

**An Analysis and Evaluation of the
Compassion in Dying
End-of-Life Rights Information Line**

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Executive Summary

*This is a study of the *Compassion in Dying* End-of-Life Rights Information Line ‘in action’: what kind of people call about what issues; what happens in calls; and how effective the Information Line is.

*It is based on an analysis of 227 calls to the Information Line. Four call-takers recorded a sample of their calls, with informed consent, between June and November 2012.

*The study found that most callers are female, over 60, and that they tend to be from London and the South-East. Most calls are to request (one or more) Advance Decision Information Packs, but the majority also involve further questions and explanations about end-of-life issues.

*Detailed content analysis of the calls reveals that callers’ main reasons for wanting to write an Advance Decision are: family experiences, media coverage, health concerns, and age. In writing an Advance Decision, they hope to achieve: being prepared for the future, continuing quality of life, dignity, and protection of their loved ones.

*The main barriers they identify to writing an Advance Decision are: not understanding legal issues, problems with professionals, concerns about effectiveness, and translating their wishes into a formal document.

*The study concludes that the *Compassion in Dying* Information Line is very effective - in terms of the number of people reached, the scope of the service, and the praise and appreciation offered by callers. It also identifies a number of areas in which changes could be made to further enhance the service provided.

(1) Background to the study:

Compassion in Dying is a (UK) national charity which supports people in planning what they consider to be a ‘good’ death by enabling them to understand and exercise their legal rights at the end of life (Satherley, 2013). In particular, it provides a free template and guidance notes for completing a legally-binding Advance Decision to Refuse Treatment (an ‘Advance Decision information pack’). The law governing Advance Decisions is the Mental Capacity Act (2005), which came into force in England and Wales in 2007. Provision in Scotland and Northern Ireland is slightly different.

The *Compassion in Dying* End-of-Life Rights Information Line, launched in May 2011, is a unique helpline providing people with information about their rights at the end of life, and support to ensure that their wishes for treatment can be respected (*Compassion in Dying*, 2012; Satherley 2013). In 2012, I was invited – as an expert in helpline interaction – to study what happens in calls, and to help *Compassion in Dying* evaluate the second year of operation of the helpline.

(2) Overview of the study:

The study involves an analysis of recorded calls to the *Compassion in Dying* End-of-Life Rights Information Line. It has been fully approved by the Loughborough University Ethical Advisory Committee. The four members of *Compassion in Dying* staff who were taking calls to the Information Line during 2012 - a ‘dedicated’ call-taker and three more occasional call-takers - each recorded a sample of their calls for me to analyse. Between them, they recorded a total of 227 calls, with informed consent from callers, between June and November 2012. This sample is opportunistic, rather than representative of all calls received during the six-month period, as call-takers did not record (or severely limited their recording) at times when they were particularly busy (see (3) below). All calls were fully transcribed and anonymised prior to analysis. The analysis examines both the content of the calls and the effectiveness of the service provided.

(3) Context of the sample:

According to figures provided by *Compassion in Dying*, the total number of calls received by the helpline during the study period of June-November 2012 was 1774: i.e. an average of 295 calls per month. This is more than double the number of calls received in this period in the first year of operation of the helpline (*Compassion in Dying*, 2012). This average, however, conceals significant month-by-month variation. During the ‘holiday’ months of June, July and December, the average was around 100 calls per month; and – most particularly - there was a huge ‘spike’ (to more than 700 calls) in September, following the publication of an article in *Saga* magazine about Advance Decisions, which included contact details for *Compassion in Dying*.

Excluding the ‘spike’, then, the study sample constitutes about 20% of the calls received in the six-month period during which calls were recorded. Callers refer to the Saga magazine article in approximately 40% of the calls in the study sample.

According to a YouGov survey carried out for *Compassion in Dying* in 2011, only about 3% of the UK population has an Advance Decision. This makes callers to the *Compassion in Dying* Information Line a rather unusual group of people, with an atypical interest in understanding and exercising their end-of-life rights. In calling a national helpline to seek information and/or support for putting an Advance Decision (or some related form of provision) in place, they show a much greater degree of awareness of, and engagement with, end-of-life issues than the population at large.

(4) Overview of the calls:

4.1 Demographic characteristics of the callers:

- *4.1.1 Sex:*

The majority of callers (84%) were female; 16% were male.

- *4.1.2 Age:*

Most of the callers were older people: of those who gave their age, 16% were over 80, 73% between 60 and 80, and only 11% under 60.

- *4.1.3 Geographical location:*

It was possible to ascertain where callers were located from the address they gave for receiving an information pack, or follow-up monitoring questionnaire. The majority of the callers (86%) lived in England, with 8% in Scotland, 4% in Wales, and 2% in Northern Ireland. Of the callers from England, nearly half (48%) were living in London or the South-East, with 23% from the South-West, 12% from the Midlands, and 17% from the North of the country.

