences on personal views on assisted dying

On the question of how people's attitudes to assisted dying had been formed, we sought to establish whether people were basing their opinions on religious belief, personal experience or other values. In general, people who believed that a partner or close relative had been assisted to die were more likely to be positive about a change in the law. The people who were most strongly against assisted dying were those with strong religious beliefs, all of whom identified themselves as Christian. One female service user commented: 'It's not right that people are helped to die. It should be up to God. [...] God created life, and it's up to God to take that life away.' In addition, many of the residents at the hospice emphasised the importance of good end-of-life care, and some said that they felt that the debate around assisted dying obscured the existence of other options – such as the hospice care that they had chosen.

With regards to a potential minimum age for eligibility, there was little consensus beyond the belief that assisted suicide should not be open to children. One male service user argued that assisted dying should only be eligible to those 'over 40. I don't think you're properly grown up until you're 40, 45.'

Potential risks posed by assisted dying

In general the people that we spoke to who were positive about the option of assisted dying being available felt that the risks associated with such a change could be largely controlled through safeguards. However, one female service user did comment: 'I worry about pressure on the elderly. It needs a thorough assessment to make sure someone's not depressed and to make sure they've got the capacity.' Regarding the different risks posed by assisted dying and voluntary euthanasia, the same respondent pointed out that people have been known to recover from comas. She felt that there would always be a risk that someone who had their life ended as the result of voluntary euthanasia (especially if sanctioned by an advanced directive), could have their life terminated prematurely, when they might in fact have recovered.

As mentioned above, one female service user with a degenerative disease described the suicidal thoughts that she had experienced following her diagnosis. She told us:

I went through a stage of thinking that I wanted to commit suicide. I didn't want to commit suicide, but I just thought, wouldn't it be easier if I just stopped breathing. That was about 7 years ago, 3 or 4 years after I was diagnosed.

Whilst this woman thought that some people should be allowed to request an assisted suicide if they were depressed as the result of an illness, others argued that depression was a risk factor that required careful safeguards, and that people who were depressed should not be able to have an assisted death.

Safeguards

The majority of the people we spoke to cited assessments of mental capacity as the most important factor in safeguarding people who

asked for an assisted death. One female service user with a background in working with disabled people was particularly forthcoming on this issue. She said:

I'm reluctant to see a change in approach because I think that the risk of abuse is so high. Countries where they allow people to commit suicide worry me. They are allowing people to act on the symptom and not making a judgement with capacity. [...] I think that being sure that people have made a judgement with capacity is key with anything to do with assisted dying. And it's 'how do you make sure that somebody's not under pressure?' – you'd have to have a very careful capacity assessment. [...] The problem with somebody going over to Switzerland is that they haven't had the capacity assessment.

Another interviewee expressed concern about the sort of people wanting to work in the field of assisted suicide. She told us: 'You'd have to have stringent controls of those getting involved – strict controls of their motivation.'

2.2 - Focus groups with young people

During the 23rd and 24th of June, Demos researchers conducted focus groups with young people from a performing arts school in South London. The focus groups took place at the hospice where we also conducted interviews with service users. We conducted both mixed focus groups, in which the young people and service users were both present, and smaller focus groups which were just with the young people. A summary of the key points is included below, and a full transcript of the sessions can be found at the end of this document.

The current law in the UK

The young people we spoke to were largely in favour of a change in the law to legalise assisted dying. The view that they took can be characterised by one young woman's statement that: 'I don't think it's fair that people should have to live, suffering, and not make the

choice for themselves.’ Some people felt that the current law was too vague, and that, as another young woman said: ‘If people are basically doing it anyway, and they’re not getting prosecuted, then what’s the point of it being illegal?’

People were also worried about the loopholes offered by the current system, within which there is no standard way to test for capacity. There was a feeling that, because legalising assisted dying would have to be coupled with increased safeguards, it might lead to more stringent gate-keeping to assisted dying. One young woman commented: ‘If they legalise it, they’ll be able to set things in place to stop bad things happening.’

Opposition to the idea of a change in the law came primarily from a young woman with strong religious views. As a Christian, she felt that assisted dying was not something that should be considered by society. She said: ‘I don’t agree with it, I think that, from a Christian point of view, life is a gift, and if you kill yourself then you’re throwing it away.’ Despite being largely positive about the idea of a change in the law, the young people we spoke to did not think that the UK was ready to make the change in practice. They saw assisted dying as: ‘a taboo [that] no one wants to talk about.’ None of the young people thought that assisted dying would be legalised within their lifetimes.

Attitudes to assisted dying in the UK

One recurring theme in the discussions was that of the importance of giving people a wide range of options following diagnosis. Many of the young people felt that if assisted dying was legalised, it should be one option among many, rather than becoming the default response. One young man said:

That’s why counselling’s needed, to give other options for different services. Otherwise you’re just resorting to one option, and then basically assisted death is pressuring you. You should be able to explore things.

There was a sense, however, that if an assisted death was the most appropriate option, it should be available: 'It shouldn't be a rash decision. But people should be listened to.'

The young people we spoke to felt strongly that, were assisted dying to be legalised, it should be seen as a last resort, rather than as one option among many:

If it was considered, I think every option should be considered first. Counselling, talking to the Doctors. I think it should take time. Once you've said, 'I'm going to do it,' then you come back six months later. So that way you have your time to opt out.

One young woman argued that that in banning assisted dying in this country, people may jump too quickly to seek this assistance abroad, without considering their other options fully.

By not legalising assisted dying, we're failing to allow people to think it through as an option, so people do it because they think it's the only route open to them. If it were provided as a service, then people would be able to consider it alongside other options.

Who (if anyone) should be eligible for assistance?

There was a broad range of opinion as to who should be eligible for assistance to end their lives. Several of the young people talked about elderly relatives who had expressed their wish to end their lives: 'My granddad is 85 years old, he's in his house, week on end. And he would just like to go now. We've all come to terms with it, and he's had his time.' Others felt that assisted dying should only be an option for those who were terminally ill: 'I think if there's no further medical help that would aid your situation, then you should have that choice,' or those who had become paralysed: 'I think if you're paralysed, and you can't talk, but you're not dying, then it should be allowed.'

Many of the young people said that they would not be comfortable with a system in which some people were eligible and others not. As one young woman put it:

I don't think it should be only for this, only for that. As a dancer, if I got paralysed... obviously I can't tell now, but who's to say that I wouldn't get seriously depressed, and want to end my life.

However, others countered that counselling and increased support were more appropriate responses to the sudden onset of physical disability than the option of assisted dying. One young man commented: 'If your life changes suddenly after an accident, then there should be a waiting period.'

This reluctance to set limitations regarding the eligibility criteria for assisted dying was repeated in the discussion regarding a minimum eligible age. Whilst some of the young people felt that 'Children shouldn't be able to have that decision. They need to be grown up and wise, to know that they don't want their life anymore.' Others were more equivocal:

I think when it comes to this question you need to treat everybody equally, no matter their age or gender, you have to take everyone's difference into account. Because if you say to someone, 'You're only 17, you have to wait for a year', that person might suffer, for a year... But then after a year someone might go, 'Actually, no, I don't want that.' I think you'd probably have to go through a lot more talking, and a longer process. But you still shouldn't have the option taken away from you.

Who (if anyone) should provide assistance?

The young people were very aware of the psychological burden that assisting with a death places on the person providing the assistance: 'It's hard for the person who has to do that, because they might think afterwards, "What if I hadn't done that, maybe they would have had a couple more years."' Some of the young people felt that family members should be allowed to assist with a death: 'If I were

to end my life then I'd want to be away from anything to do with illness, away from a hospital. And just with my family.' Others felt that some professional assistance would be needed:

But if you were to do it in your home, there'd still have to be a paramedic, or someone, in case something goes wrong. And so there can be no accusations – like a witness.

Potential risks posed by assisted dying

The young people were acutely aware of the risks posed by assisted dying. In particular they emphasised the problems associated with external pressure, depression, and mental capacity. To counter these risks several young people emphasised the need for psychologists and social care experts to be involved in assessing someone's mental state when requesting an assisted death.

Discussing the risk that: 'Depression could, in a way, be manipulated by someone else,' one young man said: 'I don't think there are enough psychologists. There could be a workforce, like an industry, sort of thing.'

One young person also highlighted the problems associated with creating a system to facilitate assisted dying. She said:

The risks are people abusing the system, and using it for murder. It could work but the risk is someone not doing their job properly. It's like with social care, there are always mistakes going on. When it's a system that should work perfectly. And it's slipping up with someone's life, so that's a big thing.

Safeguards

Discussing the safeguards that would need to be in place, several of the young people described a specially-designed, non-medical system, where doctors, social workers and psychologists would work together to assess a person's mental state and assess their eligibility for an assisted death. One young woman said: 'It

shouldn't just be a Doctor, it needs to be a specialist thing.' Others added: 'If someone does bring up the issue then somebody should come and visit, and spend time with them, and try and really understand them. Rather than just a Doctor'; 'it needs to be a whole service, a specific service, like a social worker.'

2.3 - Focus Group convened by a Disabled People's Advocacy Organisation in Preston on the 22nd July 2011

The session had 11 participants. They had all been contacted by staff at a disabled people's advocacy group in Preston on behalf of Demos.

The group was made up of individuals who mostly had physical impairments and one person with a learning disability. Not all of the participants chose to discuss the nature of their impairments. Members of the groups included: a male participant with significant physical impairments; a female participant with a learning disability; a female participant who had a chronic medical condition; and a female participant who had physical impairments and was a wheelchair user. The group also included two participants who were hearing impaired, who participated with the assistance of a lip-speaker. A summary of the key points is included below, and a full transcript of the session can be found at the end of this document.

The current law in the UK

Most of this group agreed that there were always going to be some instances where an individual might have legitimate reasons for asking for an assisted death. However, opinion was divided on whether a change in the law was the most appropriate response. Participants were concerned about a blanket approach to assisted dying and one woman commented: 'I think the idea of it being done on a case by case basis is essential.' Some people felt that the law should be changed, because: 'We have the right to a dignified life so

why can't we have the right to a dignified death?' Others felt that the current law provided the best possible safeguard against abuse:

I would keep it illegal, and then look at each case afterwards. I say this with some reservation though because the process is not perfect. We should look at the existent process and assess where the faults lie.

Attitudes to assisted dying in the UK

The issue of whether either assisted suicide or voluntary euthanasia should be legalised was a contentious one. One participant commented that:

I think it is a little bit unfair to make a distinction between somebody who is able-bodied and somebody who is disabled. If someone is able-bodied but very depressed and they want to go and kill themselves they can. Whereas if someone is disabled they are put under all this stress, when all they want to do is what someone who is able-bodied could just go out and do. I don't think it is fair to make that distinction.

Another person commented: 'Right now, if I wanted to, I could go and walk out in front of a bus. Why should someone who hasn't got the capacity to do so be deprived of the right to do so?'

There was also some discussion of the difference between voluntary and non-voluntary euthanasia. One participant argued that:

If somebody is in excruciating pain with no hope of recovery, prolonging life is not being helpful. We should not keep somebody alive just because we are uncomfortable with assisting them in their death.

Another participant expressed clear concerns about the potential for non-voluntary euthanasia. Describing the experience of watching her father die she said:

For fifteen years I watched my father-in-law get sicker and sicker, to the point where he could not sit up, couldn't talk, go to the toilet nor remember who we were. He was constantly getting ill because his immune system was shot. It was very difficult, as a relative, to come to

terms with the way you felt about the situation. I tried to establish how he may have felt. Did he want to live? Or was he waiting for it to end? He suffered for so long, and there were times where we would wish for him to go. But we would never have killed him. Whatever life he had, he was still alive. We could not determine what his wishes were, so it was not our decision to make.

Who (if anyone) should be eligible for assistance?

Unlike most of the other groups, this group did not single out people with terminal illnesses as being a special case with regards to assisted dying. Many people in the group found the idea of eligibility criteria too limiting or potentially discriminatory, and preferred the idea of assessing requests on a case-by-case basis. One person commented:

I think it is all subjective. I don't think any panel of people can assess the unique situation that another person lives in. It is a very difficult thing to limit or restrict. I think they should have the right to die, but to avoid some people being taken advantage of it might mean safeguarding the process so strongly that some people are denied that right. I wouldn't have the authority to say where the line should be drawn. But I would say that if somebody is in constant pain and there is no way to relieve that, they should be allowed to ask for assistance in their dying. With some levels of pain you can't think, cannot watch TV, cannot have a conversation.

The discussion of who might be eligible for assistance brought up a range of issues around the impact that legalising assisted dying might have on disabled people. In particular, participants were worried that people who suddenly became disabled might choose to have an assisted death rather than being given the time and the support to come to terms with their disability. One female participant, who herself had chronic health conditions, commented on the case of Daniel James:

Is it not inevitable that if somebody is suddenly made quadriplegic or paraplegic they will feel like they do not want to live? You have to try

everything that is available. You cannot just after six months say 'Right, there's nothing out there for me,' unless you have actually tried everything that is available, and have got the right support around you.

Whilst people were unwilling to deny people in extreme suffering the right to an assisted death, they were also aware from their own experience that people may ask for an assisted death as a cry for help. One young man commented:

There are times when you say you want to die, but you don't mean it. You may be mentally incapacitated for whatever reason; you have been through trauma or a major operation. I had a major operation and was in intensive care. I said I did not want them to resuscitate me, but I didn't mean that. I needed the safeguard.

A second participant concurred:

From a personal point of view, I have in the past asked to be allowed to die, or asked somebody to kill me, and I don't think I have ever really meant it. Quite often the situation that you're in is not going to be permanent even though you may think it is. You perhaps cannot see the light at the end of the tunnel.

While many of the participants had had personal experience of the potential risks that could stem from permitting people to request an assisted death, some of them – including those quoted above – agreed with one participant's statement that: 'If somebody is in constant pain and there is no way to relieve that, they should be allowed to ask for assistance in their dying.' Whilst some members of the group felt that maintaining the status quo was the only possible way of making sure that mistakes were not made, others felt that, if sufficient safeguards were in place, the law could be changed to allow assisted dying.

Who (if anyone) should be able to provide assistance?

The participants were very concerned about the emotional impact of assisting with suicide. One participant crystallised the debate when they said:

Whose do we take more seriously; the rights of the person who is asking to die, or the rights of the person we are asking to kill them? I think it's very selfish in some respects, to ask a person to continue to live having done that to you when you are not prepared to continue to live yourself. Asking a relative to help them to die, inevitably they will be emotionally bound in some way, and will experience horrendous emotional conflict.

There was a range of opinion on who – if anyone – might take responsibility for assisting with suicide. One participant suggested that the fact that relatives would have difficulty in refusing to assist a loved one was ‘an argument for assisted suicide being performed by medical professionals, because it takes that burden off the relatives.’ Other participants disagreed that a doctor was the appropriate person, asking: ‘Is it fair to put a doctor in that position? A doctor’s role is to prolong and save lives. Is it fair to then make a doctor take on the role of executioner?’

Potential risks posed by assisted dying

The people we spoke to in Preston were particularly concerned about the risks that might be posed to disabled people should assisted dying be made legal. Several people pointed to existing negative views about disability and to value-judgements about disabled people’s quality of life, which they saw as endemic within mainstream society. One participant pointed out:

The social perception of people with a disability is generally a negative one. So when people, such as Daniel James, get placed in a situation where their life has changed, they see no other option but death.

As mentioned above, several of the participants spoke of having felt suicidal at some point in their lives, and these people agreed that this had just been a phase, and that it would not have been helpful or appropriate for assisted dying to be have been available as an

option. Several participants made a link between suicidal feelings and the negative view of disability prevalent in mainstream society. One participant noted: 'People probably think that most of us in this room have a reduced quality of life. It's those people who will be prone to depression if they acquire a disability.'

Safeguards

A small group of people felt that the only appropriate safeguard was for assisted dying to remain illegal. Others were more positive about a change in the law, but felt that work would have to be done alongside it to improve the provision of palliative care and social care. One participant argued:

In Sweden they have assisted suicide, but there is still a high quality of palliative care treatment. They lead Europe in the quality of their hospices at the moment. An introduction of assisted suicide may not mean a withdrawal of emphasis on social care.

One of the participants who had a hearing impairment expressed concern for people who had issues communicating effectively. Whilst positive about the idea of a change in the law to permit assisted dying for people experiencing considerable suffering, she called for safeguards which were 'to do with communication, especially for older people who are hard of hearing, the deaf and the blind.' She felt that without effective methods of communication 'there are likely to be mistakes made and communication breakdowns.'

2.4 - Focus Group with a Disabled People's Advocacy Organisation in Solihull, 28 July 2011

The focus group had nine participants. The group included: one female participant with Parkinson's disease; one male participant with a nerve impairment that affected his ability to walk; one participant who had mental and physical impairments caused by a stroke; one participant with a visual impairment, and one participant with ME. One participant was also the parent of a child with a disability. A summary of the key points is included below, and a full transcript of the session can be found at the end of this document.

The Current Law in the UK

Most of the individuals in this group felt that the current law was not satisfactory, although they did so for a range of reasons. One participant expressed concern that the current law is not clear-cut, and leaves too much power in the hands of one individual: 'The current situation is a dog's dinner. The legal system needs to be sorted out, you can't leave it to one man.'

Another participant expressed the belief that euthanasia already happens in the UK. She said: 'It might not come to law but it does happen, it does go on.' Because of this, she felt that a change in the law to allow assisted dying would be a positive move as it would enable more safeguards to be put in place: 'I think if it was legal and done properly and maybe done like people write a will, which surely you can write, "If this ever happened to me..."'

There was some debate about whether the UK was ready for a change in the law. One female participant said that, although she believed that assisted dying should be allowed for people with certain degenerative conditions, she was concerned about the current palliative and social care system: 'I don't think our palliative and social care are up to scratch. I think that when people make

that decision when they are of sound mind and sound body that's because the alternative is too terrifying for them.'

Attitudes to assisted dying in the UK

Most of the people in the group were positive about a change in the law to make some form of assisted dying legal, and felt that it would be possible to put appropriate safeguards in place. The general consensus was that assisted dying was something that should be available to people with terminal illnesses, and also those suffering from degenerative conditions like Huntington's and motor neurone disease.

Some people in the focus group felt that it should be possible to determine in advance which groups would be eligible for an assisted death, and to establish protocols for particular circumstances:

Instead of leaving it open that if somebody does assist they have to go through this legal chain and it ends up being the decision of one man, [...] a normal human being. Let's have it cast-iron, let's have thresholds.

Whilst there was some support for this view within the group, others worried that continuing medical advances would make it impossible to forward-plan in this way:

As time goes on and we get things improving all the time, there's no reason to believe [people with degenerative conditions] might not have a much longer life than most of us recently considered.

Who (if anyone) should be eligible for assistance?

The majority of the group felt that assisted dying should be allowed for people with terminal illnesses, who have the mental capacity to make the decision themselves. In addition, one participant cited certain 'hereditary degenerative conditions, in particular I'm thinking Huntington's, and motor-neurone as well'. In these cases: 'the patients who suffer those diseases, there is time to put those measures in place. If somebody knows they have that condition years in advance, it allows them to prepare themselves.' Again,

there was some concern about people with terminal illnesses making advanced directives far in advance of the fact: ‘The problem is that you’re making a decision about a scenario that you’re imagining. The issue is a minefield.’

Whilst people were largely positive about a change in the law for people with terminal illnesses, there was less consensus on what should be done for people with non-terminal conditions. On the subject of people suffering from paralysis one female participant commented: ‘These decisions are made for different reasons, they’re about quality of life and access to lifestyle. And that’s a completely different ball game to somebody with a terminal illness.’