4.2 Characteristics of the calls:

- *4.2.1 Length:*

Calls generally lasted between 2 and 5 minutes (the shortest was just under a minute; the longest 23 minutes). Only 9 calls were longer than 10 minutes.

- *4.2.2 First or subsequent call?:*

Most of the calls (82%) were first calls to the helpline; 18% were follow-up calls of some kind.

- 4.2.3 *Who for?:*

Most calls (66%) were made on behalf of the caller herself or himself; however around a quarter of calls were made both on behalf of the caller and on behalf of someone else; and 8% were made entirely on behalf of someone else. The ‘someone else’ was most commonly a spouse or partner, but included parents, children, other relatives (e.g. an aunt, a sister, a mother-in-law, a brother-in-law), friends, a friend’s spouse, a colleague, and a patient (this last was a call from a healthcare professional – there were only three of these in the sample).

- 4.2.4 *Content – info pack requests:*

The majority of calls (77%) included a request for an Advance Decision information pack. [This is an almost identical proportion to that seen in the first year of operation of the Information Line (*Compassion in Dying*, 2012)]. Notably, however, around a quarter of the ‘pack request’ calls involved a request for multiple packs (generally 2-5 packs, although one healthcare professional asked to be sent 20 packs on a monthly basis). However, two-thirds of the ‘pack request’ calls also involved the call-taker providing an explanation of Advance Decisions and/or further additional information – only a minority of calls (around 11%) were information pack requests-and-grantings pure and simple.

- 4.2.5 *Content – other:*

The remaining 23% of calls were quite diverse: for example, some focused on the specifics of completing an Advance Decision, or on the relationship between an Advance Decision and a Lasting Power of Attorney; others related to broader end-of-life issues - such as assisted suicide, supporting a dying parent, or relationships with care home staff.

(5) Detailed content analysis of the calls

The following analysis of the content of the calls is divided into three main sections: Callers' reasons for wanting to write an Advance Decision [5.1 below]; What callers hope to achieve by writing an Advance Decision [5.2]; Barriers to writing an Advance Decision [5.3].

5.1 Callers' reasons for wanting to write an Advance Decision:

The helpline callers were not specifically asked why they want to write an Advance Decision: however, more than half spontaneously offered reasons, usually towards the end of the call (Wilkinson, 2013d). Their reasons fell into four main categories: family experiences of a 'bad' death (23%) [5.1.1 below]; media coverage of 'bad' deaths (16%) [5.1.2]; concerns about their own current - or possible future - health (27%) [5.1.3]; and simply being old and having 'had enough' (16%) [5.1.4]. The remaining 18% of reasons fell outside these categories.

- *5.1.1 Family experiences:*

Callers frequently reported direct experience of the 'bad death' of a family member (or occasionally a friend) as a reason for wanting to write an Advance Decision. Typically, such 'bad' deaths involved protracted illness or incapacity:

I've got a family situation with a cousin, first cousin, who had an almighty stroke when she was- well she just still had small children, she was in her early 40s I think, and she was kept alive and she died the other day, having been 15 years a cabbage.

I just happened to see my 90-year-old sister being kept alive long after she could have uh had help, I think, because she's got Alzheimer's as well ...

As a child I can remember my grandmother had a severe stroke and I could not understand why she spoke a lot of gobbledygook. She kept smacking herself around her face, and that hurt me more than anything to see my beloved grandma, you know, hitting herself.

Some callers were explicit about their desire to avoid such a situation for themselves:

My brother-in-law's had a stroke. He's a lot younger than me. He's in a wheelchair and he can't talk to people, and oh god no, I don't want that. ... I'm a lively outgoing person, you know, can talk for England, and I just think 'Oh god, to be confined to a wheelchair not being able to talk' ... to me that's a living hell.

I've got an aunt who's completely demented. She doesn't know who she is or where she is, and I just don't want to do all that. I can't see any point in doing it quite honestly, you know. Personally I would like to be able to go to the chemist and buy a goodbye kit, you know, when I want to go.

If I had such a massive heart attack or a massive stroke, I just wouldn't want to be resuscitated having seen my brother [who had advanced MS for 30 years] live the life he lived. He had to have every mortal thing done for him and I just wouldn't want that for myself at all.

Some had direct experience of relatives being resuscitated, and of living with the consequences:

My husband was resuscitated after having a bad stroke, and honestly, you know, I'd never want to see anyone go through that again, and I don't want to go through it myself.

My grandmother was resuscitated and when she revived she didn't know anybody. And I don't want- I can't see any point in doing that, you know. ... I think there's a thing in medicine, isn't there, treating too much, you know.

The reason I want to do it is my daughter-in-law's father is- when he was 80 he had a stroke and they revived him and he's now in bed in a nursing home. He doesn't know what time of day it is and it's just, you know, it's awful for the family.

And one caller, whose husband had not been resuscitated, was absolutely clear that his death was the 'right' outcome:

My husband died 18 years ago with leukaemia, and he'd been in hospital 14 months with leukaemia, every treatment under the sun. But one day he wasn't very well and the hospital said would you like to come and see him, he isn't very well. And we went and stayed with him a little while and he was sitting up and talking and suddenly he closed his eyes and he was dead. The nurse came running out and she brought a doctor in, and this doctor said 'Oh we're going to try and resuscitate him'. ... I just stood there, I didn't know what to say. And luckily my daughter-in-law is a proper nurse, a good nurse, and she said immediately 'No, no, no.' I mean the man was dying for 14 months and he was dead, he was totally dead, and they wanted to resuscitate him. What for? You know, it was ridiculous.

- 5.1.2 *Media coverage:*

Another reason offered by callers for wanting to write an Advance Decision was media coverage of 'bad' deaths - particularly that of the 'locked-in' syndrome sufferer, Tony Nicklinson. The recording period for the study coincided with media coverage of Nicklinson losing his right-to-die case in the High Court (Nicklinson v Ministry of Justice & Ors [2012]), and his subsequent death after reportedly refusing food and treatment for pneumonia.

I think that chap's had a lot to do with it, the one that's just died, hasn't he, you know. I mean it's something one thinks about, but you have to do a bit more than thinking.

I mean obviously this recent thing in the headlines, you know, it's so traumatic.

If I had a severe stroke like that poor chap Nicolson [Nicklinson], I'd rather not be resuscitated.

I felt so sorry for that poor man with locked-in syndrome ...

I'm just very interested to have some information about that [an Advance Decision], especially in the light of the recent case of that gentleman who did eventually pass away.

We've sort of, you know, seen it in the press, the distressing stories that people have ...

In 2011, there was an increase in calls to the Information Line when the case of the minimally-conscious woman known as 'M' (W v M & Ors [2011]) was widely-reported in the media (*Compassion in Dying*, 2012).

• 5.1.3 *Current or future health concerns:*

Callers often raised concerns about their own health, in the present and/or in the future, as a reason for wanting to write an Advance Decision. Most often it was their medical history – particularly of strokes (or 'mini' strokes) - that had led them to this point:

I have been carted away with a stroke before now, but have recovered ... it gets very worrying.

I'm anxious that should I have a stroke, or anything like that, I don't want to be revived. ... I've had one small stroke, a mini stroke.

... it [Advance Decision information pack] does mention something like a very severe stroke. That's my biggest risk. I've got high blood pressure and I've had a couple of mini ones. The two mini strokes I had affected my speech so I knew what I wanted to say but it came out a load of rubbish. And just experiencing that in a slight degree ... that only lasted for a few minutes, so that if I was locked into that sort of situation ... That's the main thing that I'm, you know, concerned about.

I have a number of quite serious or potentially serious medical problems.

I live on my own and I'm suffering from arthritis. And life is not easy.

Some callers, however, were prompted to want an Advance Decision by a recent discrete health event, such as receiving a diagnosis or prognosis, or by an upcoming event, such as an imminent hospital admission for an operation:

I've recently been diagnosed with dementia and I want to make sure ... I'm very, you know, very firm about, uhm, I don't want to linger.

I have advanced bone cancer and I have been given a prognosis of 18 months. I'm 75, my time is limited ...

Call-taker: Well you should get this [Advance Decision information pack] within about a week or a week and a half unless you wanted it sooner than that.

Caller: I'd like it sooner, I'll have had the operation then.

- 5.1.4 Age & 'had enough':

A number of callers who described themselves as 'perfectly healthy' cited advancing age as a reason for wanting to write an Advance Decision (this, of course, reflects the relatively 'old' age of the sample):

I am 90 years of age and extremely well really but I just- I would not want to be brought back to life if I'd had a bad stroke or something and be left like a cabbage.

I'm 82 years old, it seems a very sensible thing to me. I'm- I'm, touch wood, fit and able. But I do a lot of visiting people who are not, so uh yeah, it seems a sensible thing, yeah.

We're getting on a bit, we're sort of late seventies, so we think it's perhaps time we tidied up a few loose ends.

You know, 73, got to sort things out, that's it.

Some callers explicitly said that, with advancing age, they simply felt that they had 'had enough' of life. Sometimes this was related to deteriorating health, and/or the prospect of (yet another) medical intervention:

I had surgery and the surgery failed. So now I've got to have more surgery. I'm getting a bit fed up. I'm not suggesting that the surgery is likely to finish me off, but I certainly don't want to go on living for another ten years at this rate. I think I've had enough. ... It's probably not this one but further surgery, which is pretty certain. If I did have a heart attack I think I would be happy to- quite happy to just let it happen and not be resuscitated. I mean I've seen my grandchildren grow up and so on, so you know, it's not like I'm waiting for something to happen.