With regards to the question of whether only assisted suicide or only voluntary euthanasia should be allowed, the group seemed not to have strong feelings either way. One participant commented: ‘It’s up to the individual to choose for themselves. It depends on their particular needs.’

Who (if anyone) should be able to provide assistance?

The issue of who should be able to provide assistance was one that the group were very concerned about. In particular people thought that it was important to recognise the emotional impact on family members who are asked to assist a loved one die. One participant told us:

The problem I have with [assisted suicide] is that if you asked me to help somebody close to me take their life, I could do that, but I don’t know how I would react to it, if I would have a nervous mental breakdown the next day. If a doctor does it, at the end of the day, they can cop out. It’s like with abortion, they can say I can’t prescribe that or the morning-after pill because of my own conscience. As a family member, how do you deal with the aftermath? You’re asking people to do something that you don’t understand what the ramifications would be afterwards for them.

Another commented:

We get a lot of people phone us up at the Samaritans years later, who have assisted somebody, played on their mind and it's driven them crazy. Everybody's got a conscience.

Rather than family members, the group suggested that a panel of legal and healthcare professionals would be the most appropriate people to decide who should be eligible to die. On the question of who should sit on the panel, one participant suggested people who were involved with day-to-day care, rather than higher-level management. Another participant was concerned that the decision should be made by the individual affected, rather than by doctors. She said: 'It's the people themselves, who will say, not the doctor. [...] No, it's the main person themselves.'

Potential risks posed by assisted dying

One participant argued that the focus should be on palliative care, rather than assisted dying. She said:

I just think people will make decisions for the wrong reasons. We're not a very caring society, we purport to be very caring on the surface, actually nobody gives a monkey's anymore. We purport to be very caring in helping people to end their lives, but actually how about we make it so that people don't feel that's their only option in the first place?

There was also some concern in the group that problems with palliative and social care, and financial pressure on the NHS might lead to assisted dying being seen by professionals as a cost-effective route. As one participant put it:

The problem now is the NHS does not have the money to keep the people living, even though they're going in the next three months, [since] they're going anyway, [we] might as well get it over, saving the money'.

Another participant voiced the concern that legalising assisted dying might have a 'slippery slope' effect: 'It's going to become very

much like abortion, it started off with a very good reason and is now a shambles and used as a method of control.'

Safeguards

One participant highlighted the risk that people might change their minds over the course of their illness. She said: 'Somebody reacting to therapy, [...] could decide today they don't want to live their illness, but learn tomorrow that they're expecting their first grandchild and that's another milestone to look forward to.' In order to safeguard against this she suggested that: 'You need to assess people over a time-frame, in different environments. So not just mental capacity in a particular moment that a social worker assesses.' Another participant suggested that: 'Money and property must be looked and carefully checked that a person is not under pressure to become a suicide so the family can benefit.'

2.5 - Focus Group with older people living in sheltered housing, 26 July 2011

Demos conducted a focus group at a residential home for older people in London. The group was made up of seven older people between the ages of 63 and 87. A summary of the key points is included below, and a full transcript of the session can be found at the end of this document.

The current law in the UK

The group were largely in favour of a change in the law to legalise assisted dying. One female participant (70 years old) said: 'I believe that if that's what somebody wants, they should have that choice.' A male resident (87) concurred:

I feel that if a person is bed-ridden, has to be washed, and cannot do anything for themselves, then they are no use to themselves or anybody else and they should be allowed to be put to sleep.

There was one resident who was strongly against a change in the law because she felt that assisted dying was wrong for religious reasons, and another who felt that the current legal situation was the correct approach to take.

Attitudes to assisted dying in the UK

One participant felt that changing the law was unlikely to change the numbers of people helped to die: 'It's alright for committees and organisations and laws to turn around and say you can't do this, you can't do that, but we're all aware that sometimes emotions are so great that you do do things'. He also commented that he felt it was right that the law looks favourably on cases where a long-term partner helps end the life of a terminally ill individual who has long expressed a desire for a peaceful end.

Who (if anyone) should be eligible for assistance?

While several people initially suggested that they thought that elderly people who were distressed, and ‘who can’t look after themselves’ should be eligible for euthanasia of some form, as the discussion progressed the majority of the group expressed the opinion that any change in the law to allow assisted dying should be restricted to people with terminal illnesses.

There were two participants who felt that eligibility to request an assisted death should be related to the level of suffering, rather than to specific illnesses, and should be available to anyone who requested it. One female participant (72) said: ‘[it should be restricted to] those who are not going to get any better and who are in terrible pain.’

On the question of whether people with conditions such as locked-in syndrome should be eligible for an assisted death, one participant said he thought that the situation was much the same as for people with terminal illnesses. He felt that people with physical disabilities who have consistently said that they would rather not be alive should be allowed to die.

Who (if anyone) should be able to provide assistance?

The group were very aware of the psychological burden imposed by asking someone to help with an assisted death. One male participant (80) felt that it was not something that family members could do on their own, and said that: ‘the family is going to need professional help’. Whilst he stated that he didn’t think he would be able to do it himself, he also said that it was unfair to put all the weight on doctors, many of whom might not agree with the practice themselves. Ultimately, the participant felt that the difficulties involved meant that, ‘to bring in the practice, I don’t think its possible.’

Potential risks posed by assisted dying

The group felt that elderly people would be particularly vulnerable if the law were to be changed. As one male participant (80) put it: 'There's always a risk when you get somebody really old, that the family wants to knock that person off to get their money'; 'I know an old lady. She is way into her 90s...and she is really wealthy. And I'd hate to think that...her brain is OK, her body is not. There is that possibility.'

In addition, a female participant worried that legalising assisted dying would put older people who lived in residential care at risk, because it might encourage doctors to think about the cost of keeping you alive: 'They might decide it's your time to go because you're 75 or 70 and you're in and out of hospital a lot and you've used a lot of medicine.'

Safeguards

There was a spread of opinion as to who should be responsible for deciding who is eligible to have an assisted death. One male participant (87) said that: 'the immediate friends and family shouldn't make that choice, it should be somebody completely away from the family'. However, two other participants thought that it should be up to the family to make the decision. One male participant (63) strongly disagreed, arguing: 'It is such a major decision, you need a range of people, such as a doctor, social worker, policeman, to agree.'

2.6 - Focus Group with adults with learning disabilities, 18 July 2011

The focus group was made up of individuals between the ages of 18 and 50 who all had learning disabilities. During the session we showed a clip from Emmerdale dealing with assisted death, and this served as a point of access to the ideas under discussion. The clip was a scene in which Jackson, a young man who has recently been paralysed, discusses his wish for an assisted death with his mother and boyfriend. Jackson's mother is very against the idea, and describes the increased support that she is going to give him, but Jackson is adamant that he wants an assisted death. A summary of the key points made in the discussion is included below, and a full transcript of the session can be found at the end of this document.

There was considerable discussion of the definitions of assisted suicide and voluntary euthanasia, which were explained using basic vocabulary. The majority of the group had difficulty understanding and discussing these concepts. Some of the participants had experience of taking medication regularly and for some, comments focused on the importance of taking this medication in the appropriate dosage. Other points that emerged from participants who were more confident discussing these concepts focused on the potential impact of an assisted death on the family members left behind. There was a consensus among the group that family members should not be involved in administering an assisted death.

The current law in the UK

There was some debate about the current legal situation, and the different meanings covered by assisted dying. One female participant was strongly in favour of a change in the law. She said: 'Get the law in, it's better to have the law. Other countries have got it, why can't we get it?' In response to the question: 'Why do you think we should have a law like that?', she added: 'Because a lot of people want to die. They go to court and try and fight it, and the courts say "No, sorry, you're not allowed to do that, you can go to another country".'

One male participant was strongly against a change in the law, and expressed a concern that making assisted dying legal would be dangerous, and would lead to a rise in the number of vulnerable people being murdered.

Attitudes to assisted dying in the UK

There was a split of opinion in the group, between people who believed that assisted dying was a matter of personal choice, and people who felt that assisted dying would place too much of a burden on people's families. One male participant felt that in 'extreme cases', perhaps where individuals were paralysed, people should be allowed to choose to die: 'If people want to pass away, it's up to them.' Another female participant agreed, saying: 'If someone wants to end their life, end their life. They shouldn't be put in prison. It's like, if they want a new pair of trainers they should have them.'

There was a second subsection of the group who were worried about the effect on family members. Following the screening of the clip from *Emmerdale*, a female participant expressed concern about the potential effect of Jackson's death on his mother: 'She's only got one boy, and she don't wanna lose him. If she loses him, how's she gonna cope with her grief?'

Most of the participants did not feel that assisted dying was something that should be allowed for young people. One male participant said that assisted dying should only be allowed for people 'over 100', another said that people should be at least 60, 'because then they've had a good life.'

One participant expressed concern about people 'putting words in [her] mouth.' In response to the question: 'Do you think it's up to you to decide when you want to die?' She said: 'When I'm ready, I will. I don't like people putting words in my mouth. Saying, "Oh, die." I say, "No. When I'm ready. When it comes."'

Who (if anyone) should be eligible for assistance?

The male participant who was most strongly positive about a change in the law to allow some form of assisted dying said that individuals with terminal illnesses and people who had been paralysed should be allowed to die if they were in pain and close to the end of their lives.

Several of the participants said that they did not think that Jackson, the character from Emmerdale who is paralysed, should have been helped to have an assisted death. In particular one participant raised the question of treatment and care. Saying that she didn't think he should be allowed to die, the participant said: 'I think he should get a social worker to help him, a carer. [...] He needs to go to the hospital to get it treated and get his life back.'

Who (if anyone) should be able to provide assistance?

In direct response to the question of whether people should be able to ask someone in their family to help them kill themselves, the group were unanimously negative. 'It shouldn't be a family member. It should be a neighbour or doctor, [...] I think the doctors and the nurses will know how to do things, will know what to do.' However, several participants also felt that doctors should not be involved in assisted suicide, arguing that doctors should be concerned with curing people rather than ending people's lives: 'They help you out. Help you to stay alive.'

Potential risks posed by assisted dying

One male participant expressed a fear that assisted dying would get out of hand, and that individuals would be more at risk of being murdered. He felt that allowing doctors to assist people to die could create a danger that: 'They are going to give tablets to all the elderly, the old pensioners and that.' Another male participant who was in

favour of a change in the law on assisted dying cited depression and bullying as potential risk factors.

Safeguards

The group did not come up with any safeguards to prevent the risks mentioned above. However, discussing the role of doctors, one participant commented on the importance of proper paper work and written consent: 'If they haven't got signatures [of consent], they should be arrested'.

2.7 - Responses to the online call for interview participants

In June 2011 Demos posted a call for participants on online forums for people with terminal illnesses and mental and physical impairments. The majority of people we spoke to were individuals with motor neurone disease. We received responses in the form of email submissions, conducted two telephone interviews, and had one face-to-face interview. A summary of the key points is included below, and texts and transcripts from the interviews can be found at the end of this document.

We received 12 responses to the online call for participants, and their responses covered a broad range of opinions. Seven of those interviewed supported the legalisation of both assisted suicide and voluntary euthanasia. Three were against the legalisation of either. Of those who expressed a clear opinion on who should be eligible for an assisted death, one respondent felt that assisted suicide should only be available for people with terminal illnesses, and seven felt that it should be a judgement based on quality of life.

Three of the respondents were strongly against legalising assisted dying. One of these was a disabled woman who felt that:

Disabled people are already worried about people assuming their life isn't worth living or seeing them as a burden, and are genuinely concerned that a change in the law could increase pressure on them to end their life.

Another was a woman with motor neurone disease. She already felt under pressure from people around her to make an advanced directive asking for non-resuscitation, and thought a change to the law on assisted dying would increase the pressure on her to choose to die. Describing her current situation she said:

I feel an increasing pressure not to have life-saving and expensive treatments and care. Every time I turn the news on, I'm faced with another example of how I'm perceived as some sort of leech.

In addition, her own experience of dealing with medical professionals had led her to the opinion that legalisation would be 'dangerous':

You've got these professional medical people urging you towards saving money. I don't think the doctors individually are consciously thinking in those terms, but if there is an ethos that is persuading people that the sensible kindly option is to take 'an easy option' then I fear that that would be encouraged.

Among the remaining nine respondents was a general consensus that assisted dying should be available to people with terminal illnesses, and those who are undergoing extreme suffering. One female respondent said: 'I would like to see assisted dying available to all who truly want it, terminally ill, and those suffering what they consider to be unbearable suffering be that of a physical or mental nature.'

This set of individuals were generally less clear on the detail regarding safeguards and the risk to vulnerable people. Several of the respondents in this group argued that it was the responsibility of the state to support people in having an assisted suicide. One male respondent said:

In tightly controlled circumstances, assisted suicide should be made entirely legal. So should euthanasia - it is an obligation of society not only to look after us in the cradle but look after us into our grave.

Another said that: 'I believe that something so important should be a legal right, and not depend on the discretion of a certain individual.'

SECTION THREE: FULL TRANSCRIPTS

1. Transcript of the focus groups with service users and young people at a hospice in South London
2. Transcript of the focus group at a disabled people's organisation in Preston
3. Transcript of the focus group at a disabled people's organisation in Solihull
4. Transcript of the focus group with older people living in residential accommodation
5. Transcript of the focus group with people with learning difficulties
6. Transcripts of individual submissions from people with motor neurone disease contacted via online forums.

3.1 - Focus Groups at a South London Hospice, 24 – 25 June 2011

Demos researchers spent two days with hospice service users on Thurs 23th and Fri 24th June. We also interviewed young people who were taking part in group-work with the service users. The young people were all A-level students at a local performing arts school. The group we spoke to on the 23rd were drama students and the group on the 24th were media studies students. On the first day we ran a large focus group with service users and the drama students, followed by two smaller focus groups with the young people. We also conducted individual and small group interviews with service users. On the second day we did a large focus group with service users and the media studies students, followed by one smaller focus group with the young people. We also did more individual interviews with service users

The following discussions took place:

1. Interview with male service user

2. Focus group with service users and young people
3. Interview with male service user
4. Group interview with three male service users
5. Small focus group with drama students (1)
6. Interview with male service user
7. Focus group with service users and media studies students
8. Large focus group with media studies students
9. Interview with female service user
10. Interview with male service user
11. Interview with female service user
12. Small focus group with drama students (2)
13. Interview with female service user
14. Interview with male service user
15. Interview with female service user

1. Interview with a male service user with terminal cancer, Thursday 23rd June 2011:

“I personally think it should be legal. Because the country doesn’t stop people going abroad to be done, they don’t stop husbands and wives taking their partner abroad to have this done abroad. So if the government allows you to do that, then they’re halfway there aren’t they. And I think anyone, whoever it may be, when they come to end of their life, sometimes they are in pain, agony or whatever you like to call it. And they’re still allowing us to sustain that, and to be in that kind of pain. And that’s totally wrong, I think.”

‘There’s a lady died two days ago, and I was in the ward next to her. And she wasn’t in pain, but she was.... She said to me, ‘I’ve only got a couple of weeks to live, and I might just as well go now.’ And why shouldn’t she? Why couldn’t someone just allow her to do it? And she went for about 8 weeks in the same condition; and to me, that’s a great shame.

“She wasn’t in pain, but she was constantly on oxygen, 7 or 8 times a day. She said nights were worse than days. And I think the Doctor should have helped her.’

So you think that if somebody asks for help, then? “It has to be a request from the patient, and then the Doctor should be allowed to do it. and I think not have this is a tragedy”

What are the circumstances in which assisted death should be allowed?: “I don’t think it really matters. If the person themselves is in pain. I believe that if the person themselves says ‘I can’t take anymore’, then it should be possible. That’s how I feel. I’ve got no other feelings about it.”

And you think it should be a Doctor who does it?: “Oh yes, it should be a Doctor who provides that assistance. I don’t think you should have doctors who do it, I think it should be up to the GP. Normally it’s in a hospital and you should have a consultant who orders someone to do it.”

“Should the family be consulted? I don’t know. In the case of a husband and wife, that’s another matter altogether. I think it has to be discussed with them, but whether they have any say in it... I don’t know.”

Do you foresee any risks if assisted dying were to be made legal? “I think it could get out of hand. Yes I do. I think it would have to be done very carefully. I think Doctors could do it without the patient wanting to have it done.”

2. Focus group with service users from the hospice and a group of drama students, Thursday 23rd June 2011

Do you think there any circumstances in which assisted dying should be legal?

Woman with speaking difficulties, response repeated back by interviewer/carer:

“You thought that it was important for people to have a choice”

Should there be an age limit?

Woman with speaking difficulties, response repeated back by interviewer/carer:

“No, It can happen at any age.”

Young Person: “Children shouldn’t be able to have that decision. They need to be grown up and wise, to know that they don’t want their life anymore.”

Young Person: “I wouldn’t say under 18 at all. But other than that...”

Young Person: “I think when it comes to this question you need to treat everybody equally, no matter their age or gender, you have to take everyone’s difference into account. Because if you say to someone, ‘You’re only 17, you have to wait for a year’, that person might suffer, for a year... But then after a year someone might go, ‘Actually, no, I don’t want that.’ I think you’d probably have to go through a lot more talking, and a longer process. But you still shouldn’t have the option taken away from you. If you look at the teen suicide rate it starts at 13 years old. And that’s people who don’t have terminal illnesses.”

Does anybody think that assisted dying is a bad thing, and that it shouldn’t be allowed:

Woman with speaking difficulties, response repeated back by interviewer/carer:

“It can be abused, if you’re going to make the decision you have to be mentally capable before you decide to do it. And it could be open to abuse, because someone might kill someone off because they’ve had enough of them.”

Young Person: “Sometimes people decide before their illness has reached the worst stage. And I feel that they don’t know that they might have the next couple of years, that they can enjoy their life. I feel like if you cut it too short, you could be missing out on family”

Woman with speaking difficulties, response repeated back by interviewer/carer:

That’s why I won’t do it myself. Because I think life’s too precious, and I need to make the best of it that I can.”

Who should be able to ask for assistance?

Woman with speaking difficulties, response repeated back by interviewer/carer:

“The trouble is when you most need help, when you most need it to happen and you can’t carry on, then you’re not in a position where you can do it yourself. If you’ve got a terminal illness, and it’s progressive, and you most need to end the thing, you’re least capable of doing it yourself. When you’re got an illness that’s progressive, and you’re frightened of the outcome, then you want to end it. And people are frightened that they won’t be able to do anything themselves.”

Does anyone have any thoughts about the difference between assisted suicide and voluntary euthanasia?

Male service user: “If I want to go, I’ll just go. I don’t believe in Doctors and things like that. Life should just run its course.”

Young Person: “I agree. Everything in life happens for a reason, and I don’t know if it’s really effective for a person to say, I want to end it now, unless you’re in so much pain that enough is enough. Because you will never know what will happen tomorrow.”

Woman with speaking difficulties, response repeated back by interviewer/carer:

“I agree. But there are people with muscular dystrophy who are in so much pain that they can’t carry on. I take a positive view of life, but you have to be able to make a decision if you can’t cope.”

3. Interview with a male service user with terminal cancer, Thursday 23rd June 2011

What do you think about the current status of assisted dying in the UK?

Male service user: “Until you’re in that position you can’t really know. It’s easy for us to talk. If you’ve been in that severe pain in your life, and you can make that decision. Then I say so be it. Provided it’s done in a human way.”

So, do you think assisted dying should be legalised? “Until you’re in a position...I mean, I’ve got this cancer, and it was such a shock. And they can’t cure me. But they’re trying to give me a quality of life. Well, as you say, with these people, if they’re not getting that quality of life, the perhaps that’s the way to go.”