I've had enough. I don't want an operation. ... I don't want to go [into hospital].

If the time comes when my health has gone to that point, I mean I really don't want to stick around, you know. I mean there really wouldn't be any point. It's not that I'm feeling miserable about it, it's just that, you know, when you get to a certain age and a certain condition and you've got no grandchildren or anything, you know ... if it could be- just say that I don't want to receive treatment for these things, that would be something that I'd like to put down.

In addition to these four main reasons given by callers for wanting to write an Advance Decision (i.e. family experience; media coverage; health concerns; and age), other reasons were mentioned by around 18% of callers. These included: being prompted by a friend or neighbour to do so; updating an old 'Living Will'; and amplifying a 'Do Not Attempt Resuscitation' order.

5.2 What callers hope to achieve by writing an Advance Decision:

Callers were not specifically asked what they hope to achieve by writing an Advance Decision: however, more than a third of them spontaneously offered this information (Wilkinson, 2013d). Most frequently mentioned were: 'being prepared' (36%) [5.2.1 below]; quality of life (27%) [5.2.2]; dignity (19%) [5.2.3]; and protecting loved ones (13%) [5.2.4]. Together, these accounted for 95% of the desired outcomes given as a result of writing an Advance Decision.

- *5.2.1 'Being prepared':*

Many callers indicated that writing an Advance Decision was a way of 'being prepared' for an uncertain future; that setting down their wishes in writing enabled them to put in place their wishes 'just in case' or should 'things go wrong':

It's a rather different way of being frightened rather than prepared. I'd rather be prepared frankly.

And I thought, well to me, this is more important for me [than a will] because I've had quite a few treatments and if anything goes wrong ...

A friend of mine once said to me that she's got DNR in her will and I thought, 'Well that won't be a great deal of help' ... so I thought I need to at least get something in place just in case.

You need something written, don't you, in case of a stroke or something ...

I think I should do it ... you never know (laughs). At the moment I'm quite okay, but I'd rather have it down.

I feel strongly for the whole set up, so you know, I'm absolutely adamant. So I want to just get everything all settled down.

- 5.2.2 *Quality of life:*

In writing n Advance Decision, callers were concerned to ensure a continuing quality of life, often including a degree of independence:

It's just about quality of life. It's really just about quality of life, you know – that, God forbid, you know, you have an absolutely horrendous stroke or something like that, where your quality of life is just completely impaired.

I wouldn't want to be resuscitated and things like that if I got into that state [dementia]. I see no point – there's no quality of life.

Basically my situation is I'm 42 and I have secondary progressive multiple sclerosis, and basically don't believe in quantity of life over quality of life.

Yeah, quality of life. Yeah, or lack of. Indeed.

It's just I don't want to be revived if I'm not going to be able to look after myself.

I am very insistent on my independence.

- 5.2.3 *Dignity:*

Closely related to quality of life was maintaining one's dignity. The word 'dignity' was sometimes used to refer to achieving a timely death, rather than continuing to live a life the caller considered less-than-dignified:

We've all got to go sometime, the thinking behind it is, you know, that I would prefer to go with dignity than to soldier on for what might be several years ...

I have always believed in dignity in dying, and at last I have a phone number.

For many callers, the opposite of living with dignity – and the fate to be avoided at all costs - was living with advanced dementia or a vegetative state (often referred to as being 'a vegetable' or 'a cabbage'):

I don't want quite frankly to go into a nursing home and live another three or four years with Alzheimer's just as a vegetable.

Naturally if I had a stroke or something nasty like that. I really don't want to be a vegetable.

I definitely don't- you know, I don't want to be a vegetable, no.

I just don't understand why, you know, if you're not wanting to be a cabbage or a vegetable by the end, or if you're going to be completely demented, you shouldn't be able to say goodbye.

I've always dreaded the fact that I would be a bit of a cabbage [if she had a stroke].

- 5.2.4 *Protecting loved ones:*

An important outcome that callers hoped to achieve by writing an Advance Decision was protecting their loved ones. One aspect of this was callers' intention to relieve family members from having to make treatment decisions (particularly withdrawal of treatment decisions) on their behalf:

He [a distant relative] doesn't know what time of day it is and it's just, you know, it's awful for the family. I mean he doesn't know much about it ... and to be quite honest, if he was, you know, really compos mentis, he'd say 'Well, what a shocking waste of money to keep me here'. ... And that's how I feel. I feel I don't want my family to have to, you know, make a decision. I'll make it for them.

I just want to make it as easy as I can for them, because it's one of those things you make up your mind about ... it can save a lot of hassle, so I will get that sorted out.

I want to be made doubly sure that my daughter isn't taking- or my granddaughter isn't taking, that actual decision. It's going to be my decision.

A second aspect of the wish to protect loved ones was the hope of minimizing the emotional distress they might experience:

I'm sort of looking after my mother at the moment. Well, she's just gone into a nursing home following a second severe stroke. ... I didn't want my children to have to go through this. I mean it's awful seeing my mother like that. I mean she hasn't been out of bed since March. It's just awful, it's harrowing. So I thought 'Well, I must do something about it'.

A friend just lost her mum recently and that was unsatisfactory for a while, while she was in hospital, because she hadn't done this [an Advance Decision]. And very traumatic for everyone around. So you know all about this, it's trying to pre-empt that.

I'm so anxious my family doesn't have the anxiety that these other families have had with their mother or father [in sheltered housing]. You know, completely out of this world, there's no other way of describing it. And so you're not really taking care of the person you first loved or knew.

A third aspect of the attempt to protect loved ones by writing an Advance Decision was the desire to relieve them of the potential burdens of being a long-term carer:

My husband died from Alzheimer's so having looked after him for seven years, I don't want to lumber anybody else with that, should anything happen to me.

I would like to have something on my notes in the doctor's surgery saying that I do not wish to be resuscitated should I have a big stroke, and I would like to leave one for my daughters as well so that they know. Otherwise you go on ... and you don't know where you are and you've wrecked their lives. That's how I look at it, so that's what I'd like to do.

If anything happened to me, I don't want to be hanging around being a pain and an expense to everyone. So it seems like a bit of a sensible idea just to leave a few instructions.

I don't want to be a bloody pain.

This finding that callers hope to be able to protect their loved ones as their life comes to an end accords well with that of Shale (2012), in her analysis of narrative interviews about the experience of living with a terminal illness.

In sum, then, what callers most wished to achieve by writing an Advance Decision was dignity, quality of life and preparedness for themselves; and protection of their loved ones from difficult decision-making, emotional distress, and the potential burdens of caring.

5.3 Barriers to writing an Advance Decision:

Callers were not specifically asked what barriers they had encountered – or anticipated – in writing an Advance Decision: however, almost half of them spontaneously offered this information (Wilkinson, 2012; 2013e). The barriers mentioned fell into four main categories: not understanding the law (25%) [5.3.1 below]; problems with professionals (11%) [5.3.2]; concerns about the effectiveness of an Advance Decision (34%) [5.3.3]; and ‘getting it down’ – i.e. difficulties in translating their wishes into a formal document (22%) [5.3.4].

- *5.3.1 Not understanding the law:*

Callers often did not understand the nature and legal status of various documents relating to end-of-life issues (not just Advance Decisions, but also Lasting Powers of Attorney for Health & Welfare, and for Finance, ‘Do Not Attempt Resuscitation’ Orders, and Advance Care Plans or End-of-Life Care Plans); and about the relationship between these different documents. This problem has been exacerbated by changes in terminology over time (e.g. from Living Will to Advance Decision, or from Enduring to Lasting Power of Attorney).

My mum and brother took out Living Wills [in the 1990s]. But I thought this sort of thing had vanished with the onset of these uhm, you know, with the Power of Attorney thing, is it?

My wife’s had one of these sort of Living Wills and of course it was updated in 1999. ... And it’s no longer acceptable in these homes. She had to go into a home and they don’t recognize that. They’re talking about one of these ones with a red border [‘Do Not Attempt Resuscitation’ Order].

My sister was the next of kin, she would have had more rights ... and she didn’t sign anything to agree to it [End-of-Life Care Plan].

Is it [an Advance Decision] rather like a Power of Attorney type of thing that gives you the ability to act on their behalf?

He [solicitor] mentioned Lasting-, I hope I’ve got this right, a Lasting or Continuing Power of Attorney ... And of course I’ve got the Living Will. I just wondered if you could- I mean are they the same? Is there a subtle difference?

I see a conflict, uhm, or not necessarily a conflict, but perhaps a difficulty between the financial Power of Attorney and the medical one, in that presumably if you say ‘I want to be looked after in the lap of luxury til the end of my days’ you know, the medical one has to go to the financial one and say, you know, ‘She wants to go and live in Buckingham Palace residential care home’. I’m looking for some information on how to resolve this difficulty.

- 5.3.2 *Problems with professionals:*

Another barrier to writing an Advance Decision was problems with professionals whom callers had consulted (or tried to consult), and the service they provided (or failed to provide). These professionals included doctors, other healthcare professionals, and solicitors. One issue was apparent ignorance about Advance Decisions, resulting in a failure to provide information, or the provision of incorrect or incomplete information:

You hear about these Living Wills and you ask the surgery, the girls in the surgery, you know. And they don't know anything about it, the receptionist you know.