Do you think people should be able to have an assisted death in the UK?

“When you think about it, it’s a big thing to do. There’s all these people trying to save lives, and then someone trying to lose it, it’s a bit of a body blow. But then people are suffering, and that’s not justice. They say there’s a God and that but why do people have to suffer? Some of these people have been to hell and back. I do think should be offered assisted dying, but you should make sure they mean it. You’ve got to be 100%”

“It could be a family thing. If you lose somebody you do miss them, very much. I lost my daughter to cancer. You don’t expect to be doing this. Putting someone into the ground. I do miss her a lot. But if you’ve got a brother or sister you don’t want them to suffer.”

**4. Group Interview with three male service users,
Thursday 23rd June 2011**

Do you think the current legal situation is the right one?

First Male service user: “Nobody should take somebody else’s life. We’ve got our own lives, and when the time is right you should be a piece with yourself. If I was dying, I’d sooner die peaceful. No injections or anything. I watched my own wife die. And she was in agony; she had cancer. But she died peaceful. And that’s the Irish way.”

“I don’t think it’s right. People go into comas, and it’s been proven that they come out. People have got to live.”

Do you think your religious beliefs inform your view on the issue?

“Even if I weren’t religious, it’s the same thing. Everybody’s got their own lives to lead.”

Second Male service user: “At the end of my father’s life, the Doctor had to give him injections every day. And I’m certain that at the end of his life; he helped him. And I couldn’t say nothing, so I just said “Thank you Doctor.””

And did you think that was a good thing? “I thought it was a blessing. I wasn’t living at home but I used to go visit. He was riddled with cancer, but I couldn’t tell him, I told him he had very bad arthritis, and it was going to get worse before it got better. But to see him go through that. I think I’m for – personally - yes. When people get to a certain stage, and they’ve got no quality of life...”

First Male service user: “But there’s always hope. You take the rough with the smooth”

Second Male service user: “I wouldn’t like to see a loved one suffering right to the end.”

Third Male Service user: “I don’t think you should change the law. But I think that terminally ill people should be given the choice.”

And who do you think are the people who should be given the choice?

“People with terminal illnesses, and people with dementia, that’s a terrible illness.”

5. Small focus group with A-level drama students, Thursday 23rd June 2011

Do you think there are any circumstances in which assisted dying should be legal? If so, what are these?

Young Woman: “ I don’t strongly disagree with it. If my mum was dying and in pain, and didn’t want to carry on. I would respect her decision. But I suppose if people were ill they might not be in the right frame of mind to make that decision.”

Young Man: “If it was considered, I think every option should be considered first. Counselling; talking to the Doctors. I think it should take time. Once you’ve said, ‘I’m going to do it, then you come back six months later. So that way you have your time to opt out”

Young Woman: “It shouldn’t be a rash decision. But people should be listened to.”

Young Man: “But the only way I would disagree with assisted dying is only because, there are sick people out there who will kill their husbands or wives, and make them sign something.”

And is that something that could be checked for?

Young Woman: “Yes. If a person has a lot of money, and there is pressure on them. There needs to be a whole – it wouldn’t just be through your Doctor – it needs to be a whole service, a specific service, like a social worker.”

Young Woman: “It shouldn’t just be a Doctor, it needs to be a specialist thing.”

Should assisted suicide or voluntary euthanasia be permitted?

The group felt that it was safer to have just assisted suicide, rather than voluntary euthanasia

Young Woman: “I don’t think it should be really publicised. But if it’s absolutely necessary...”

Young Woman: “If someone does bring up the issue then somebody should come and visit, and spend time with them, and try and really understand them. Rather than just a Doctor.”

Do you think it should be limited to people with certain conditions?

Young Woman: “It’s kind of discrimination if you don’t let young people do it.”

Young Woman: “I don’t think you should have a – I don’t think it should be only for this, only for that. As a dancer, if I got paralysed... obviously I can’t tell now, but who’s to say that I wouldn’t get seriously depressed, and want to end my life.”

Young Man: “But that’s why counselling’s needed; to give other options for different services. Otherwise you’re just resorting to one option, and then basically assisted death is pressuring you. You should be able to explore things.”

Young Man: “If your life changes suddenly after an accident, then there should be a waiting period.”

Young Woman: “That’s why there should be a service - because there is no service is there, there is no organisation - you shouldn’t just get completely turned down, it should be something that’s considered. It should be an option.”

Young Man: “I don’t think that family members should be prosecuted for an assisted death. If I ever got to that stage, I would want someone there with me. And if I knew that they were to go to prison....”

Young Woman: “If I were to end my life then I’d want to be away from anything to do with illness, away from a hospital. And just with my family. Then it could be the best memory.”

Young Woman: “But if you were to do it in your home, there’d still have to be a paramedic, or someone, in case something goes wrong. And so there can be no accusations – like a witness.”

What are the circumstances in which someone shouldn’t be allowed an assisted death?

Young Woman: “If they were healthy, or if there was depression. Because there’s always going to someone there to help you, like a social worker. I think that in a way is taking advantage of the whole idea of assisted death.”

Young Woman: “Depression could, in a way, be manipulated by someone else,”

Who should be qualified to make the decision as to who should have an assisted death?

Young Man: “I don’t think there are enough psychologists. There could be a workforce, like an industry, sort of thing.”

Do you think it should be a separate profession?

Young Man: “I think it should be separate, but linking with Doctors.”

It's important to keep it confidential. Maybe a phone service, people who come and visit you in your home.

What about people who are physically disabled?

Young Woman: "It's hard for the person who has to do that, because they might think afterwards, what if I hadn't done that, maybe they would have had a couple more years."

Young Woman: "Maybe there should be someone there who is a professional, but maybe they shouldn't be in that much contact."

Do you think it will happen in your lifetime?

Young Woman: "I don't think it will happen because I don't think it's that much of a priority. It's a taboo and no one wants to talk about it."

Do you foresee any risks that would be posed to society or to individuals by legalising assisted dying?

Young Woman: "The risks are people abusing the system, and using it for murder. It could work but the risk is someone not doing their job properly. It's like with social care, there are always mistakes going on. When it's a system that should work perfectly. And it's slipping up with someone's life, so that's a big thing."

Young Woman: "By not legalising assisted dying, we're failing to allow people to think it through as an option, so people do it because they think it's the only route open to them. If it were provided as a service, then people would be able to consider it alongside other options."

6. Interview with male service user with terminal cancer, Friday 24th June 2011

Male service user: "When I was first diagnosed with cancer I wanted to end it. Blow my brains out with a shotgun. But, the doctor said to me, you've got a month to a year, but you won't make

a year. So you think, why bother? But that was 18 months ago, so, it all depends on yourself. If I hadn't of thought of my kids, I'd have done it. So I think you should be able to do it if you want. But I don't think you should give someone the actual right to do it. ”

“I don't think you should give someone else the right to do it. I don't think that's fair on the other person. If you're going to do it, it should be down to you, and then no one's responsible.”

“If you're in hospital and you're physically able to do it, you should have the means to do it.” *[he is talking here about someone giving you a prescription, so assisted suicide not voluntary euthanasia]*

Who should be responsible for administering the prescription?

“Definitely not family. I wouldn't put that responsibility on the family. I think it's wrong.”

“We were 13 in my dad's family, and I've seen at least 6 of them die, I've been at the bed when they've died. And it's not a nice thing, when they're in pain. Anyone who is in pain should be given the right to end it.”

If assisted dying were to be legalised, should assistance be limited to certain types of people, such as people experiencing suffering that they find unbearable or who are terminally ill?

“It should be about quality of life. If your quality of life's not that bad, then I think you should carry on. But if your quality of life is less than a... than you'd expect an animal to live through, then you shouldn't carry on. You wouldn't let a dog suffer. It all depends on how you're suffering. There's a bloke comes here on a Wednesday, and he can't barely walk, or talk, and he's all hunched over, but he's happy. But if he were unhappy, he should be entitled to end it.”

Should there be a minimum age?:

“Oh yes. Over 40. I don't think you're properly grown up until you're 40, 45. I think you're still a knucklehead, up until 84!”

“It’s an individual thing. Some of these young people, I don’t think they’ve got the knowledge. They can make the choice but there should be other people in it.”

“You should be able to decide. If you’re intelligent enough to make a will, you’re intelligent enough to decide your own fate. As soon as we leave our mothers aprons, you should be able to decide your own fate.”

“I had an uncle went through 5,6 years of Alzheimer’s. And to be honest, I wish he’d died the day he got it. It was just down hill, down hill down hill. Terrible disease.”

“If they’d have said when he first got it, I think he’d have said give me a year or so and then nut me.”

Who should decide if an assisted death can go ahead?

“It shouldn’t go to a panel. Once it’s decided - it’s his wishes, or her wishes.”

7. Focus groups with service users and media studies students, Friday 24th June 2011

Is there anything that you would change about the current law?

Young woman: “I don’t think it’s fair that people should have to live, suffering, and not make the choice for themselves.”

Young woman: “I don’t agree with it, I think that, from a Christian point of view, life is a gift, and if you kill yourself then you’re throwing it away.”

Young woman: “My granddad is 85 years old, he’s in his house, week on end. And he would just like to go now. We’ve all come to terms with it, and he’s had his time.”

Service User: “But he’s still got his memories. You come into this world – you’re born, and you should die the same way. You don’t

need any injections, or to go to a foreign country. The majority of people would sooner die natural.”

Young woman: “Where is the line drawn about, when you’re allowed to make a decision about your own health, and when you’re not. Because if you are depressed, and you don’t want to carry on, and then people might tell you that you can.”

Young woman: “I think euthanasia should be available, but I don’t think it should be easy. It should be a long process. If it became legal it doesn’t mean that everyone would do it, you might find that nobody would do it.”

8. Large focus group with media studies students, Friday 24th June 2011

What has informed your attitudes? [E.g. Particular experiences, beliefs or values]

Young woman: “I think your opinion changes when you get older. Near the end of your life you want to live the most out of it

Young woman: “I think if there’s no further medical help that would aid your situation, then you should have that choice.”

Should assisted suicide or voluntary euthanasia be permitted?

Young woman: “I think that administering the thing yourself, I think that should be allowed. I can see that very clearly. And if there’s no further medical help that could aid your situation, then you should be allowed your help.”

Do you think assisted suicide should only be open to people with terminal illnesses?

Young woman: “I think if you’re paralysed, and you can’t talk, but you’re not dying, then should be allowed.”

Young woman: “My uncle’s paralysed, and he can’t talk. But he has a young son, and his wife’s dead. So if he were to have an assisted suicide then my cousin would be an orphan. So you have to think about the people around you as well.”

Young woman: “I think at the moment if you want an abortion you need to see more than one Doctor. So I think something along those lines.”

Young woman: “You should have to have a system where you have to make a case, for why you want an assisted suicide.”

Do you think you’ll see a change in your lifetime?

Young woman: “I think it’s not going to be in our life times I think it’s going to be a very long time in the future.”

If the law were changed, what safeguards should be in place?

Young woman: “there needs to be some kind of psychiatric assessment of the patient.”

Young woman: “People with mental health issues tend to have a therapist, and I think the therapist should be involved.”

Young woman: “there’s a need for people to be facilitated to speak for themselves, rather than communicating through a carer or partner.”

9. Interview with a female service user. Friday 23rd June 2011

The interviewee is suffering from terminal cancer; she has a background in working with people with disabilities.

Is there anything that you would change about the current law?

Female Service user: “I’m reluctant to see a change in approach because I think that the risk of abuse is so high. Countries where they allow people to commit suicide worry me. They are allowing

people to act on the symptom and not making a judgement with capacity.”

“I think that being sure that people have made a judgement with capacity is key with anything to do with assisted dying. And it’s how do you make sure that somebody’s not under pressure. You’d have to have a very careful capacity assessment”

“The problem with somebody going over to Switzerland is that they haven’t had the capacity assessment.”

If assisted suicide was to be legally permitted, who should provide the assistance? [E.g. Friends, family members, doctors, nurses, volunteers?]

“You are asking such a big thing of your family to ask them to help you to die. And what about the impact on them afterwards?”

The interviewee was unsure as to the best way of judging capacity, but made several suggestions: “We’ve have to have a very clear, and very careful assessment of capacity, and it’d have to link into the mental capacity act in some way, and advance directives and all the things that are around at the moment where people can say they do or don’t want a treatment. So we have started to go into that area because people can say they don’t want to be resuscitated.”

“Maybe the better alternative is to find ways to help people to get satisfaction and achieve in life despite their disability.”

The interviewee cautioned that people have been known to come out of persistent vegetative states.

“Not everyone can afford that [digitas] so at the moment it’s wealth based.”

“We need to explore the whole topic further, but it’s difficult because it is so open to abuse.”

Do you foresee any risks that would be posed to society or to individuals by legalising assisted dying?

“They may feel pressure, that they’re a burden to their family.”

“Anyone whose asking should be subject to a full psychological assessment, which should be done by a psychiatrist rather than a GP. Doctors are very variable in their ability pick up on depression. And not a one off visit; it should be a reasonable lengthy assessment.”

“From working with people with disabilities I can see that it’s a fudged line in this country, people are on so many painkillers and their systems get depressed and then they die. The impact of painkilling drugs may lead to them dying more quickly anyway. It’s a grey area in palliative care anyway.”

“I worry about pressure on the elderly. It needs a thorough assessment to make sure someone’s not depressed and to make sure they’ve got the capacity.”

“There’s the option of hospice care, it’s about exploring and making sure people understand the alternatives.”

“It’s about understanding how they want to die and to be in control of that process.”

“Because I wouldn’t want it, I can’t impose that on other people.”

10. Interview with male service user, Thursday 23rd June 2011

The interviewee began the interview by making links between involuntary euthanasia and the ‘Mickey Finn’ – drugging an individual’s drink in order to kill them without their knowledge. He suggested that this already happened in hospitals, and that it might be the kindest way of ending suffering. The interviewee felt that his mother’s life had been prolonged for too long.

“people should have the choice to end their lives.”

Do you think the law should be changed?

“As long as it’s not used as a means to an end.”

Who should be responsible for assessing patients and making the decision?

“It’s got to be the GP, or the doctor who assesses you. Someone the patient’s got faith in. I still think the best thing’s the Mickey Finn.”

What sort of safeguards should there be?

“Their life must be over – practically over. They’re not going to be getting out of bed doing Irish Jigs”

Who should make the decision?

“Family, the existing family. Families should know before what you’re thinking; if you can’t go on anymore. Because normally it’s the family keeping you alive. ”

“If I got to a stage where I couldn’t manage myself, then I would want to pass on. I wouldn’t want my grandson and everyone around the bed, wondering...”

Should there be an age limit?

“It would be very hard to put an age limit. Maybe the only way of doing it would be on the amount of treatment you were willing to give.”

11. Interview with female service user. Thursday 23rd June 2011

The interviewee has a progressive, degenerative condition and is a wheelchair user. She has some difficulty speaking, and at times during the discussion she was aided to express herself by a carer.

“I was diagnosed 11 years ago with a condition that’s quite rare, and it’s progressive, and they told me I had anything between 4 -20 years to live. And that’s not much to go on. So I decided, having gone through various stages, I thought I’d stay positive, and hang on to as much life as possible, because life is precious, and I don’t think you should give it away easily. So that’s where I’m coming from. But I can quite understand why someone would want to give up. Because I went through a stage of thinking that I wanted to commit suicide. I didn’t want to commit suicide, but I just thought, wouldn’t it be easier if I just stopped breathing. That was about 7 years ago, 3 or 4 years after I was diagnosed.”

And are you saying that although you wouldn’t want it for yourself, you think the choice should be there for other people?

“Yes, because I can quite imagine that plenty of people would not be able to cope with the type of things that happen. I’m just a stubborn soul, and I’m not going to give up easily.”

Do you see a difference between assisted suicide and voluntary euthanasia?

“This is the crux of the matter, because, when you’re in a position to decide, you might not want to do it. That’s what frightens people, the fact that they’ll be incapable of doing it to themselves. And it gets someone else into trouble if they assist them. So to be able to decide in advance is important.”

“I feel strongly that people should have self determination; they should have the right to control what happens to them in the course of their lives.”

Who should make the decision?:

“I think it should be like when I was in practice. If anyone is considered unable to give consent, there should be a meeting of anyone who has a relationship with that person; here would be a meeting with (dis)interested parties to decide if they should have anaesthesia (interviewee used to practice as a dentist).”

But more specifically, on the issue of assisted dying:

“It can’t be anyone else who decides such a thing for you”

But then there should be a panel to decide if it should be allowed?:

“at least 4 or 5 independent people.”

“I am against killing. But it’s not on religious grounds.”

Should the law allow anyone to have an assisted death, or should it be limited to certain groups?

“It’s difficult to limit it to an illness, because there are other reasons why people don’t want to prolong their life. In the case of motor neurone or multiple sclerosis, or any of those, it can be considered in a physical sense. But I think there can also be mental conditions...”

For eg. If someone had a psychological disorder.

“Yes, if someone is very unhappy, and there’s no way of getting out of it... If you give someone with a physical illness the right to die, then you have to give someone with a mental illness the same facility.”

“I don’t think you ought to dismiss depression. I think sometimes it can be a very traumatic thing to have. And you can be in a condition where you just don’t want to carry on. But it’s a tricky area to decide.”

“in the Swiss case, you have to speak to at least two Doctors. I think you get into a difficulty about whose going to make the decisions; who to employ in that position.’

Do you foresee any risks that would be posed to society or to individuals by legalising assisted dying?

The interviewee had some concerns regarding the people employed to work in assisting suicide:

“you’d have to have stringent controls of those getting involved – strict controls of their motivation.”

**12. Smaller focus group with drama students, Thursday
23rd June 2011**

Young Man: “It should be legal, but you should have the chance to make up your own mind.”

Young Woman: “There need to be boundaries. If I broke my back and I couldn’t dance, and I decided that wanted to die – there should be specific people you go to to talk about it. To see if there are ways around it.”

Young Woman: “people need to be educated, before they make that final decision.”

Who should be eligible?

Young Woman: “It shouldn’t be available to people who are just depressed. Coming to the hospice is a wake up call - seeing people with difficulties just getting on with it.”

Is there a risk of people feeling under pressure?:

Young Man: “If someone really wanted to end their life, they would. Having that element of nicety (the formality of an assisted death) is good.”

Young Woman: “If it was legal there would have to be lots of checks and conditions. Because I think people would abuse it.”

There was a general discussion of the importance of checking for mental competence.

Who should make the decision? Young Woman: “I think it should be a mix between the legal, the medical and the family.”

Young Man: “Just because it’s been illegal for so long doesn’t make it right. People can make their own minds up.”

Young Woman: “If people are basically doing it anyway, and they’re not getting prosecuted, then what’s the point of it being illegal.”

Young Woman: “If they legalise it, they’ll be able to set things in place to stop bad things happening.”

Young Woman: “I don’t think it should be advertised as a right or wrong thing, it should just be there for people. I don’t think we should make a big thing of it.”

Young Woman: “If it was legal, they’d have to offer support for the family. But I think it should be that person’s decision, and not the family, because the person has to go through it every day of their lives.”

13. Interview with female service user, Thursday 23rd June 2011

Do you think the law is appropriate or should be changed? “If someone doesn’t want to live any longer, it should be up to that person. It’s not something the medical profession should be involved in.”

Voluntary Euthanasia: “I think it’s wrong. If someone doesn’t want to live, they just stop eating. They shouldn’t be helped. People often change their minds, and once it’s done it’s too late.”

Current law: “It’s not right that people are helped to die. It should be up to God.”

Does your opinion come from your religious beliefs? : “Yes, I think so. Because God created life, and it’s up to God to take that life away.”

Any circumstances where a person should be able to ask for an assisted suicide: “No.”

14. Interview with male service user with terminal cancer, Thursday 23rd June 2011

The interviewee began by talking about his desire for his family not to suffer following his death. The interview was then terminated because interviewee became too distressed to continue.

15. Interview with a female service user with terminal cancer. Friday 24th June 2011

The interviewee had recently lost her husband to cancer, and much of the discussion was taken up with her describing her feelings about the family's decision to withdraw food and water from him at the end of his life.

“I think the law should be changed so that people have got their own choice, when they're ready to die. You have to take into consideration the people around you. Last year, when my husband died, we had to agree whether he should be let go back into the hospital. We discussed it very carefully. I'd always said - half jokingly – that I'd go off to Switzerland. And that's what half wanted for him. But my daughter wouldn't allow it because she said, dad was always an optimist, and would be hoping he could be cured. But there was one evening when he was in such a poor state we didn't think he would live through the night. And she said, having seen that, she wouldn't want him to carry on. To see him subjected to such misery for the sake of somebody else. But I can see the difficulty about giving people the choice. Because now, having buried my husband, I feel like an absolute murderer, in a way. He could have dragged on for another few days, but it was my decision, not to give him any more food or water.”

Is there anything that you would change about the current law?

“The quality of life – palliative care should be changed. Rather than the dying part.”

“Having said that that’s what I chose for him; nobody asked us. And he just died at 4am, when there was nobody with him. So I suppose you can’t blame yourself.”

“I don’t think you can pre-empt this. But you’ve got to have a deadline, about how much more people can take.”

Which people should be allowed an assisted death:

“I’m back to this timespan thing. If it was only a matter of time, they should be assisted. But for anybody to do it, then no. It’s a terrible responsibility. I don’t think anyone can realise what it’s like.”

What are the risks?:

“I think it might cause too many deaths. When you go upstairs here, it’s such a peaceful atmosphere. There’s nothing wrong in dying in that fashion than somewhere where people are slamming doors.”

Do you think we should have a similar situation here that they do in Switzerland?

“I don’t like that idea. I think it’s touting your body around, going from one place to another. I think the best thing to do is have some final agreement between the family, and...”

“If it was legal you’d be able to have guide-rules. Whereas at the moment you just have people’s opinions.”

3.2 - Focus Group at a disabled people’s advocacy organisation in Preston, 22nd July 2011

Introductions - *It would be really useful to us if we could go around the table and if you could say who you are, how long you’ve been involved with [the advocacy organisation] and in what way you are involved with [the advocacy organisation], and*

why you were interested in taking part in this discussion.

Male 1 (M1): He got to hear about this through an email sent to him by somebody in an organisation in a university which promotes public involvement of service users and carers, people with various kinds of disability. He wishes to express his strong views on the subject.

M2: He has been involved with this on a personal level. It is an emotional subject. Two years ago he asked for non-resuscitation, and it was refused.

Female 1 (F1): She has been involved with *[the advocacy organisation]*, since 2005. She joined to meet new people and enjoys the company of the people she has met.

F2: She has been involved with *[the advocacy organisation]*, since 1999. She has a long history of various conditions and at times has often felt down and contemplated suicide.

F3: She has been involved with *[the advocacy organisation]*, since the late 90s. Originally started as a volunteer, and has now been on the committee for several years, currently vice chair. She thinks the subject is a grey area without right or wrong answers. There are situations in which it could be abused and situations where it might be the more dignified approach.

F4: She has worked with *[the advocacy organisation]*, since 2003 and is now one of their trustees.

“When I was born, it was quite a complicated situation but basically my parents were told that if they wanted me to be left and not to be treated, everybody would understand. Obviously they chose not to listen, but the fact that that was even suggested in the first place, I think, is an issue.”

F5: She thinks this is an interesting topic and wants to hear more about assisted suicide.

F6: She has been working with a *[the advocacy organisation]*, since 2007.

F7: Her role is chief exec here, but is interested in this in a personal capacity. She is interested to have her views as an individual fed through to this kind of report, rather than simply as a representative of an organisation.

M3: “This sensitive subject matter needs reviewing because people have a right to live and a right to die”

F8: Also recently got involved with *[the advocacy organisation]*. She is deaf and feels that her knowledge and expertise will be of use to this discussion. Her concerns on the subject matter are to do with communication, especially for older people who are hard of hearing, the deaf and the blind. She feels those people do not know how to communicate and so there are likely to be mistakes made and communication breakdowns.

The current law in the UK

Under the current law in the UK, providing assistance with suicide is illegal and is punishable by up to 14 years’ imprisonment. However, in each individual case it is up to the Director of Public Prosecutions to decide whether or not it is in the public interest to prosecute. If the person provided assistance for wholly compassionate reasons, it is less likely that they will be prosecuted.

Could we start by discussing your views on the current legal status of assisted suicide? Does this strike the right balance and is there anything that you would change?

F6: “I think the idea of it being done on a case by case basis is essential. In some cases people want to assist somebody else in their suicide, but they do not want to risk being sent to prison. These cases can perhaps be decided in advance. They must ascertain whether this person is in the right frame of mind, whether they have depression, whether they are in a fit state to decide these things. This is an idea that might be an alternative to actually prosecuting people.”

Could make the decision as to whether a crime has taken place or not beforehand?

F6: “If that decision was made beforehand, it would not be necessary for them to go to Switzerland”

F8: “If the person who is the victim of the crime says to the police ‘I don’t want you to prosecute’ then the police do not have any powers to carry through the prosecution. Where there is an assisted suicide and the person has stated they do not want any prosecution to take place; that would be the same kind of situation” (It would remove necessity to go to Switzerland)

M2: “We have the right to a dignified life so why can’t we have the right to a dignified death? There does have to be stringent safeguards though. Because there are times when you say you want to die, but you don’t mean it. You may be mentally incapacitated for whatever reason; you have been through trauma or a major operation. I had a major operation and was in intensive care. I said I did not want them to resuscitate me, but I didn’t mean that. I needed the safeguard.”

“Right now, if I wanted to, I could go and walk out in front of a bus. Why should someone who hasn’t got the capacity to do so be deprived of the right to do so.”

Does anyone agree with that or does anyone think that it is right to keep assisted dying completely illegal and to review the case after it happens to see whether it is right to prosecute? *Does any one think that the status quo is the best solution?*

F7: “I would keep it illegal, and then look at each case afterwards. I say this with some reservation though because the process is not perfect. We should look at the existent process and assess where the faults lie”.

M1: “There are people who want to live but who are denied the medication to allow them to live because it is so expensive. Is that classed as involuntary euthanasia?”

M2: “In palliative care, high dosages are used to sustain symptoms.”

“It’s doing good but it has effectively polished people off. It’s the same thing but just slower and through the back door”

F9: “I think it is essential that we have stringent rules. There is a big issue surrounding depression. So people do feel like they want to die and want to commit suicide but they may not feel like that after a while. Is it the pain? Is it depression? We don’t know. Another risk is that people might feel that they are a burden, and therefore want to commit suicide. I also think within the timing of such a decision, you should be given the opportunity to change your mind. With a bit more morphine the pain may be a lot more endurable”

M2: “Why should they have to go out of their life on a morphine pump?”

“But at the same time you don’t want a Daniel James situation. I don’t think somebody should have the power to end their life because they are suddenly a paraplegic.”

F2: “Is it not inevitable that if somebody is suddenly made quadriplegic or paraplegic they will feel like they do not want to live. You have to try everything that is available. You cannot just after six months say ‘right, there’s nothing out there for me’ unless you have actually tried everything that is available, and have got the right support around you.”

F5: “I think we need to make sure that every other alternative route has been explored before we go to voluntary euthanasia or assisted suicide.”

F8: “I think it is a little bit unfair to make a distinction between somebody who is able bodied and somebody who is disabled. If someone is able bodied but very depressed and they want to go and kill themselves they can. Whereas if someone is disabled they are put under all this stress, when all they want to do is what someone who is able bodied could just go out and do. I don’t think it is fair to

make that distinction. I don't think the medical profession has the right to decide what is good for us. As people we have the right to do what we want for ourselves."

Eligibility criteria: in which circumstances should a person be able to ask for assistance in ending their life?

M1: "What if they can't ask though? If someone is totally paralysed or brain dead, do you prolong their lives just because you can or is it better to let them go peacefully? Personally I would say let them go peacefully because they haven't got any real quality of life."

M2: "I have worked for many years with people who have very extreme learning difficulties, who cannot communicate. Their mental capacities are reduced to a point where they may be easily persuaded to do the most convenient thing. Also many elderly people falsely believe that they are a burden. Any sane person feels like a burden at some point in their life. To be eligible for assisted suicide, therefore, there has to be good cognitive understanding and an ability to communicate; whether that be through machinery, through sign language, or pictorially. I think they have to be over 18 or preferably 21."

F4: "It is important to question whether the person has been given the right support and the right tools to enjoy their life before we consider ending it."

Can you imagine circumstances in which a person should be allowed to ask for assistance in helping them end their life?

F9: "There are so many variables unique to each person. The focus of discussion needs to be on the act itself. It's not legal right now but is it murder? We need greater clarification on how we define these acts."

Are you saying that it's not about the categories people fall into it's about the many aspects of their life? You wouldn't restrict eligibility for example, to someone with terminal illness?

F9: “I think it is all subjective. I don’t think any panel of people can assess the unique situation that another person lives in. It is a very difficult thing to limit or restrict. I think they should have the right to die, but to avoid some people being taken advantage of it might mean safeguarding the process so strongly that some people are denied that right. I wouldn’t have the authority to say where the line should be drawn. But I would say that if somebody is in constant pain and there is no way to relieve that, they should be allowed to ask for assistance in their dying. With some levels of pain you can’t think, cannot watch TV, cannot have a conversation”

The individual person’s experience of suffering would be an important consideration in the question of whether someone should have the choice of assisted suicide?

F7: “I think it should be as it is now with assisted suicide and voluntary euthanasia being illegal. I don’t think we should get into ‘It’s ok for some groups but not others’. There are two things in life that we should not have control over and that is when we are born and the other when we die.

Regardless of what condition that person is in, it isn’t our decision as to when they die.”

F9: “Nobody has the right to kill anyone else.”

F7: “If it wasn’t legal in some countries, would we be having this debate? How and why has that law been put in place in those countries?”

F7: “You will be putting a lot of power into the hands of medical professionals who themselves have their own personal views, cultural backgrounds and opinions about what should and shouldn’t be done.”

F1: “It should not be allowed.”

F9: “People, even if they initially have very strong opinions may change their mind. I think we need to look at improving palliative

care. People are concerned with how they are going to die rather than when they are going to die.”

So palliative care is essential whether or not we have assisted dying.

Assisted suicide vs. voluntary euthanasia: Do you think there is a big difference between assisted suicide and voluntary euthanasia? Assisted suicide is where you as the person wishing to die carry out the act; in voluntary euthanasia, somebody else does.

F9: “Killing somebody is a very, very big deal. Not just legally, morally, but emotionally.

Whose do we take more seriously; the rights of the person who is asking to die, or the rights of the person we are asking to kill them? I think it’s very selfish in some respects, to ask a person to continue to live having done that to you when you are not prepared to continue to live yourself.

Asking a relative to help them to die, inevitably they will be emotionally bound in some way, and will experience horrendous emotional conflict.”

F5: “Perhaps that’s an argument for assisted suicide being performed medical professionals. It takes that burden off the relatives.”

M1: “I agree with [F4’s] point that we need to consider the people left behind, and what suffering might be caused if someone’s life is taken. But I disagree that nobody has the right to kill somebody. It’s true in the UK that nobody has the legal right to kill another, but morally, it could be the case that one does have that right.”

M2: “Is it fair to put a doctor in that position? A doctor’s role is to prolong and save lives. Is it fair to then make a doctor take on the role of executioner?”

M3: “If somebody is in excruciating pain with no hope of recovery, prolonging life is not being helpful. We should not keep somebody alive just because we are uncomfortable with assisting them in their death. Assisted suicide should be part of a doctor’s role.”

F8: “The human species is a victim of its own success when it comes to medical intervention. We have given ourselves these ethical dilemmas that we would not have had in the past.”

F9: “For fifteen years I watched my father-in-law get sicker and sicker, to the point where he could not sit up, couldn’t talk, go to the toilet nor remember who we were. He was constantly getting ill because his immune system was shot. It was very difficult, as a relative, to come to terms with the way you felt about the situation. I tried to establish how he may have felt. Did he want to live? Or was he waiting for it to end? He suffered for so long, and there were times where we would wish for him to go. But we would never have killed him. Whatever life he had, he was still alive. We could not determine what his wishes were, so it was not our decision to make.”

What risks might be posed by assisted dying if we had it in this country? Let’s discuss the concerns you might have about a change in the law.

F5: “The first issue is depression. The second issue is that feeling of being a burden.”

F7: “The risk is having it as an option instead of putting in place a system to support somebody. It would often be the cheaper option, which would put some vulnerable people at risk. It’s a slippery slope.”

So it would change the framework in which people are making decisions, and it would threaten social care funding?

F8: “It may reinforce the idea that disabled people have less worth. If you look at the financial rather than the social model, your view will be skewed.”

F2: “From a personal point of view, I have in the past asked to be allowed to die, or asked somebody to kill me, and I don’t think I have ever really meant it. Quite often the situation that you’re in is not going to be permanent even though you may think it is. You perhaps cannot see the light at the end of the tunnel.”

F4: “The social perception of people with a disability is generally a negative one. So when people, such as Daniel James, get placed in a situation where their life has changed, they see no other option but death. Was he ever shown a positive image of disability?”

That’s an interesting point about if somebody becomes disabled; they may go through a transition period, becoming accustomed to their new situation. It’s important that they are given the right support through that period.

M2: “From the point of view of a parent, if my child had such an accident, the last thing I would want to support them in doing is killing themselves. I can’t see how parents get to that. There’s got to be something wrong in their perception and understanding of disability.”

F9: “You need to be given enough time, say, 3 years to come to make that decision. You may need to adjust, or alter your lifestyle. You need to know what the possibilities are. People have worked tirelessly to save your life and make you as able as possible. To then throw that all away.”

M1: “But is it prolonging life or prolonging suffering? If it’s prolonged suffering that is only going to get worse, if I put myself in their shoes, I would want out.”

M2: “Suffering is about our own individual perception of it. I might think somebody is suffering, but that is *my* emotion. I don’t know

how they feel, I can never get into their head. So you can never make that judgement for someone, they have to make that judgement themselves. Daniel James did not have a terminal illness, he wasn't in any physical pain. It was his own choice, but to assist somebody in such an emotionally raw situation is risky."

F3: "Disability is a different journey for every different person. Daniel James' decision says a lot about the experiences he was given. If he was given more options, he may have felt less suicidal and like may have come out of that period of wishing to die."

F8: "People who are born with a disability have never had the experience of being able bodied. People who acquire a physical or sensory disability have very different views. It's very important to support this group in ways that you don't get through normal education and training. When you have that support you get rid of the depression and everything that comes with an acquired disability. If we had that, maybe we would not be asking this question at all."

F4: "You need to take into account that grief and bereavement period that comes with acquiring a disability."

F7: "They and their family are grieving the loss of the life they had. But also there are media stereotypes; people who acquire a disability have previously been subjected to society's attitude towards disability. All these pressures are bound to influence decisions to do with assisted suicide."

F9: "It is internalised prejudice."

F7: "People probably think that most of us in this room have a reduced quality of life. It's those people who will be prone to depression if they acquire a disability."

F8: "That also applies to doctors. They think, for example, that they know what it is like to be deaf. They haven't a clue. Doctors

often cannot understand what we are going through. I would not trust them to make a decision on my behalf.”

The commission has evidence about a man called Tony Nicklinson who has locked-in syndrome, which means he does not have any motion at all. He is able to operate a computer. Although lots of people with locked in syndrome have good quality of life, Tony says he wants to have the option of assisted suicide. Due to his own perception of his own quality of life, he wishes to die.

F9: Would not encourage eligibility for assisted suicide to be conditional upon the specific syndrome, illness or condition of the person e.g. all people with locked in syndrome are eligible.

F4: “If he truly has been given all the support he can get, and he has the best possible quality of life for his condition, and still wishes to die, then he should be allowed that.”

F3: “The person who commits suicide has lost hope. Losing hope, really, is the only factor that determines whether somebody chooses to end their own life.”

F9: “People who suffer from depression cannot reason in the normal way. They are so introspected they cannot see anyone else. There need to be very careful assessments about how much pain and suffering the person would go through if their treatment were withdrawn. If the doctors agree that there would be a great deal of pain involved in the withdrawal of treatment, then something should be done to end their life more quickly.”

F8: “We have to be very careful with communication. Don’t assume that just because somebody is unable to communicate, they don’t want to.”

Parting comments on assisted suicide:

F8: “It has to be a controlled situation where there is some prior knowledge of the intentions of the person.”

M3: “Life is precious, you only get one life. You are on this earth for a very short period and then you are dead for eternity. It is a difficult question to answer but personally I do not think assisted suicide should be legal”

F6: “If an individual has been through a long period of suffering and they cannot cope with it any longer, then their views should be considered. Under certain circumstances people should be allowed to ask for assistance.”

F3: “We need to consider how people would prefer to die”

M2: “Just as you have the right to a dignified entrance to this world, you should have the right to a dignified exit. In Sweden they have assisted suicide, but there is still a high quality of palliative care treatment. They lead Europe in the quality of their hospices at the moment. An introduction of assisted suicide may not mean a withdrawal of emphasis on social care“

M1: “The circumstances have to be very well defined to ensure things do not get out of hand. With certain physiological conditions it is not going to be well defined enough to be practical. Also not enough research has gone into different ways of ending lives.”

“There’s also an issue with previously expressed desires to be left to die under certain conditions, and then being unable to express your wishes which may have changed once you are in that condition. It would then be a case of involuntary euthanasia.”

3.3 - Focus Group at a Disabled People’s Organisation in Solihull, 28th July 2011

Assisted suicide and voluntary euthanasia are different because in those cases you’re asking to receive something that will actively end your life rather than refusing something that will keep you alive.

M1: So there is intent in both cases

F2: you can say in your will that you do not want to be resuscitated. And that should be enough, but you can't do the other two.

Introductions...

The current UK law: We'd like to hear your views on whether the current legal situation on assisted suicide is the right one or whether you think another approach should be taken?

F2: I know somebody who did go to Switzerland; I think it's a choice that should be made. I've also experienced somebody dying of cancer and the doctor did overdose and it did finish the lady. It does happen, it might not come to law but it does happen, it does go on. I think if it was legal and done properly and maybe done like people write a will, which surely you can write, "if this ever happened to me..." I would choose to end mine. I think there are a lot of people out there who are suffering mentally, physically.

F4: I agree, I think should be made legal.

F3: I don't agree, I have huge issues with it. I've been thinking about this, something struck a chord with me years ago, when I heard... I'll read it out to everybody. This was said by a country's leader in this century:

"I am convinced that the multiplication of the feeble minded which is proceeding now on an artificial rate, unchecked by any of the old constraints of nature and actually fostered by civilised society is a very terrible race danger." – Winston Churchill

I have huge concerns about it, what F2 said earlier about sound, mind and body, I think there are other issues to consider. I don't think our palliative and social care are up to scratch. I think that when people make that decision when they are of sound mind and sound body that's because the alternative is too terrifying for them.