I said 'Well he's [her husband] made an Advance Decision'. This is the Registrar. He looked at me and said 'What's that?' So I then explained to him. 'Bring it to hospital' he said. But I was horrified to think that there was a Registrar who didn't have a clue.

When I went to see the doctor, they said 'Oh you have to do it [Advance Decision] online'. Well, I don't do online, so that's the end of it, isn't it?

He [her GP] said 'When you get the Advance Decision, run it past your solicitor'. So there's no understanding, they've obviously very limited experience of this and don't understand.

I took it [Advance Decision] along to a lawyer – because I'm doing a Will and Power of Attorney at the same time – and she didn't have much clue to be honest. I would have been better to do it through you [Compassion in Dying] entirely.

The solicitor told me that I didn't need that [Advance Decision] with having a Power of Attorney [for Finance].

Another issue concerning doctors was apparently over-stretched resources, resulting in problems with the service they provided - including failures to respond to enquiries, and failures in record-keeping:

I've done that [written to GP]. But do you know, they disregard it. I don't get any replies from the GP.

I've asked him [her GP] to call me back six times, and his receptionist says he'll call me back when he's finished surgery, but he never has.

In actual fact, we have spoken to the doctor and he said 'I'll see about it [Advance Decision]', but you know what doctors are like, they're busy ... so I thought, 'Right, we'll do it on our own bat.'

I had a letter from my GP yesterday. She has this [an old Living Will dated 2002] but I think she didn't notice that I had an Advance Decision dated 2010.

[Caller attempting to find out whether her aunt has an Advance Decision] I'd had this major argument at Christmas time, December, and the GP, I presume, you

know, now wasn't looking at ancient records, wasn't going to plough through anything. ... I just had to give in, in the end. There was no way they were going to listen to me.

A third problem with doctors was their reported failure to engage seriously (or sometimes at all) with Advance Decisions:

Unfortunately, when I saw my GP, which I had to do, to make an Advance Decision, he sort of didn't seem to take much notice of it. Anyway, he wasn't a lot of help, his reaction ... It seemed to me as though he was, he didn't want to be bothered, to be honest.

He's [her GP] not taking any notice of me. He thinks I'm not serious and I am serious.

[On taking her recently redone Advance Decision to her GP] Well, he ignores it.

[GP will not discuss her Advance Decision] All he wants to do is give me antidepressants and I'm not depressed and I don't wish to take them.

Taken together, these problems with professionals – deficiencies in the information or services they provide, together with (sometimes) their attitudes toward Advance Decisions – constitute a significant barrier to getting an Advance Decision in place (Wilkinson, 2013c,e). There is independent evidence that doctors are not knowledgeable about, or engaging with, Advance Decisions (e.g. Boyd et al, 2010). Such failures are particularly salient given that studies in the US have shown both that patients respond well to physician-initiated discussions of Advance Decisions (Smucker et al, 1993); and that discussions about Advance Decisions impact positively on patients' satisfaction with primary care (Tierney et al, 2001). The implication here is the need to improve awareness of, and knowledge about, Advance Decisions among (UK) primary health care providers.

• 5.3.3 Concerns about effectiveness:

Callers also often expressed concerns about whether, having written an Advance Decision, it would then be effective. These concerns were of two broad types. The first type was a concern with how healthcare providers – particularly the emergency services – would know about the existence of their Advance Decision:

Just say, hypothetically, I'm in the town and I have a stroke, right? I get picked up by the ambulance. How do they know not to resuscitate me?

But what happens ... if you have, say, an accident and you're taken to the outpatients', you know, emergency, and you've had a terrific fall or whatever, they don't know anything about you ...

What I have found in the past is that when the ambulance come to you they don't look for your SOS bracelet. So if I wasn't able to speak, it would cause a problem... They wouldn't know I've done it [an Advance Decision], would they?

Three ways of dealing with this issue were raised: two callers mentioned tattoos, and two the Lions ‘message in a bottle’ scheme; however, most frequently discussed – in about 17% of calls - was the MedicAlert service (with which *Compassion in Dying* has recently gone into partnership). Relatedly, in some calls, the call-taker mentioned the possibility of lodging a ‘Do Not Attempt Resuscitation’ Order (or, occasionally, an Advance Decision), with their Ambulance Trust. However, a report by Satherley and Hehir [2012] for *Compassion in Dying* revealed that, even when these are lodged, most Trusts are not able to report on whether they are adhered to. The situation may improve with the introduction of schemes like London’s ‘Co-ordinate My Care’ (Hough, 2012).

The second type of concern raised by callers about the effectiveness of an Advance Decision was whether it would be respected:

I’m still having challenges from doctors who obviously- you know, they have a conscientious objection to not treating.

They [doctors] just can’t get their heads around that somebody else can make decisions. They’re still in the mode, medical mode, that ‘I am in charge’, sort of ‘my decisions’. ... But there’s a duty to consult and work very closely with them [families].

I think this is often the case with the dealing of the elderly who’ve dementia in a care home, unfortunately. Their [doctors’] job is to keep patients alive because that’s what they’ve signed the Hippocratic Oath to do.

Such concerns may, of course, significantly affect the likelihood that someone will complete an Advance Decision. *Compassion in Dying* has published a systematic review of research evidence, mostly from the US, on whether end-of-life wishes are respected (Satherley and Hehir, 2011). This highlights the need for training and awareness-raising for healthcare professionals about the legal status of Advance Decisions.

- 5.3.4 ‘Getting it down’:

Callers also reported problems with the writing of the Advance Decision itself. They experienced two kinds of difficulties in attempting to translate their end-of-life wishes into a formal document (such as the *Compassion in Dying* Advance Decision template). The first of these was a difficulty in understanding what was needed in order to complete an Advance Decision (i.e. a general conceptual problem):

I have downloaded the 18 pages of Advance Decision. What I want to know is what do I do now?

I have in front of me the papers that you sent me, which is- it’s a sort of- [reading] ‘This document should be used in the event of loss of capacity.’ I’ve not lost any capacity.

I think these [Advance Decision forms] are rather complicated to fill up. I don't know whether other people find them a bit complicated. ... Filling up these forms is very difficult when you've really nothing wrong with you except arthritis, to put anything down other than that. ... I mean, what do I put, uhm, when I'm perfectly well?

[Reading out the form] 'I refuse the following treatments'. I've put nothing. I don't know what to refuse. I haven't got any knowledge.

The second kind of difficulty callers experienced with actually writing an Advance Decision was with how to word it, or to word specific items within it:

I know what I want, went through the wording round in my mind, but it's putting it into a coherent form, you know, on the form ...

I've been trying to uh, phrase the word, get the right wording you see to write it down. And I've found it terribly difficult.

[In relation to question 1(D) on the AD form] Do you have a- or can you tell me where I could find, a sort of a catch-all phrase that will cover more or less anything whereby ... I'm incurable, I'm in great pain, or I'm out of it, you know, with a stroke or whatever.

[Also in relation to 1 (D)] Do you know where I could find some sort of phrasing whereby I'm kind of like- that more or less takes care of everything

[In relation to question 1(C) on the AD form] The question uhm [reading] 'I'm persistently unconscious and I have been so for at least-' How many weeks do most people put in there? I've got no idea what to put in there.

[Also in relation to 1(C)] On page 2, I've chosen four weeks. That seems enough to me to be persistently unconscious. Is that the average?

[Also in relation to 1(C)] And uhm do you happen to know how many weeks of unconsciousness do people go through, or have I to talk to the GP about that?

Taken together, then, difficulties around legal issues and interaction with professionals, and concerns about how to write an Advance Decision and how to ensure its effectiveness, constitute significant barriers to putting an Advance Decision in place.

In sum, the analysis presented above reveals the strong motivation that callers to the End-of-Life Rights Information Line have to write Advance Decisions, both in terms of the reasons they give for writing them [5.1], and what they hope to achieve by doing so [5.2]. It also reveals some of the difficulties they experience in attempting to get their end-of-life wishes appropriately documented, noted, and respected [5.3]. The barriers identified by callers are a key part of the context within which the helpline call-takers are working to provide information and support.

(6) Evaluation of the service:

The following evaluation of the service provided by *Compassion in Dying's* End-of-Life Rights Information Line is divided into two main sections: Evidence of effectiveness [6.1 below]; and Issues to address [6.2].

6.1 Evidence of effectiveness:

The overview of calls to the *Compassion in Dying* Information Line presented above - as Section 4 - incorporates two useful indicators of the effectiveness of the helpline: the number of people reached (in terms of pack requests) [6.1.1 below]; and the scope of the service (in terms of content of calls) [6.1.2]. The detailed content analysis of the calls offers a third indicator: the substantial amount of praise and appreciation offered by the callers for the service [6.1.3].

- *6.1.1 Number of people reached:*

One indicator of the effectiveness of the service is the number of people reached. In its second year of operation, the Information Line took twice as many calls as in its first year (*Compassion in Dying*, 2012), so awareness of the service is clearly growing (particularly since the Saga article in September 2012). Further, insofar as *Compassion in Dying* logs only the number of calls to the Information Line, it considerably underestimates the number of people reached. Given that, as noted above [in 4.2.3], about a third of calls are on behalf of two or more people, and that around a quarter of the callers who request an Advance Decision Information Pack actually ask for multiple packs to be sent out (typically between 2 and 5 packs per caller) [in 4.2.4], it is possible to suggest that for every 100 calls, around 130 – 140 people are actually reached.