M1: We get this situation where people ask what can happen... It has to be a yes or a no, you can't have hovering in between. What is

boils down to is – Director of Public Prosecutions – why? Who elects him?

(No one)

It's like a lot of things, barristers, wheels within wheels, went to the same school... It works most of the time but sometimes you get a nutter. The legal system needs to be sorted out, you can't leave it to one man, unless what that man's views are known before. For me, it's far too complicated in terms of the legal situation.

F3: It's like asking the Pope to make a decision of whether anybody can have a termination. ... Why should a lawyer make these decisions, there needs to be a much broader viewpoint.

F4: My concern is it's going to become very much like abortion, it started off with a very good reason and is now a shambles and used as a method of control. I have a feeling that this could happen with assisted suicides and euthanasia. I've seen my mother-in-law be assisted, very gently, very quietly, very peacefully. But she wasn't conscious, that is peaceful. But the 2 years previous, if she'd had her way she'd have taken euthanasia. It's very, very difficult. Unless you've been there, you can't give a true opinion, because you don't know the emotional scores. There's an awful lot of people who would have it done for them.

F5: 'It is, 'yay or nay,' but you can't do things like that. Everybody has different disabilities.' People who are able bodied look at disability in a different way.

M3: My grandmother had liver cancer, she had to come live with us but she'd do her personal washing right until the end. One day she was in the kitchen with her GP, and he said, 'I'm going to give her an injection, in a few days time she won't want to get out of bed, and 7 days later she died. It could have been coincidental of course...And then about 7 years ago, my mother herself had Parkinson's and then she had Alzheimer's and I went to the nursing home on the evening the doctor was going to see her. She couldn't speak in the end, she murmured. I had a phone call at 1.30 in the morning to say she passed away. It again could have been coincidental but...

So you're saying that voluntary euthanasia may be already happening....

F2: It has been happening for years. It happens in hospices, it happens in ordinary lives. My mother had cancer and the doctor came at 5 in the afternoon, gave her an injection, and again at 8.30, gave her an injection and he said she'd go peacefully by 7 in the morning, and she did. That's 25 years ago.

We get a lot of people phone us up at the Samaritans years later, who have assisted somebody, played on their mind and it's driven them crazy. Everybody's got a conscience.

F3: My dad died when I was in my early 20s, he was 52, died of bowel cancer. I know at the time had my dad asked me to support him, I would have helped him to die, but I don't think I could live with the consequences of it. People might be able to do it, and think they can do it, but can they live with the consequences?

F1: I've worked for many years at a hospice and it's known that a hospice is where you go to die, however which way, it's where you will die, and it's a lot of the families that you see, crumbling afterwards. So if it's going to be legal it's the families that need support.

F2: I think there should be, not this big man at the top who makes all the decisions, on the ground there should be people that have got support groups for people that have experienced and done it.

Eligibility criteria: Are there any circumstances in which a person should be able to have an assisted death legally?

F1: Absolutely, there was this man at the hospice who was absolutely terrified and didn't want to choke to death, he thought very long and hard on how he could do because of his disabilities and lack of movement. We had many conversations, it was just one weekend, 4 weeks after I'd last seen him, he went on holiday and I had a phone call to say he'd died, he'd gone into a train off a railway

station. He knew everything was accessible for him and that's how he did it. It is a very, very individual thing and they've got to have lots of access to counselling, being able to talk to people, to find out if that is actually what they want.

F2: If it's done alongside family and medical staff and other people, then the support network is there.

M1: If you get to a situation where the only way you can continue existing is by artificial means, that is certainly one threshold you can make legislation on.

So do you think there are circumstances when assisted dying should be available?

F3: My heart tells me no but my head tells me yes. In certain, in particular in hereditary degenerative conditions, in particular I'm thinking Huntington's, and motor-neurone as well, the patients who suffer those diseases, there is time to put those measures in place. If somebody knows they have that condition years in advance, it allows them to prepare themselves.

F4: My neighbour, he's only in his late 30s, he's got MS. He can't do anything for himself, he's in pain and has to be fed. He's screaming out all the time to his carer, please help me, please do something. The carer came down to me and said, 'I don't know what to do.' It's wearing. It's horrible.

M1: But all these are specific diseases, you can establish specials for particular circumstances, instead of leaving it open that if somebody does assist they have to go through this legal chain and it ends up being the decision of one man, which is no one, a normal human being. Let's have it cast-iron, let's have thresholds.

F4: There are a lot of peculiar diseases these days and the people getting them are getting younger and younger. Surely at that stage - the diagnosis stage - it would be feasible to get groups to discuss, to

prepare themselves, the brain is the last thing to go... They know what's happening, if you can make a decision ... that surely is better than waiting until the last minute; it's being pro-active.

M1: But if you start establishing outgroups for people who are very young who at the moment have a prognosis that's very short, as time goes on and we get things improving all the time, there's no reason to believe they might not have a much longer life than most of us recently considered.

I had a nephew who had spinal bifida, we were informed that he'd be lucky to make 21, he's 52 now and still working.

Does that suggest you would need a tighter definition of people who could ask for assisted death?

M1: Yeah.

F3: It needs to be updated and reviewed in line with medical research and advances in treatments and drugs and whatever else. Just because something wasn't curable 15 years ago doesn't mean its not going to curable in 15 years.

F5: There's many things that are changing. My mother died from cancer in the intestine, because they put her into a room to die. The doctor came one day, next day she died.

Are you saying you wouldn't trust doctors opinion necessarily?

F5: I wouldn't.

Does anybody think there are no circumstances at all in which assisted dying should be legal?

F5: It has to be looked at very, very seriously. The past, the things are happening. 2 years ago I was doing nothing, now I have a driving license!

Does anybody think there are circumstances where if you don't have a terminal illness that assisted dying should be allowed?

M1: No... that could be open to all sorts of... You always assume that people are going to be rational about this, but there are a lot of cases where they aren't rational. For instance there's a lot of cases of drugs now with younger people, where the fact that they're on these drugs will mean that they have a fairly constantly altered state of mind. Again, thresholds have got to be established.

F4: There's a court case going at the moment... he really wanted to but he couldn't, he was paralysed neck-down. I thought, if that was my son, he'd still be here.

F3: These decisions are made for different reasons, they're about quality of life and access to lifestyle. And that's a completely different ball game to somebody with a terminal illness because the issues are so, so different it's untrue.

Because if you know you're going to die naturally, I firmly believe people choose this route because they don't want to die in pain.

F2: Also there are a lot of manic depressives out there, and there are times when they want to do it. But for somebody to think about it, there's a little seed there. What quality of life are they going to have, and if they carry on how many people are they going to hurt. It is very sad when it happens, but at the same time it's what that person wanted.

There are a lot that think long and hard, spend years planning...

F3: Look at Christopher Reeve... it's different when you have money. That's another issue, I can't quite understand why Terry Pratchett's opinion is more valuable than anybody else's. I do get quite annoyed at the airplay he gets, he's got plenty of money, if he wants to go and do it, go and do it. But don't tell me that I should allow you to do it, make your own decision.

When we say doctors should be involved in the decision. Going back (to abortions) currently unless there is a serious danger to the health to a woman, you are not allowed to have a termination yet every year we have 1000s and 1000s and 1000s of terminations, you just need 2 doctors to sign a form to say your mental health is at risk. But how many women go back years and years later consumed with guilt...

M1: We really have to question the integrity of those 2 doctors. You have to have some sympathy for, in many cases, the girl. But if you had more control on it...

F3: It's become the norm and that's what worries me.

If we did have some form of assisted dying, a very tightly defined group of people, who do you think should be providing the assistance needed?

F2: Not one person. A group of people. Professionals and family.

Which professionals do you think should be involved in that process?

F3: I think an ethics group. A mixture of people.

F4: I think people like Macmillan, places that deal with things like that on a day-to-day basis.

F3: Often these decisions come down to people who are quite high up in the medical profession but are not clinicians, who don't deliver the service on the day-to-day basis.

F5: The problem now is the NHS does not have the money to keep the people living, even though they're going in the next 3 months, they're going anyway, so might as well get it over, saving the money, that's what he said.

So you're worried about the motivation of the doctor?

F5: There is very little personal care.

If we were to have assisted dying in this country, do you think an assessment of that person's care would be needed to make sure that person had everything they needed to make that choice?

F5: It's the people themselves, who will say, not the doctor who will say this, this and this. No it's the main person themselves. If they say I want to be killed, they could feel differently, you get somebody who's got a disease where they're going to go anyway, or it might be something where 'all my use has gone', I can't do anything. They have got to know everything is there that they could have. They should know they've been offered everything.

F3: We're all dying now but we just don't all know when. That's the difference. It's about fear of the unknown and the barriers to access and services and support.

F5: I have no help at all. I take morphine twice a day because that is for the pain that I have all the time and that's not going to put me down. Somebody else taking morphine is different, everyone has to be separately looked at.

F4: The mental attitude as well as the person. Some of us can be stronger than others. Some of us can be plain stubborn, don't give in. Some people diagnosed with something will just give up. The mental attitude is extremely important.

So that needs to be taken into account, if the person is asking for assisted death?

F4: For me, it would be my last resort, be stuck in bed and having my husband look after me. That, I would not like. I would say, I've had a good life, that's it. Others, at first signs of disability, they would just give up.

F5: If people look at that first, that's no good.

Can we come back to the difference between assisted suicide and voluntary euthanasia? They're two separate categories – should both be legalised, one or the other or neither?

M2: It's up to the individual to choose for themselves. It depends on their particular needs.

F5: But every person is different. Doctors are also different – one doctor will want to fight, another might...it's just an attitude.

F3: The problem I have with that (assisted suicide) is that if you asked me to help somebody close to me take their life, I could do that, but I don't know how I would react to it, if I would have a nervous mental breakdown the next day. If a doctor does it, at the end of the day, they can cop out. It's like with abortion, they can say I can't prescribe that or the morning-after pill because of my own conscience. As a family member, how do you deal with the aftermath? You're asking people to do something that you don't understand what the ramifications would be afterwards for them.

F2: You need to look at the role of the person who's actually assisting.

F3: Until you, as an individual human being, have seen your first dead body, I don't think anybody can prepare for that, for the finality of that. It's just so affecting. I think assisted is more open to abuse.

Assisted suicide could involve a doctor rather than a family member. So it could be a nurse. A professional person.

F4: Like the vets, they're used to it aren't they!

M1: With assisted suicide, you've certainly got to contact the doctor and he or she has to be aware of what's going on, if he's not willing to take part in it, that's a different matter.

Doctors do think assisted dying should be legal.

F3: That's very different from, 'would you be prepared to carry it out?' But it's also because there's a disparity in the quality of care, some doctors would go absolutely out of their way to make sure the patient is as comfortable as possible and they end their lives with as much dignity as possible. My dad's doctor actually knew he was lying in pain and wanted to get back into hospital, but closed the surgery for the afternoon and put the answer phone on, he didn't care that he was dying in agony.

F2: I think somewhere in there should be a clause, "if at any time you wanted to depart this will, would you 'yes' or 'no'?" And that should be given when it comes to it.

M1: I've told my son and nephew that if I'm being kept alive by artificial means, pull the plug.

Potential risks: if the UK was to legalise assisted dying in quite limited circumstances that we discussed earlier e.g. when someone is terminally ill, are there still risks and concerns you would have?

M2: There would always be concerns. Sometimes it's kinder, they are all individual cases.

M1: There's always going to be a risk, you can't avoid it, in cases where people want to do it to get the money, and others where they say, "I don't care how much pain she's in, I don't want her to go;" so there's always going to be a risk, it's just a question of controlling it.

F4: I've got an article here, it says, "a legally binding witness record of patients wishes is expected to be kept on an NHS database which will be accessible to all medical staff involved in the care, this is a new Patients Charter, dying people and their relatives have been encouraged in by GPs in 8 500 English surgeries to set the record straight, about what they want." Now, who's going to monitor that database? Such a thing could be used in court by doctors to prove that's what they wanted and that they've taken the patients wishes into account, and could equally be used by bereaved relatives to

prove that they haven't. But what about the patient? Is it right to put any pressure on him or her to confront something that they'd sooner put to the back of their mind at what is already a distressing time?

If written witness wishes are in place would it sway medical staff, who are only human, to remove life support in certain cases? Can they be 100% certain that they won't recover?

F3: But it still goes back to what I said earlier I think, people make this decision out of fear about how they're going to end their days and about the support. It's almost like its the flip of the coin: I either die screaming in agony or I make my own decision. And actually somewhere in there what should happen is every step should be put in place to ensure that I don't die in agony.

So you would be uncomfortable about people making decisions quite far in advance about what they would like?

M3: Yes. The danger is that people make decisions with incomplete information.

F3: The problem is that you're making a decision about a scenario that you're imagining. The issue is a minefield.

So do you think the person would need to be experiencing suffering at that time in order to make a decision, rather than anticipating suffering?

F3: I don't know. I just think the whole issue is a minefield.

F2: You've got to be in a mental state to make a decision. And if you haven't got the resources to enable you to make the right decision, whatever it is for you, you're never going to do it.

F3: And then you have people making these decisions and you go back to the stage where we're almost cleansing society of people who are ill or have a disability. We've almost come full circle in which case.

F2: How many of you who are disabled, have you been looked at in a peculiar way? 'You're not normal.' I can't open doors, and I was out the other day and I told my friend I can't open doors, so to open the door and a lady behind said 'she shouldn't be coming out then.'

F3: It feeds into this whole mentality that people with disabilities and illnesses are not as valued as everybody else, it feeds into this Daily Mail scenario that you're all on benefits.

F2: We have to not take offense at what they say, because they can't understand, you have to feel sorry for them for their ignorance.

Safeguards: if the law were changed, what safeguards should be put in place?

F2: Money and property must be looked and carefully checked that a person is not under pressure to become a suicide so the family can benefit.

F3: Somebody reacting to therapy, somebody could decide today they don't want to live their illness, but learn tomorrow that they're expecting their first grandchild and that's another milestone to look forward to. So you need to assess people over a time frame, in different environments. So not just mental capacity in a particular moment that a social worker assesses.

M3: So who would decide that? A medical team, a legal team or lay people? Or a combination of all of them?

M1: A group of people. If we're going to have panels or committees, it's certain that those are the people with the most experience to deal with it.

F3: Another thing that worries me is that there will be this carte blanche attitude. That older people might ask for assisted death because it's almost expected of them.

F5: But that is already there, if you're waiting for a kidney at 25 or 30, you're going to have a...well you can work for another 20 or 30 years...

F3: I just think people will make decisions for the wrong reasons. We're not a very caring society, we purport to be very caring on the surface, actually nobody gives a monkey's anymore. We purport to be very caring in helping people to end their lives but actually how about we make it so that people don't feel that's their only option in the first place?

M2: You also get people who don't want to be a burden and want to leave an inheritance for their children and grandchildren. It could be internal mental pressure to want the family to benefit.

F3: And can we have some equity so that whatever happens here happens in Scotland?!

Additional thoughts

F3: What does concern me is that if this body was set up, that there would be an overarching politician, "Minister for Dying", and the last thing we would want would be somebody making these decisions..

3.4 - Focus Group with older people in sheltered housing, 26th July 2011

Views on the current legal situation – is this the right approach?

Female (64 years old): 'I am religious, and when the time comes, Father must take it.'

Male (79): thinks that it is time that euthanasia should come in. Hospitals are full of people that can't look after themselves, nobody visits them, they are shouting and screaming. Thinks that they should be put to sleep. He believes that the reason they are not is

the possibility of a new drug being discovered tomorrow that could cure them.

F (70): ‘I believe that if that’s what somebody wants, they should have that choice.’

M (87): ‘I feel that if a person is bed-ridden, has to be washed, and cannot do anything for themselves, then they are no use to themselves or anybody else and they should be allowed to be put to sleep.’

F (72): Also believes in it if there is no hope left, this should be an option.

M (80): He was less certain and brought up the issue around the role of the medical profession – care vs. administering a lethal drug. He thinks that many doctors would find it very, very difficult and he is not certain they would want the responsibility. Also there is the risk of a family who want to bump off an elderly relative to get their money:

‘There’s always a risk when you get somebody really old, that the family wants to knock that person off to get their money’;

‘I know an old lady. She is way into her 90s...and she is really wealthy. And I’d hate to think that...her brain is OK, her body is not. There is that possibility.’

He thinks that we should leave things as they are. The debate will go on and on and on in Parliament, religious beliefs will be influential, but in the end, it will not be possible to actually change the law.

M (80) also noted how many people in hospital would be unable to take the final action anyway, if it is assisted suicide that is legal –

‘A lot of people in hospital are helpless, so they can’t decide anyway. For suicide, they’ve got to have the final word’

- To which **M (79)** replied that that is why you have euthanasia, where the doctor takes the final action.

M (63): On care in hospitals, he believes that this is whole other discussion: older people do not get the quality of care that they deserve in hospitals and he believes that people often die in hospital because of lack of care and lack of food and water, of which he has had experience within his family.

‘I don’t think that older people get the quality of care that they deserve in hospitals and that quite often people die in hospital because of lack of care’

On assisted dying: ‘It’s difficult for any person individually to be aware of what the pressures may be on them emotionally.’

He believes that for those cases where a long-term partner, for example, helps end the life of a terminally ill individual who has long expressed a desire for a peaceful end, the law should look upon this favorably, as it already does.

‘It’s alright for committees and organisations and laws to turn around and say you can’t do this, you can’t do that, but we’re all aware that sometimes emotions are so great that you do do things’.

M (63) on vulnerable people: severely disabled people, who may be perceived to have a less fulfilling life, ‘it’s very difficult to know where they would draw the line on assisted dying.’

‘There might be so much strain on someone that they may actually help to do that.’

Who would you envisage being eligible for an assisted death?

M (87): ‘I feel that the immediate friends and family shouldn’t make that choice, it should be somebody completely away from the family’

It should be two or three people who decide. He believes that it should be related to quality of life and when you have become a burden.

If the individual is capable of deciding what they want, then that is what matters:

‘What is life if you can’t smile or be happy?’

M (79): He spoke of a friend of his who is bed-ridden, incontinent and cannot eat for himself: ‘he is absolutely finished.’ Friends and family are praying for an end, but there is nothing they can do and the law says that he can’t be put to sleep. (So **M (79)** is actually in favour of involuntary euthanasia.)

F (72): She thinks that the family should make the decision too, but **M (63)** does not agree: it is such a major decision, that you would need a range of people, such as a doctor, social worker, policeman, to agree on the decision.

Should anybody at any stage of life, in any situation (who is competent) be able to ask for an assisted death? Or nobody? Or in certain circumstances?

M (80): You need some kind of outside/professional feeling about it, not just a family/personal feeling about it. Just being unhappy is not a reason enough to commit suicide:

‘I think they would have to talk to experts in the field who just wanted to talk it over, to make sure that they knew what they were deciding; if they don’t agree with you then they can stop it’

‘They must be very clear in their own mind’.

F (72): She doesn’t think that it is up to the doctors, but to the family and the individual. She believes that if you have cancer, or other terminal illness...it is up to the individual.

‘I don’t think it is a decision for the doctors to make really... it’s up to the family and it’s also up to the person if you’re conscious and you know what’s happening. If you’re in pain and it’s unbearable and you’re going to die in six months whatever.’

Some disagreement over whether incompetent people should be ‘put down.’

Over half agree that it should be limited to people with a terminal illness: **F (72)**: ‘those who are not going to get any better and who are in terrible pain.’

M (63): ‘there are gray areas with that though.’ E.g. Alzheimer’s; he thinks that there has to be some kind of rule and that terminal illness would be as good a rule as any.

Potential risks posed by assisted dying: Disability e.g. locked in syndrome/Tony Nicklinson

M (87): ‘I don’t think he should be allowed to kill himself’; he can do things and he has a good brain.

M (80): He admits that it is rare, but sometimes people do make unexplainable recoveries:

‘I don’t think we must ever give up hope; there’s always hope’.

‘You might be suffering at the moment, but you never know, it might change and you might do brilliant things’ e.g. Stephen Hawking.

M (87): He disagrees and believes that this would be ‘condemning thousands of people because of one recovery’.

F (64): ‘Just because your body has gone, it doesn’t mean your brain has gone.’

M (63): He believes it’s a very difficult area and links in to questions over terminating a pregnancy because of a disability that might happen. For adults with a disability, if over a period of time, they have consistently said that they would rather not be alive because their quality of life was completely dependent on other people, he doesn’t think that this situation is much different from the individual with a terminal illness who wants to die gracefully and with dignity. For **M (63)**, it is more about suffering.

F (70): ‘I feel that people should have their own choice’

F (72): ‘If somebody is suffering and they want to go, I agree with it.’

M (79): He doesn’t believe that it should matter if you are disabled or not; if you want to die you should be able to die.

Age Limit: what should be the minimum age limit for someone to be able to make such a decision?

F (70): She states that under 18 is really young

M (80): ‘At that age, one day you’re up, next day you’re down.’

M (63): Children often know they are ill, but they don’t always understand the severity and therefore are likely unable to make that decision. He believes that minors (under 16s) generally don’t have a say in legal matters and that this shouldn’t be any different.

M (79): ‘If someone is really severely disabled, and whether they are eight or eighty, the doctor should decide and that should be the end of it. Anybody who wants to die should be allowed to die, full stop.’

M (63): You have to take into account religious beliefs and the parent’s feelings

M (79): ‘Life for old people in the future is going to be very bad.’

Assisted suicide vs. voluntary euthanasia: should both be legalized? Or just one type of assisted death? Or neither?

M (79): He believes that both should be legalised.

M (63): Both should be allowed, but not necessarily legalised:

‘there should be obviously great thought in how it is set up and safeguards put in.’

M (80): If someone is helpless and can't do anything for themselves, then they will need someone to press a button for them. They wouldn't be able to administer it themselves.

M (87): He thinks that 'each case should be looked at on its own merits' and it is very difficult to make a rule about who can live or not.

F: 'If it becomes legalised half of us wouldn't be sitting here. They would be getting rid of all the old ones to keep the young ones in. They'd be paying no pensions out, the Government then.'

M (80): 'If I was a vegetable lying in a bed, very unlikely to regain consciousness, I'd say flick the switch any day.'

Who should provide the assistance?

M (80): He thinks that 'the family is going to need professional help'. He doesn't think he could do it himself. But equally, you can't put all the weight on the doctor. He believes that this is something that we can talk about, 'but to bring in the practice, I don't think it's possible.'

M (87): He believes you need a range of professionals.

'Could you have a points system to help you come to a decision?'

F (70): She thinks that a doctor would be best placed to provide the assistance.

What are the potential risks posed by assisted dying?

F (64): She repeats her assertion that assisted dying should be illegal.

F: She thinks that the doctors might begin to decide that it's your time to go in order to free up the beds on the ward. It might encourage doctors to think about the cost of keeping you alive.

‘They might decide it’s your time to go because you’re 75 or 70 and you’re in and out of hospital a lot and you’ve used a lot of medicine’

Safeguards and checks: If the law were changed, what safeguards should be in place?

M (87): There should be more than one person giving the go ahead; it needs to be discussed, alternatives need to be offered.

M (63): He believes all alternatives should be looked at first: medication, quality of care, is the decision being made by the individual, or by the family or doctor?

‘Everything should be exhaustively looked at before a decision is made.’

He thinks it should be allowed, but is not certain that it should become legal. However people should be free from prosecution; decriminalisation.

There should be range of individuals involved in the assessment. It must be something severe; not just that they want to end their life for no good reason. There should be safeguards put in so that does not happen.

Depression

M (87): He thinks that if you are depressed ‘you can’t make a rational decision.’

M (80): ‘They’re not thinking normally; they might get out their depression tomorrow and might want to carry on living.’

M (63): Desire for death should stem from a physical reason.

‘I think there should be a physical reason’.

M (80): ‘The illness has got to be terminal within a fairly short period’.

M (63): ‘In a sense the hospitals are assisting people with dying by not giving them the care to keep them alive. We’ve all got examples of it. So they are assisting dying and it should be noted somewhere’

Closing thoughts

F (70): ‘I still feel that it is people’s choices. If they want to die, why not? And I don’t feel that people should be prosecuted for it.’

F (72): ‘If they are terminally ill and they want to go, it should be their decision.’

M (80) – ‘On the whole, I think I’m against it. But at least at the moment, people, if they are as an individual, determined to end their life, they can go to the continent to do it. That at least shows that they were very determined.’

(F (72) noted how not everyone can afford to go to Switzerland.)

He thinks there would be too many loopholes, and that you can’t possibly make the rules and that people change their minds too often. Whilst some may be determined, others will change their minds more frequently.

‘There might be a few people who are very, very determined but most people are liable to change their mind or they’re not really even capable of making a choice’.

M (87): He is slightly more positive: feels that the government should discuss this and come to some decisions on the criteria for who should have an assisted death. He thinks that there should be a legal option for some. But it must be a collective decision.

3.5 - Interview with people with Learning Difficulties, 18 July 2011

The focus group was made up of a group of individuals between the ages of 18 and 50, who have a range of learning difficulties. During the discussion we showed a clip from Emmerdale dealing with assisted death, which served as a point of access to the ideas that we were seeking to discuss.

There was some debate about the different meanings covered by assisted dying:

‘If you get a doctor to put you to sleep. It’s no good you living anymore, if you’ve got pains in your body, and your partner might help you, your partner might ask the doctor’.

Many of the respondents had experience of taking complex sets of medications and there was a level of confusion and worry about the potential for this medication to be administered in a lethal dose.

One female respondent confessed to having tried to kill herself by overdosing in the past.

There was a sense amongst the respondents that Doctors should be concerned with curing people rather than ending people’s lives.

‘They help you out. Help you to stay alive.’

- We showed the group the clip from Emmerdale in which a character (Jackson) who is paralysed asks his mother and boyfriend for an assisted death.

Attitudes towards assisted dying in the UK: should someone be able to get help to commit suicide because they want their life to end? Should it ever be legal?

One female respondent was concerned about the potential effect of Jackson’s death on his mother.

“She’s only got one boy, and she don’t wanna lose him. If she loses him, how’s she gonna cope with her grief?”

One respondent detailed the preparations she had made to dispense with her belongings following her death. In response to the question: *Do you think it’s up to you to decide when you want to die?* She said:

“When I’m ready, I will. I don’t like people putting words in my mouth. Saying, ‘Oh, die.’ I say, ‘No. When I’m ready. When it comes.’

‘If someone wants to end their life, end their life. They shouldn’t be put in prison. It’s like, if they want a new pair of trainers they should have them.’ (Female respondent)

If someone needs help to end their life, for example if they’re paralysed, who should they be able to ask for help?

‘It shouldn’t be a family member. It should be a neighbour or doctor.’

‘I think the doctors and the nurses will know how to do things, will know what to do.’

Many of the respondents found it hard to grasp the consequences of asking for an assisted death.

Discussing Jackson’s situation, one female respondent called for better palliative care; she didn’t think he should be allowed to die:

- ‘I think he should get a social worker to help him, a carer’.

- ‘He needs to go to the hospital to get it treated and get his life back’.

There was some confusion around the use of the word ‘Help’, which respondents didn’t understand in the context of ‘help to die.’ Help was conceived of entirely in terms of personal care, rather than as assistance to die.

One female respondent felt very strongly that Jackson should not be given assistance to die.

Should the law be changed so if one person helped another person to end their life they wouldn't be arrested?

One female respondent was strongly for a change in the law:

'Get the law in, it's better to have the law. Other countries have got it, why can't we get it?'

Why do you think we should have a law like that?

'Because a lot of people want to die. They go to court and try and fight it, and the courts say 'No, sorry, you're not allowed to do that, you can go to another country'.

Some people say that this is a matter of people having personal choice over their life and that if somebody wants to die, they should be able to make that choice because it's their decision. What do you think?

One male respondent felt that in 'extreme cases', perhaps where individuals were paralysed, people should be allowed to choose to die:

'If people want to pass away, it's up to them'.

The same respondent felt that individuals with terminal illnesses should be allowed to die if they were in pain and close to the end of their lives.

One male respondent expressed a fear that assisted dying would get out of hand, and individuals would be more at risk of being murdered.

Eligibility criteria: Who should be eligible for assistance?

If it was to be legal to help somebody to die if they asked for help, should they have to be a certain age to be able to make that

decision? Would they have to be over the age of 18 or a different age?

Respondents were for the most part unclear about whether there should be an age limit for assisted dying.

One male respondent said that assisted dying should only be allowed for people 'over 100'.

One male respondent said that people should be over 60, 'because then they've had a good life.'

--Break--

Who should be able to provide assistance?

Should a person be able to get help for assisted suicide from their family?

In direct response to the question of whether people should be able to ask someone in their family to help them kill themselves, the group said unanimously no.

One male respondent said that it was 'too emotional for the family members, they should get help, call 999'

Should you be able to ask a doctor to help you to commit suicide?

One female respondent said that a Doctor should be able to help:

'Yes, it's better. A Doctor knows your case, your family doesn't know your case properly; the doctor knows everything.'

'If you don't tell your doctor, you're going to get another tablet from somewhere else.'

Where do you think that would be?

'If I say to my friend, get me a tablet, she can go to the chemist.'

Another respondent found it hard to understand the idea of a Doctor assisting someone to die, but nonetheless was broadly against the idea.

Those people who said you should be able to ask your doctor for help to die, do you think there are any risks attached with that? Do you think that there is a section of society that would be put under pressure to kill themselves like that?

‘If they haven’t got signatures [of consent], they should be arrested’.

One male respondent was very worried about the idea that Doctors might be able to kill people, again warning that it could lead to murder:

‘They are going to give tablets to all the elderly, the old pensioners and that.’

One male respondent who was pro-assisted dying cited depression and bullying as potential risk factors.

Additional thoughts

One female respondent raised concerns about the effects on friends and family left behind: ‘families do get worried’.

3.6 - Interviews with individuals contacted through online forums for people with terminal illnesses, critical conditions and mental and physical impediments.

Interview with a woman with MND

The interviewee, referred to as ‘Anon’, is a woman who was diagnosed with motor neurone disease five years ago. She contacted Demos through an online support group called ‘Build UK’, where

Demos's research for the Commission on Assisted Dying had been advertised. She was interviewed on Wednesday 15th June 2011.

LB (interviewer): Thank you for agreeing to be interviewed; just to reiterate, everything you say will be kept confidential.

To start off, what do you think about the current legal position of assisted dying in the UK?

Anon (interviewee): I think that it's the safest way to protect vulnerable people.

LB: Have you always had a view on this issue or have you come to your opinion more recently?

Anon: Within the last few years, having been asked about it by many people, since being diagnosed with MND.

LB: So you came to your view since being diagnosed with MND. How about before that?

Anon: I think I'd spent about half an hour thinking about it since I was 12.

LB: Do you think it's right that the DPP has discretion in deciding when to bring

Anon: Yes, when it's in the public interest. I think it's a very sensible approach.

LB: Is there anything about the current situation that you'd change?

Anon: I understand why people want to look at change, particularly to protect a loved one who helps them to commit suicide. But I think that it is far too dangerous to have a legalised way of not prosecuting them, that isn't to do with each individual case.

LB: So you think it should be looked at on a case-by-case basis?

Anon: Yes, as it is now.

LB: What makes you think that assisted dying would be dangerous to vulnerable people?

Anon: A number of ways. There are various forms of coercion. For instance, one thing that is an option – not the same thing as assisted dying – is that we put ‘do not resuscitate’ in a living will.

Now, every time in the past five years that I have been for a medical review or have changed doctors or seen a medical person or a solicitor or even a member of my family, I have been asked if I want to sign a ‘DNR’. And when I say ‘No, in fact the opposite, I would like you to do everything in your power reasonably to resuscitate me,’ I’m looked at with shock and then even on occasion told what a horrendous quality of life I would have on a tracheotomy.

LB: Have doctors told you that?

Anon: Yes, at least three or four doctors, on separate occasions.

LB: Does that include specialists in your condition?

Anon: Yes. That’s something that I’ve already experienced. I feel an increasing pressure not to have life-saving and expensive treatments and care. Every time I turn the news on, I’m faced with another example of how I’m perceived as some sort of leech.

LB: Is that in news coverage and things like that?

Anon: The Terry Pratchett documentary about Dignitas has been on this week. I was not impressed by his attempts to pay lip-service to impartiality. I thought it was very weighted to being pro-assisted dying. Worse than that, in the discussion afterwards there was some clergyman and Liz Carr trying to argue against and a whole panel of people in favour. They imply that they’re doing this for disabled and terminally ill people. The fellow with MND was positively sporting compared to me.

In my opinion, it’s dangerous. You’ve got these professional medical people urging you towards saving money. I don’t think the doctors individually are consciously thinking in those terms, but if there is

an ethos that is persuading people that the sensible kindly option is to take “an easy option” then I fear that that would be encouraged.

LB: And if doctors were not allowed to suggest assisted dying?

Anon: I don't think that would be possible. The nature of my illness means that there is nothing I don't discuss. My MND affects every instance of my life and I could not avoid discussing something with my consultant team and the social workers at the hospital.

They would need to be involved. They may say ‘I can't advise you, but are you aware how horrible your life will be?’

LB: Do you think they often make judgements about your quality of life?

Anon: Certainly. That is one of their main areas, to tell me about my illness progression and see how I'm coping. I need to have those discussions concerning my palliative care.

I also think that a number of people would feel obliged to take that option if they looked at the financial and emotional pressure they're putting on their families and loved ones. They may feel compelled to take that option.

I'm also aware that discussions like this generally only affect the disabled or terminally ill. I find it quite objectionable. It's like telling me that it would be correct to assume that my life is not as valuable. If an able-bodied, non-terminally ill person said ‘I can't face the future, I will die one day and I'm worried about it, I want to commit suicide now, and I want help to do that’, we would look at every aspect of their life and try to make life more bearable by changing physical things in their life or suggesting ways of improving their social life or medication. What we would not do would be to say: ‘Yes, you're right, it's not worth it, you might as well die’.

LB: Do you sympathise with those people who do want a change in the law?

Anon: I've listened to a lot of people trying to argue that case and I've yet to find a compelling argument as to why they should die. I understand why it's frustrating not to have the same possibility and choice as able-bodied person who can commit suicide themselves if so choose. But that's generally discouraged by society, for whatever reasons. And the whole 'dying with dignity' thing generally means dying before they get to the stage that I'm at.

And it's not nice having somebody else prize your stool out because you can't, you no longer those muscles. It's not nice to have your children wiping the dribble and snot from your face. It's not nice to have to have to have to be mechanically moved or to spend hours sitting with a mask breathing for you. It's not nice having a machine that talks for you when you can't. But it's not anywhere near as bad as not seeing the birds or sharing your thoughts on issues...

Worries about not being able to communicate can be fixed by machines like this, with help, with carers, with assisted *living*. We should be concentrating, as we would with anyone else, on making the lives of the terminally ill bearable. I really haven't heard anybody say a reason that is compelling for having assisted dying.

LB: If everybody really did just listen to the individual's own view on their quality of life and if people were able to access the support they need, would you think that the choice should be there?

Anon: In a world like that, the choice should be for anybody. You'd be able to walk into the doctors and say 'I've thought long and hard and I don't like living, I'd like to die.' No, I don't want that. Why would you look at that? What is the argument in favour of it?

I'm not going to die in pain. I've been assured by doctors that palliative care will ensure that I'm not in pain. And that surely is what we can all expect and hope for.

I really do not understand why we're even considering killing people because they don't want to wear nappies. I do understand that it isn't a flippant matter and people do feel that they are a burden to their loved ones. I know people whose life-long romantic partner has become their nurse-maid and that is a horrendous prospect, but

we should be looking at solutions to that issue rather than looking at letting people die.

LB: You said that you have discussed palliative care with your specialist. Do you know what kind of care will be on offer?

Anon: It's frightening. But at the end of my life I will spend more and more time in hospital. And I would like if possible to remain in my own home. If that is possible then it would be provided either by the hospice outreach team or the district nurses. If not, then finally hospital.

LB: You said that in the past doctors have asked you if you want to be resuscitated. Do you have an advance decision stating that you *do* wish to be resuscitated?

Anon: Reluctantly, my solicitor has drawn one up. I haven't had it back yet. My solicitor was reluctant, he's a family member. He was encouraging me to write an advance directive that was 'do not resuscitate'.

LB: Do you feel better knowing that that legal document will exist?

Anon: Personally I think that it should be left to the doctors and care team at the local specialist centre. They all know my wishes and that unless there is anything contra-indicating on my notes, they should be saving my life anyway.

I think they would have understood anyway, and that they were trying to make sure that I was aware that they would resuscitate me, unless I put a 'DNR'. I think that is exactly how it should be.

LB: Is there anything else you would like the Commissioners to know when they're considering this issue?

Anon: Yes, that it is worrying and frightening when you're given a diagnosis like mine and that of course it should be discussed so that the patient is aware of 'end of life issues', but that the emphasis should be on assisted living, not assisted dying.

Telephone Interview Transcript

Ok. Okay, so Part I of the questions we want to ask you are about the current law in the UK. At the current moment assisted suicide is illegal, but the director of public prosecutions can choose not to prosecute people if he decides it's not in the public interest. Do you think that's right or do you think it should be changed?

Well, I do think that in desperate measures, in desperate situations... [inaudible]...I don't think that they should change it. Unless it is the case that they've done it for their own reasons, i.e., money, you know, they've gained something from the death of a relative.

Okay, so, sorry, you do think the law should be changed or you don't...?

Oh, no, no, I think that they can be let up. Obviously the only way you can do that is to change the law if they are – if they – it's a bit of grey area, really, like the situations with euthanasia. Um, I do feel that it gives too much leeway... If, um, people are doing it for their own purposes [*presumably she means their relatives' purposes?*], I think they should change it.

Okay...What in particular would you change? [More stringent? More safeguards?]

That's it -- more safeguards, yes. For the individual.

Ok.

[Inaudible] If someone...is just lying there...just can think and talk, then they might want to die, you know what I mean?

[What are the circumstances in which assisted suicide should be made legal?]

Well, obviously if, you know, if they're on life support, and they've been there for, you know, years, and if, you know, if it's the wish of the person to die, because their life has stopped, that there is no life,

they've got no quality of life, that they're in so much pain, they don't want to carry on.

Okay. Do you have an opinion on [assisted suicide vs. voluntary euthanasia]

I do think it should be allowed...But caution is – maybe like that crazy doctor who killed all those people up because they were elderly or he thought they were [inaudible] -- you have to have guidelines, I think. I wouldn't understand what guidelines you have to have, but I think you would need guidelines.

Do you think one is more appropriate for Britain than the other...?

I think, you know, voluntary euthanasia. If you want to, look, end your own life, fair enough.

So, that's it – so if you take the action, which we're calling assisted suicide, is that the –

Yep, yep, yep. But with the [inaudible] of that.

[What's informed your attitudes?]

Um, well, myself, even though I'm a Christian, I, you know, wouldn't say no – but obviously, having been in a personal situations where I've been in a lot of pain, but I wasn't there just to go to bed [did I get that right? Not totally audible] ...I could appreciate people who want to end their life if they're just lying there with no quality of life.

If the law were to be changed, do you think that assistance should be limited to certain kinds of people...or available to the individual to decide?

I think it should be to the individual still. But obviously if they're not capable of doing it themselves, they should give a verbal permission to end their life if that's what they want.

[Can anyone end their life?]

There's got to be other reasons. [inaudible] You know, I can't see the point of ending your life if you just want to, you're just... you're depressed...Or if you're dealing with these mental health people, obviously a lot of them just want to end their lives for some reason, depression...It's got to be, you know, they are in severe – well, mainly quality of life. You know, they've got no quality of life. That's where I draw the line that they can, you know, engage in euthanasia if that's what they want to.

[Minimum age]

Anyone who -- open to anyone.

[Who should provide assistance? Purely medical? Family?]

I think the family, um. Again you got to be very careful that they're not doing it for their own gain, um, you know. But I think there should be at least two doctors involved or two people, you know, that have got a connection, not just one doctor. More than one medical connection. [inaudible]

Okay, and do you –

Safeguarding the patient, really.

[any risks?]

Oh, of course, you're going to have people that will do it for their own personal gain, for wealth, you know... Or maybe somebody [inaudible] wants to re-marry or things like that.

What sort of safeguards...?

You'd have to go through - not necessarily a long term of, you know, bureaucracy, of finding out the whys and wheres... You know, um, it's got to be sort of dealt with with people who are agonized about

family environments or, you know [inaudible] connections...You understand what I'm saying?

Yeah, yeah.

Some sort of safeguards you know, like, within the NHS [inaudible] solely the [inaudible] side of the situation.

...Doctors...or legal body, like a tribunal?

A tribunal... Doctors as well, obviously giving their input. But mainly a tribunal. Like, nothing to do with the situation... But [also] the input of the doctor in dealing with patients -- the quality of life.

[Especially vulnerable groups?]

People who are disabled, mentally, like, you know, Down syndrome, people with learning difficulties, um, you know, they're going to have problems, you know, giving their point of view, that sort of thing...[inaudible] ...and children.

Do you think assisted suicide, when the individual takes the action themselves, and euthanasia...pose different risks?

Um, they're not different, really, I mean, you've just got to be general, really. The main thing is people, you know, getting into people for their own gain...Or people who are heartless and just [inaudible] kinda looking after their own children. I mean it does happen.

[anything else to say?]

Obviously this is a personal interview. I mean, you know, personal opinion. You know, I've been, [inaudible] as a Christian, I moved the boundaries accepting what the situation is to allow euthanasia. Because I've been there myself -- pain so that you don't want to carry on. But then I had got quality of life. If maybe somebody has had enough pain... [inaudible] Or Tumors, that they get really seriously. [Inaudible.] But having said that, I don't know if you watch [inaudible] "New Year's Dream".. It's about a young girl at the age of 3 who contracted Alzheimer's disease...It was brilliant

because, obviously she's, you know, just getting worse, she's going to be bedridden. You wonder what the parents [inaudible] It's mainly down to the individual. But you need those guidelines [inaudible] in place. Tribunals, independent, within the law... [inaudible].

Interview with a man with a terminal illness:

One: The current law in the UK

Do you think it is right that under current law, assisted suicide is illegal but the Director of Public Prosecutions can choose not to prosecute people if he decides this is not in the public interest?

'Absolutely crazy, it's a typical British fudge.'

Is there anything that you would change about the current law?

It should be changed to take account of the individual's conditions. Life expectancy, health possibilities, medical techniques should be considered.

'I think the current law needs to be made much more clear cut.'

'In tightly controlled circumstances, assisted suicide should be made entirely legal. So should euthanasia - it is an obligation of society not only to look after us in the cradle but look after us into our grave.'

The participant claims he doesn't understand why, if it is legal for doctors and nurses to be administering anaesthetic throughout our lives, assisted dying and euthanasia are illegal.

Two: Attitudes towards assisted dying in the UK

Do you think there are any circumstances in which assisted dying should be legal? If so, what are these?

‘The basic circumstance would be when the person wants to die and is capable of making the decision themselves. But I don’t think one needs to be imposing conditions such as having a terminal disease. Let’s face it, plenty of people go out and jump in front of a tube train, or jump off a bridge. They kill themselves in many ways. The idea that we should tell them how their set of circumstances changes their thinking is wrong. People must be allowed to decide, they decide throughout their lives on everything else.’

Should assisted suicide or voluntary euthanasia be permitted? (See definitions above)

‘They should co-exist, there should be the option of both.’

What has informed your attitudes? [E.g. Particular experiences, beliefs or values]

‘I’ve been a policeman for 30 years so believe I am a realist. I have seen too many attempted suicides fail through incompetence and have seen the aftermath of those. Because I think that society cannot Daddy its people through all stages. This is not one of these decisions that society should be making for people, other than those who cannot make it for themselves.’

If you think assisted dying should be illegal, how should the law treat people who assist a loved one to commit suicide for compassionate reasons?

‘I don’t think it should be illegal, except in certain circumstances. What about them? I guess as always that would be for a judge to decide. I don’t think a blanket solution would be possible.’

Three: Who (if anyone) should be eligible for assistance?

If assisted dying were to be legalised, should assistance be limited to certain types of people, such as people experiencing suffering that they find unbearable or who are terminally ill?

‘I think society does need the protection of knowing that people can’t be forced into assisted dying, those are the people I would want to protect. But on the other hand, if you have got Parkinson’s or Alzheimer’s, there will come a time when people won’t see you as a suitable candidate, even if you have stated clearly your desire to die at a certain point of deterioration. There ought to be a provision for a half-way house somewhere along those lines.’

If assisted dying were to be legalised, should the law find a way to assist people who are physically unable to take an action to end their own life?

If assisted dying were to be legalised, what should be the minimum age that someone must be in order to make such a serious decision?

‘16 or 18 depending on when you can give your life for your country (i.e. when you can be sent to fight in the army)’

Four: Who (if anyone) should be able to provide assistance?

If assisted suicide was to be legally permitted, who should provide the assistance? [E.g. Friends, family members, doctors, nurses, volunteers?]

The whole list that you have mentioned would, I think, at some point be appropriate.

Five: Potential risks posed by assisted dying

Do you foresee any risks that would be posed to society or to individuals by legalising assisted dying?

‘Yes, I do. I’m sure there will be cases where people will be tempted to encourage others into early dying against their interest, maybe camouflaging it. Every crime under the sun is committed in this country. So why not that one too. However, I think the balance falls very heavily in favour of assisted dying.’

Do you think that certain types of people would be particularly at risk? (E.g. older people, disabled people, terminally ill people or others?)

‘Yes, people with something that someone else wants. People with dementia, Alzheimer’s or with low development age.’

Do you think that assisted suicide and voluntary euthanasia pose different risks to individuals or to society?

‘Euthanasia with more medical involvement is going to be the safer of the routes. I don’t think that is necessarily a bar to having assisted dying anyway.’

Six: If the law were changed, what safeguards should be in place?

Who should make the decision about whether a person is allowed to have an assisted death? [E.g. doctors or a legal body like a tribunal]

‘I don’t think it should be an individual because people have personal beliefs that get in the way of objective judgements. Maybe more of a group, but I can see that becoming more of a bureaucratic nightmare.’

The participant suggests having the person who wants to die being interviewed by a public notary, though he later shows uncertainty about this answer.

‘That’s a really difficult question. I’m afraid I don’t have an answer to that one.’

What legal safeguards do you think would need to be included to prevent abuses of the law? [E.g. checks that must be made or a process that must be followed]

‘Two signatures from individuals who aren’t relatives. Who are not standing to gain.’

Seven: Additional thoughts

Please write below any additional views or experiences that you would like the Commission.

‘I am expected to look after myself through life. I should have the right to kill myself. I think I have the right to an easy, as opposed to difficult, death. I think it’s time that the people taking the hypocritical oath were a little less hypocritical about what they do. I think there is a great deal of assisted dying going on in society without people admitting what they’re doing. We’re living through a very strange stage of our attitude toward assisted dying and I’d like to see that come to an end and the doctors not having to cover up what they are doing. I’d like a bit of honesty.

I think we have the right to die peacefully. We’ve paid enough into the National Health to have a comfortable way out.’

3.7 - Interviews received via email from call-puts on online forums:

Email Interview

Part 1.

Q1. It is better that the Director of Public Prosecutions is permitted to use his/her judgement, but I would like to see Assisted Dying being made legal. I have problems with voluntary euthanasia as I think this could be forced on people who don't want it. Having to participate to end your life should be feasible with a little forethought to everyone not in a coma.

Q2. Yes, to make Assisted Dying legal, probably in a controlled environment as it is going to be hard to prove if the person took their own life willingly if there is no independent person present.

Part 2.

Q1. Yes, when a person decides that life is intolerable, be that they are in the terminal stages of illness or when their quality of life is so poor in their mind, that they no longer wish to live.

Q2. Both should be available if the person concerned has made an Advance Directive Living Will whilst they were of sound mind and there is no reason to suspect that they have changed their mind. Assisted Suicide should be available to anyone who expresses the wish for it, and repeats that wish two weeks later.

Q3. After 30 years of nursing, some of it in the field of oncology, some in elderly care, I've seen so much unnecessary suffering: as a society, we do not let our pets suffer to this degree, so why do we force our loved ones to suffer? Personally, I have debilitating back pain which is not adequately relieved, so when the time comes that I no longer wish to battle against it, I will end my life. I would like to know that I can be assisted (if necessary) to do it & that anyone helping me will not be prosecuted for assisting me. I do not believe that those who do have a faith should be able to impose their beliefs on me.

Q4. This comes back to a Living Will / Advance Directive, which needs to be in writing. If it is present, and has been shared with more than two people, then I think the law should respect the person's wishes & any individual giving assistance should not be prosecuted. If the person decides that they wish Assisted Dying without an Advance Directive / Living Will being made, then I think they should be obliged to repeat their wish verbally to at least two people twice, two weeks apart.

Part 3.

Q1. I would like to see Assisted Dying available to all who truly want it, terminally ill, & those suffering what they consider to be unbearable suffering be that of a physical or mental nature. There should be a safeguard in the law, to make those suffering from mental illness which is treatable, to wait for a period slightly over the expected recovery period.

Q 2. Yes, if they have made a Living Will / Advance Directive in writing to say this. For those who become unable to write a Living Will/ Advance Directive before getting to the point where they wish to end their life (eg a stroke), they they would need to reliably

communicate their wishes to at least two people a couple of weeks apart.

Q 3. When they are judged to be mentally competent to make such a decision, at least 16 years old.

Part 4.

Q1. It needs to **not** be part of the Health Service. There must be a strong definition between those who are trying to save life and those who are helping people to fulfil their wish to die. It would be nicer if family or friends could be supported by medically competent people, so that the person choosing to die was with those they knew, but that the act of ending their life was accomplished without errors that left them alive but with even more problems.

Part 5.

Q1. Yes, the legislation needs to be very clear that people cannot be coerced into agreeing to it for emotional or financial reasons.

Q2. All vulnerable people are at risk, so the legislation needs to be well thought through. Those with a degree of mental impairment are most at risk of being coerced, those whose mental judgement is not impaired should be able to make their wishes known so long as the process requires them to demonstrate their wish to impartial people.

Q3. Yes, as assisted suicide requires the person to take action themselves there is less risk to society that it will be forced on people. Voluntary euthanasia is more difficult to control should it become law, if the administrator of it does not have to obtain the informed consent of the person beforehand. There needs to be very robust legislation to prevent the ending of another person's life without their consent.

Part 6.

Q1. It should never be the decision of a Doctor or Nurse who is involved with preserving life. It's very important to me, that people shouldn't feel that when they go into hospital, someone can make

the decision that their life is of no value and they can be euthanised / killed. I would like to see a demand for an Advance Directive & perhaps a small admin office within the Government to which people have to apply.

Q2. As perviously stated, the person's prior request for such action. An independant person assessing that it is the person's free choice. To be supervised / administrated **not** within the health care setting.

Part 7.

This is such a complex area, but a necessary one for the UK to consider. There is a demand for ending one's own life as the palliative care available is patchy and currently not offered to all those who require it. Those suffering from Cancer stand the best chance of good care towards the end of their lives, but even so, not 100% of people are permitted hospice care and those not suffering from the big C, stand little chance. Those who find themselves with a degenerative condition are not offered adequate pain relief / care as the health professionals will not use the higher doses of drugs required for fear of causing the patients death and being sued by relatives! I feel that it is unacceptable in this day & age, that those who find themselves in an ongoing excruciating situation are forced to continue till nature eventually takes over. I don't let my pets suffer like that, but have had to watch my Mother go through it. Will it be my turn soon? or can the law be changed so that I can have a peaceful death like my Father's?

Email Interview 2

Part One: The current law in the UK

Do you think it is right that under current law, assisted suicide is illegal but the Director of Public Prosecutions can choose not to prosecute people if he decides this is not in the public interest?

No, I think this is confusing.

Is there anything that you would change about the current law?

I think assisted suicide should remain illegal.

Part Two: Attitudes towards assisted dying in the UK

Do you think there are any circumstances in which some form of assisted dying should be legal? If so, what are these?

No, I don't think assisted dying should ever be made legal.

Should assisted suicide or voluntary euthanasia be permitted? (See definitions above)

I think neither though I have less concerns about assisted dying than voluntary euthanasia

What has informed your attitudes? [E.g. Particular experiences, beliefs or values]

I am a disabled person, I have a chronic health condition and use a wheelchair outside the house. My quality of life is routinely underestimated by health professionals etc. and I am concerned that I could be for instance faced with a DNR if I was hospitalised.

If you think assisted dying should be illegal, how should the law treat people who assist a loved one to commit suicide for compassionate reasons?

Depending on the circumstances – the coroner should assess the situation as to whether pressure had been put on the loved one to take their life. If not then compassion should be extended to the people concerned and they should not be imprisoned.

Part Three: Who (if anyone) should be eligible for assistance?

If some form of assisted dying were to be legalised, should assistance be limited to certain types of people, such as people experiencing suffering that they find unbearable or who are terminally ill?

I don't think it should be legalised. Instead more money should be put into raising standards of pain management and end of life care.

2.) If assisted suicide was to be legalised, should the option of voluntary euthanasia be made available to people who are physically unable to take the action required to end their own life?

No.

3.) If some form of assisted dying were to be legalised, what should be the minimum age that someone must be in order to take such a serious decision?

N/a

Part Four: Who (if anyone) should be able to provide assistance?

1.) If some form of assisted dying was to be legally permitted, who should provide the assistance? [E.g. Friends, family members, doctors, nurses, volunteers?]

Only someone previously nominated by the person e.g. someone with power of attorney

Part Five: Potential risks posed by assisted dying

Do you foresee any risks that would be posed to society or to individuals by legalising some form of assisted dying?

Yes I think there are major risks to vulnerable people that their quality of life will be underestimated and that they will feel pressured by relatives and health professionals to agree to assisted dying.

Do you think that certain types of people would be particularly at risk? (E.g. older people, disabled people, terminally ill people or others?)

Yes disabled people. The general public and health professionals do not understand disability (and the government and the press have recently stoked up anger against disabled people by calling us benefit scroungers leading to an increase in disability hate crimes) Something which might seem unbearable to a healthy person is just a insignificant part of life for someone with a disability. My

wheelchair is my passport to an independent life but is seen by many people as a negative thing. (My mother in law said she would rather die than use a wheelchair)

3.) Do you think that assisted suicide and voluntary euthanasia pose different risks to individuals or to society?

No

Part Six: If the law were changed, what safeguards should be in place?

Who should make the decision about whether a person is allowed to have an assisted death? [E.g. doctors or a legal body like a tribunal]

A legal body like a tribunal with an advocate appointed to represent the interests of the person involved.

2.) What legal safeguards do you think would need to be included to prevent abuses of the law? [E.g. checks that must be made or a process that must be followed]

Email interview 3:

Part One: The current law in the UK

Do you think it is right that under current law, assisted suicide is illegal but the Director of Public Prosecutions can choose not to prosecute people if he decides this is not in the public interest?

It is better than if he could not choose to do so, but the law needs clarification

Is there anything that you would change about the current law?

I would have it changed so that both assisted suicide and voluntary euthanasia were legal.

Part Two: Attitudes towards assisted dying in the UK

1.) Do you think there are any circumstances in which some form of assisted dying should be legal? If so, what are these?

Yes. In the last resort an adult of full mental capacity should be able to make a decision to end his life. I think there should be a waiting period for someone in good health so that sudden, unconsidered decisions are not made, and I think there should be safeguards especially for young people. However, someone in great pain, without prospect of recovery, or facing a terminal illness should be able to make such a decision with minimum fuss. I think it should be possible to help those who do not have full capacity also.

2.) Should assisted suicide or voluntary euthanasia be permitted?
(See definitions above)

Yes, both.

3.) What has informed your attitudes? [E.g. Particular experiences, beliefs or values]

I am on the fringes of old age. I saw my mother in law die slowly, and have (and am seeing) friends miserable at the long, drawn out deaths of parents, who themselves are miserable. What on earth is the point? And when I worked I saw elderly clients, many of whom coped very well but some of whom had simply had enough and wanted their lives to end. Loneliness can be terrible. As for people living in great pain, mental or physical, with no hope of relief- why? We do not allow pet animals to suffer.

4.) If you think assisted dying should be illegal, how should the law treat people who assist a loved one to commit suicide for compassionate reasons?

Not applicable, as I do not think it should be illegal.

Part Three: Who (if anyone) should be eligible for assistance?

Any consenting adult of full legal capacity, with provisions as to waiting time as above, and some allowance for youthful impetuosity. Persons unable to give consent whose relatives or legal guardians feel that death would be in their best interests.

1.) If some form of assisted dying were to be legalised, should assistance be limited to certain types of people, such as people experiencing suffering that they find unbearable or who are terminally ill?

As above, I think assistance should be available pretty freely, but with waiting periods imposed except in cases of great suffering without prospect of relief.

2.) If assisted suicide was to be legalised, should the option of voluntary euthanasia be made available to people who are physically unable to take the action required to end their own life?

Yes.

3.) If some form of assisted dying were to be legalised, what should be the minimum age that someone must be in order to take such a serious decision?

18 years – adulthood. After all, you can go and join the army and be killed then. But I do think there have to be waiting times, and probably counselling for young people – up to perhaps 30 years of age. You can be very selfish when young and forget other people. And also, you do not have the same perspective or experience as older people.

Part Four: Who (if anyone) should be able to provide assistance?

If some form of assisted dying was to be legally permitted, who should provide the assistance? [E.g. Friends, family members, doctors, nurses, volunteers?]

I am not sure doctors will want this role. There needs to be an independent advocate of some sort involved, but other than that, anyone competent could assist,

Part Five: Potential risks posed by assisted dying

1.) Do you foresee any risks that would be posed to society or to individuals by legalising some form of assisted dying?

Most certainly.

2.) Do you think that certain types of people would be particularly at risk? (E.g. older people, disabled people, terminally ill people or others?)

Yes.

3.) Do you think that assisted suicide and voluntary euthanasia pose different risks to individuals or to society?

I am not quite sure what this means, but suppose the answer is yes.

Part Six: If the law were changed, what safeguards should be in place?

1.) Who should make the decision about whether a person is allowed to have an assisted death? [E.g. doctors or a legal body like a tribunal]

Yes. I think some legal involvement is necessary; perhaps also a doctor or at least a doctor's report, in some cases. But why should an adult of full capacity, after a period of time to reflect, not make his own choice?

2.) What legal safeguards do you think would need to be included to prevent abuses of the law? [E.g. checks that must be made or a process that must be followed]

This is going to need a lot of thought. Some sort of legal advocate or attorney will be necessary, someone independent of family and friends, especially if they are likely to benefit under a will or intestacy or some other provision. They need to be protected as well as the individual wishing to end life.

The Court of Protection and official Solicitor have a role in protecting the interests of certain people, although the processes are often cumbersome and unduly slow. Perhaps looking at this role would be a starting point.

Part Seven: Additional thoughts

Please write below any additional views or experiences that you would like the Commission to consider.

I am aware that there are numerous difficulties around this issue, and that many doctors do not want to be involved. But we are allowed to end the suffering of pets – why not of human beings? We can keep people “alive” now with very little or no quality of life, and this in an overcrowded world. Why should we maintain comatose or suffering geriatric (or younger) people at all costs to them and their families, when children are starving and the world’s resources are limited?

I am not young, and can assure you that from time to time I discuss, briefly, for it is a really horrible prospect, what might happen in the future. Of course I can’t quite believe in my own mortality, or that I will ever lose my mind and end up in a home, incontinent, demented, frightened and crying for help which even ample provision can not provide. (Yes, it happens, yes, I have seen and heard it!) I certainly do not want that for myself or for my family. Please, really start looking at the possibilities, so that people like me can know that we will not be reduced to such helpless suffering.

Email interview 4:

Setting the scene:

Part One: The current law in the UK

Do you think it is right that under current law, assisted suicide is illegal but the Director of Public Prosecutions can choose not to prosecute people if he decides this is not in the public interest?

No. I believe that something so important should be a legal right, and not depend on the discretion of a certain individual. Even though the guidelines for prosecution have been published, there is no certainty for individuals that these will not change, or be interpreted differently by future DPPs.

Is there anything that you would change about the current law?

I support changing the law to allow assisted dying, with appropriate safeguards.

Part Two: Attitudes towards assisted dying in the UK

Do you think there are any circumstances in which some form of assisted dying should be legal? If so, what are these?

People who are terminally ill, of sound mind, and who have requested it.

There are also some people whose medical condition is not, in itself, terminal but is so catastrophic and without any hope of improvement that they would prefer not to live but lack the physical capability to kill themselves (e.g. total paralysis, locked-in syndrome).

Should assisted suicide or voluntary euthanasia be permitted? (See definitions above)

Assisted suicide should be permitted. Voluntary euthanasia should also be permitted.

What has informed your attitudes? [E.g. Particular experiences, beliefs or values]

I was diagnosed with a terminal illness 18 months ago, although I would have supported assisted dying nevertheless.

If you think assisted dying should be illegal, how should the law treat people who assist a loved one to commit suicide for compassionate reasons?

Part Three: Who (if anyone) should be eligible for assistance?

If some form of assisted dying were to be legalised, should assistance be limited to certain types of people, such as people

experiencing suffering that they find unbearable or who are terminally ill?

Yes. It should not be routinely available to anyone, but only be available to terminally ill people who have requested it, or seriously ill people with no hope of recovery.

If assisted suicide was to be legalised, should the option of voluntary euthanasia be made available to people who are physically unable to take the action required to end their own life?

Yes.

If some form of assisted dying were to be legalised, what should be the minimum age that someone must be in order to take such a serious decision?

18 or 21.

Who (if anyone) should be able to provide assistance?

If some form of assisted dying was to be legally permitted, who should provide the assistance? [E.g. Friends, family members, doctors, nurses, volunteers?]

That should be a decision for the dying person to take but, for practical reasons, some medical intervention would be likely.

Part Five: Potential risks posed by assisted dying

Do you foresee any risks that would be posed to society or to individuals by legalising some form of assisted dying?

An individual might choose, on diagnosis, that they would prefer to die rather than let the disease take its course – so a “cooling-off period” might be one option to ensure decisions are not taken prematurely.

By making the option of assisted dying available, inevitably more people would consider it and take it up. The NHS and charities

should take care that assisted suicide does not come to seem the inevitable outcome after a particular diagnosis (e.g. that all people with MND must eventually accept assisted dying).

Some vulnerable people might be at risk of being pressured into asking for assisted dying, and so some form of panel to vet and agree to each request might be necessary.

Do you think that certain types of people would be particularly at risk? (E.g. older people, disabled people, terminally ill people or others?)

But these are the groups who would request such help. More useful to talk about people within these groups, such as people who live alone, people who cannot access support services, people with mental health issues. These people might be at risk of making an uninformed decision, and on whom health and social care should focus.

Do you think that assisted suicide and voluntary euthanasia pose different risks to individuals or to society?

Voluntary euthanasia is more problematic for society, as society takes the life of the ill person. But if assisted dying were made lawful then the decision about what constitutes an acceptable quality of life would be transferred to each individual, and society's role would be to enable the individual to put that decision into effect. At the moment, society decides for us, regardless of our wishes or circumstances.

Part Six: If the law were changed, what safeguards should be in place?

Who should make the decision about whether a person is allowed to have an assisted death? [E.g. doctors or a legal body like a tribunal]

It should not be doctors alone, but a panel or tribunal, with rights of appeal. The panel should consist of a medical professional, a legal

professional and a lay person and their decisions and reasonings should be open and publicly available.

What legal safeguards do you think would need to be included to prevent abuses of the law? [E.g. checks that must be made or a process that must be followed]

A legal process which allows for medical evidence to be obtained and confirmed by other doctors, interviews with the dying person, opportunities to change one's mind. It ought to cost nothing.

Part Seven: Additional thoughts

Please write below any additional views or experiences that you would like the Commission to consider.

I am 34 and was diagnosed with MND, out of the blue, last year. There is no treatment or cure for MND – and thus no hope – and as well as a life expectancy of 2-5 years I am also facing a period of severe and increasing disability. I can expect paralysis, loss of speech, loss of ability to swallow (and the need for a feeding tube) and loss of ability to breathe (and the need for a ventilator) before my early death. Prior to this I was a very fit and active young man with a good job and everything to live for. I am terrified of what lies ahead and am adamant in my conviction that I do not want to see this disease through to the end.

Because assisted suicide is illegal, there is a perverse incentive for me to kill myself earlier than necessary whilst, e.g., I still have some strength in my hands. That will also be a painful and traumatic death. But if I had the comfort of knowing that I could choose assisted dying at a later point, before things became unbearable, that would save me from potentially a premature suicide and allow me to concentrate on enjoying the time I have.

Email interview 5:

1.) Do you think it is right that under current law, assisted suicide is illegal but the Director of Public Prosecutions can choose not to prosecute people if he decides this is not in the public interest?

It's not right but it would be very callous to prosecute some people.

2.) Is there anything that you would change about the current law?

No.

Part Two: Attitudes towards assisted dying in the UK

1.) Do you think there are any circumstances in which some form of assisted dying should be legal? If so, what are these?

No, but I think that voluntary euthanasia should be legal, at end of life, to relieve suffering.

2.) Is there anything tht you would change about the current law?

No.

Part Two: Attitudes towards assisted dying in the UK

1.) Do you think there are any circumstances in which some form of assisted dying should be legal? If so, what are these?

No.

2.) Should assisted suicide or voluntary euthanasia be permitted?
(See definitions above)

As mentioned, I think that voluntary euthanasia should be permitted, but only at end of life. This would stop people suffering unnecessarily.

3.) What has informed your attitudes? [E.g. Particular experiences, beliefs or values]

I was diagnosed with motor neurone disease in 2000. I was pregnant with my 2nd child and it was a total shock. After my son was born, I quickly lost the use of my limbs, and felt very depressed.

My husband became physically and verbally abusive and my life was a living hell. I thought about committing suicide every day but I was too scared to do it. I think that there were times during those early years, when I would have chosen assisted suicide, if it were legal. I was clinically depressed and didn't care about anything anymore.

But, with the help of my hospice doctor, I managed to overcome my depression. He treated me with antidepressants and used to communicate by email if I needed to talk. I also had several alternative therapies at the hospice and used their gym. The therapist at my GP surgery told me that she couldn't help me and could only offer me a shoulder to cry on. My GP told me that I probably wouldn't live to see my children grow up.

So, getting proper care from my hospice really improved my mood and quality of life. I managed to make my husband leave me and our children, which also made my situation much better. I divorced him, was given full custody of our children and 24 hour care. I still attend my hospice twice a week and they help me with everything I need.

In conclusion, although I'm now severely disabled, I have a good, enjoyable, full life. I've achieved more during my time with MND than before. From wanting to die, because my outlook did appear hopeless, not just to me but to health professionals also, I'm so grateful to be alive. If I had chosen to die I would have missed the best years of my life. My children would have grown up without a mother. I know, from experience, that life with a terminal illness can be managed with the right care and support.

4.) If you think assisted dying should be illegal, how should the law treat people who assist a loved one to commit suicide for compassionate reasons?

I honestly don't know. My ex-husband wanted me to die, because our mortgage would have been paid off and I have life insurance. If he would have helped me to die, in the midst of my depression, would that have been acceptable?

Part Three: Who (if anyone) should be eligible for assistance?

1.) If some form of assisted dying were to be legalised, should assistance be limited to certain types of people, such as people experiencing suffering that they find unbearable or who are terminally ill?

Yes. But there is a difference between physical and mental suffering. I know, from experience, that mental suffering can pass. If a person has to live with intolerable pain, that can't be resolved medically, I think that they have a case.

2.) If assisted suicide was to be legalised, should the option of voluntary euthanasia be made available to people who are physically unable to take the action required to end their own life?

Yes

3.) If some form of assisted dying were to be legalised, what should be the minimum age that someone must be in order to take such a serious decision?

Maybe 21?

Part Four: Who (if anyone) should be able to provide assistance?

1.) If some form of assisted dying was to be legally permitted, who should provide the assistance? [E.g. Friends, family members, doctors, nurses, volunteers?]

Doctors only.

Part Five: Potential risks posed by assisted dying

1.) Do you foresee any risks that would be posed to society or to individuals by legalising some form of assisted dying?

Yes , definitely.

2.) Do you think that certain types of people would be particularly at risk? (E.g. older people, disabled people, terminally ill people or others?)

I think that all of the above will be at risk. In 50 years time, it maybe considered normal for people diagnosed with a terminal illness, to choose, or be encouraged to die. The elderly or people who are mentally ill could be in danger if they can't express their wishes.

3.) Do you think that assisted suicide and voluntary euthanasia pose different risks to individuals or to society?

I think that they do pose a risk to society, in that taking lives will eventually become normal. Do we really have the right to decide who should live and die? I fear that our society could become callous.

Part Six: If the law were changed, what safeguards should be in place?

I don't know.

1.) Who should make the decision about whether a person is allowed to have an assisted death? [E.g. doctors or a legal body like a tribunal]

A legal body.

2.) What legal safeguards do you think would need to be included to prevent abuses of the law? [E.g. checks that must be made or a process that must be followed]

I think that there will have to be a very precise, well thought out procedure, that will have to followed thoroughly.

Part Seven: Additional thoughts

Please write below any additional views or experiences that you would like the Commission to consider.

I understand that many people believe that they will benefit from being able to choose when to die. But my personal experience shows that no individual, doctor or family member can know when the right time to die is. I do think that voluntary euthanasia is acceptable if a person is actually dying anyway. It would be kinder to speed up the process for the individual and their family.

Email Interview 6:

Part One: The current law in the UK

1.) Do you think it is right that under current law, assisted suicide is illegal but the Director of Public Prosecutions can choose not to prosecute people if he decides this is not in the public interest?

Answer: Yes

2.) Is there anything that you would change about the current law?

Answer: No

Part Two: Attitudes towards assisted dying in the UK

1.) Do you think there are any circumstances in which some form of assisted dying should be legal? If so, what are these?

Answer: No

2.) Should assisted suicide or voluntary euthanasia be permitted? (See definitions above)

Answer: No

3.) What has informed your attitudes? [E.g. Particular experiences, beliefs or values]

Answer As disabled person I would be concerned if the law on assisted suicide were to change because I feel it would lead to pressure being placed on disabled people to end their lives.

4.) If you think assisted dying should be illegal, how should the law treat people who assist a loved one to commit suicide for compassionate reasons?

Part Three: Who (if anyone) should be eligible for assistance?

1.) If some form of assisted dying were to be legalised, should assistance be limited to certain types of people, such as people experiencing suffering that they find unbearable or who are terminally ill?

2.) If assisted suicide was to be legalised, should the option of voluntary euthanasia be made available to people who are physically unable to take the action required to end their own life?

3.) If some form of assisted dying were to be legalised, what should be the minimum age that someone must be in order to take such a serious decision?

Part Four: Who (if anyone) should be able to provide assistance?

1.) If some form of assisted dying was to be legally permitted, who should provide the assistance? [E.g. Friends, family members, doctors, nurses, volunteers?]

Part Five: Potential risks posed by assisted dying

1.) Do you foresee any risks that would be posed to society or to individuals by legalising some form of assisted dying?

Answer: Yes it would be 'detrimental to the way that disabled people are viewed by society.

2.) Do you think that certain types of people would be particularly at risk? (E.g. older people, disabled people, terminally ill people or others?)

Answer: Yes- disabled people would be particularly at risk

3.) Do you think that assisted suicide and voluntary euthanasia pose different risks to individuals or to society?

Answer: Yes- Disabled people are already worried about people assuming their life isn't worth living or seeing them as a burden, and are genuinely concerned that a change in the law could increase pressure on them to end their life

Part Six: If the law were changed, what safeguards should be in place?

1.) Who should make the decision about whether a person is allowed to have an assisted death? [E.g. doctors or a legal body like a tribunal]

2.) What legal safeguards do you think would need to be included to prevent abuses of the law? [E.g. checks that must be made or a process that must be followed]

Part Seven: Additional thoughts

Please write below any additional views or experiences that you would like the Commission to consider.

Email Interview 7:

Part One: The current law in the UK

1.) Do you think it is right that under current law, assisted suicide is illegal but the Director of Public Prosecutions can choose not to prosecute people if he decides this is not in the public interest?

No, I do not think that it is right.

2.) Is there anything that you would change about the current law?

I think assisted suicide should remain illegal except under specified circumstances.

Part Two: Attitudes towards assisted dying in the UK

1.) Do you think there are any circumstances in which some form of assisted dying should be legal? If so, what are these?

Yes. Circumstances in which the individual has made a 'rational decision' i.e. has clearly thought through the decision taken.

2.) Should assisted suicide or voluntary euthanasia be permitted?
(See definitions above)

Yes.

3.) What has informed your attitudes? [E.g. Particular experiences, beliefs or values]

I myself have a complex multi system neurological disorder of which the prognosis is unknown. This has led to periods of serious ill health and I have therefore given the subject some thought. I have additionally experienced

close family members and friends suffer a variety of illnesses and have shared many conversations with people directly affected by these issues.

4.) If you think assisted dying should be illegal, how should the law treat people who assist a loved one to commit suicide for compassionate reasons?

If assisted dying were made illegal it should be legal under some circumstances. Therefore in these particular circumstances a loved one taking such actions would not be prosecuted.

Part Three: Who (if anyone) should be eligible for assistance?

1.) If some form of assisted dying were to be legalised, should assistance be limited to certain types of people, such as people experiencing suffering that they find unbearable or who are terminally ill?

Yes.

2.) If assisted suicide was to be legalised, should the option of voluntary euthanasia be made available to people who are physically unable to take the action required to end their own life?

Yes.

3.) If some form of assisted dying were to be legalised, what should be the minimum age that someone must be in order to take such a serious decision?

16.

Part Four: Who (if anyone) should be able to provide assistance?

1.) If some form of assisted dying was to be legally permitted, who should provide the assistance? [E.g. Friends, family members, doctors, nurses, volunteers?]

It should be a professional, i.e. Doctor, supervised i.e. regulated to do so.

Part Five: Potential risks posed by assisted dying

1.) Do you foresee any risks that would be posed to society or to individuals by legalising some form of assisted dying?

Yes.

2.) Do you think that certain types of people would be particularly at risk? (E.g. older people, disabled people, terminally ill people or others?)

Yes.

3.) Do you think that assisted suicide and voluntary euthanasia pose different risks to individuals or to society?

they pose slightly different risks.

Part Six: If the law were changed, what safeguards should be in place?

1.) Who should make the decision about whether a person is allowed to have an assisted death? [E.g. doctors or a legal body like a tribunal]

There should be a tribunal informed by professionals.

2.) What legal safeguards do you think would need to be included to prevent abuses of the law? [E.g. checks that must be made or a process that must be followed]

That the patient is of sound mind, capable of rational thought, neither abused nor oppressed. That assisted dying is not instilled into society as an option over addressing issues of difficulty that exist within society.

Part Seven: Additional thoughts

Please write below any additional views or experiences that you would like the Commission to consider.

Whether assisted dying is legalised or not, careful regulations must be put in place for all parties concerned. The nature of this discussion is such that no one solution will meet the needs of all individual circumstances,

therefore, regulations must exist that allow for necessary specified flexibility.

Email Interview 8:

“I live with three chronic conditions, none of which are life threatening, but I should imagine life shortening, if only due to lack of exercise and poor life balance.”

Part One: The current law in the UK

1.) Do you think it is right that under current law, assisted suicide is illegal but the Director of Public Prosecutions can choose not to prosecute people if he decides this is not in the public interest? No

2.) Is there anything that you would change about the current law?
I would make both legal

Part Two: Attitudes towards assisted dying in the UK

1.) Do you think there are any circumstances in which some form of assisted dying should be legal? If so, what are these? When life becomes physically and by default mentally unbearable.

2.) Should assisted suicide or voluntary euthanasia be permitted?
(See definitions above) Yes - both

3.) What has informed your attitudes? [E.g. Particular experiences, beliefs or values] Own experience at death of family member in distress/pain/confusion for days before death.

4.) If you think assisted dying should be illegal, how should the law treat people who assist a loved one to commit suicide for compassionate reasons? Given a medal for bravery!

Part Three: Who (if anyone) should be eligible for assistance?

1.) If some form of assisted dying were to be legalised, should assistance be limited to certain types of people, such as people experiencing suffering that they find unbearable or who are terminally ill? yes both

2.) If assisted suicide was to be legalised, should the option of voluntary euthanasia be made available to people who are physically unable to take the action required to end their own life?
Yes

3.) If some form of assisted dying were to be legalised, what should be the minimum age that someone must be in order to take such a serious decision? don't know

Part Four: Who (if anyone) should be able to provide assistance?

1.) If some form of assisted dying was to be legally permitted, who should provide the assistance? [E.g. Friends, family members, doctors, nurses, volunteers?] One family/friend, one doctor

Part Five: Potential risks posed by assisted dying

1.) Do you foresee any risks that would be posed to society or to individuals by legalising some form of assisted dying? No

2.) Do you think that certain types of people would be particularly at risk? (E.g. older people, disabled people, terminally ill people or others?) No - at risk of what exactly, if you are going to die least die peacefully.

3.) Do you think that assisted suicide and voluntary euthanasia pose different risks to individuals or to society? No

Part Six: If the law were changed, what safeguards should be in place?

1.) Who should make the decision about whether a person is allowed to have an assisted death? [E.g. doctors or a legal body like a tribunal] In some cases it would have to be made quickly if someone took a turn for the worse and wanted to end their life as they knew the outcome. I would say Family/Friend/Doctor. No lengthy tribunals.

2.) What legal safeguards do you think would need to be included to prevent abuses of the law? [E.g. checks that must be made or a process that must be followed] I would follow countries who have already made protocols

Part Seven: Additional thoughts

Please write below any additional views or experiences that you would like the Commission to consider.