- *6.1.2 Scope of service:*

Another indicator of effectiveness is the scope of the service offered on the helpline, as indexed by the content of the calls. Insofar as *Compassion in Dying* markets itself primarily as a provider of free Advance Decision forms, it underplays what callers receive from the helpline. As noted above [in 4.2.4], although 77% of calls include requests for Advance Decision Information Packs, only about 11% are simple pack requests-and-grantings alone. The vast majority of 'pack request' calls also involve the call-taker in providing information (e.g. about what an Advance Decision is; what it can and cannot cover the process of completing one; and so on). And further, as also noted above [in 4.2.5], the remaining 23% of calls deal with a much broader range of issues, including assisting people with actually filling in their own Advance Decision forms; helping them untangle legal complexities; or enabling them to discuss their worries or concerns about end-of-life issues.

- 6.1.3 Praise and appreciation:

More than 40% of the callers spontaneously offered praise for, and appreciation of, the service offered by the helpline. Typical comments include the following:

Thank you for your time. You've been very patient.

Well, thank you for listening to me and giving that very clear guidance.

Thank you, that's been really, really helpful.

I've had one of your packs, which I think is excellent.

Thank you very much indeed. I'm glad you're doing this service.

You're doing a wonderful job.

... the fact that you'd actually got back to me – I didn't need any support 'cause I was just looking at a copy of the document – but I thought that was excellent.

It's nice to know that there's people like yourself around that can give the advice, that's great.

Thank you so much for all your help. Thank you.

I keep saying how wonderful this is. ... In fact, I went into the doctors soon after my mother passed away to say I'm so glad, it made life so much easier. I mean I did speak to someone at your firm afterwards. I was so adamant that it was, you know ... it was wonderful.

Thank you. I think you're providing an excellent service.

You've been very helpful. Thank you very much indeed.

I'm very impressed.

Well, you've been great, because, I mean, it took some weeks or months to complete mine, but each stage I had a problem, I phoned you and you helped me with it. It was great.

In addition, some callers reported the positive assessments of others:

Well, my friend seemed to think you did a good job for her.

One of the things that most people are saying is an absolute godsend is packs of the Advance Decisions.

My solicitor was so impressed. He said, 'This is wonderful'. I said, 'Well, I've had a lot of help, you know'.

And, finally, nearly 20% of callers mentioned wanting to show their appreciation through making a donation to *Compassion in Dying*. Although this was sometimes raised spontaneously, it was more often an enthusiastic endorsement of the call-taker's suggestion that they might like to donate, when told that there was no charge for the Advance Decision Information Pack, or the service more broadly (not all call-takers made this suggestion).

Taken together, then, these three indicators (i.e. number of people reached; scope of service; praise and appreciation) suggest that the helpline is providing a very effective, well-regarded, and much appreciated service. Its success should be regarded as providing the context for the suggestions for improvement which follow.

6.2 Issues to address:

The following suggestions of issues which could usefully be addressed in order to improve the service provided by the Information Line are divided into two main sections: feedback already given to *Compassion in Dying*, on an interim basis [6.2.1 below]; and new feedback as a result of completing the analysis for this study [6.2.2].

6.2.1 Previous feedback

An interim analysis of the first 120+ calls in the sample has already informed two types of feedback to *Compassion in Dying*: personal discussion and feedback sessions with individual helpline call-takers about their practice [6.2.1.1]; and some suggestions for revising the Advance Decision template and guidance notes [6.2.1.2].

• 6.2.1.1 *Personal discussion and feedback sessions:*

Wherever possible, I have held individual feedback sessions with the helpline call-takers who contributed calls to the sample for this study. The sessions have focused in detail on particular calls, and sections of calls, which embody good practice; and on particular calls, and sections of calls, which proved more problematic, generating specific suggestions for improvement.

Some examples of good practice identified include:

- engaging with the caller's concerns on their own terms;
- conveying warmth and humour;
- displaying empathetic understanding;
- correcting misunderstandings sensitively;
- offering practical suggestions;
- inviting the caller to raise any additional concerns towards the end of the call;
- offering the opportunity for a call-back at a later date; and
- closing the call on a personal note, by addressing the caller by name.

Some examples of problematic areas include:

- failure to explore and address the caller's needs;
- over-emphasis on the process of completing an Advance Decision, rather than the issues and concerns underpinning the call;
- offering 'formulaic', rather than 'tailored', advice;
- difficulties in handling strong emotions, such as crying or anger;
- assuming knowledge and understanding of complex legal issues (see also 6.2.2.2 below); and
- problems in dealing with 'difficult questions' (see also 6.2.2.6 below).

There is considerable potential for further individual feedback work of this kind, and also for developing training sessions based on these insights – both for new call-takers and as continuing professional development for existing call-takers. It is perhaps worth noting, now on the basis of analysis of all 227 calls in the sample, that I do not think

there are any serious or systemic problems in the way the calls are handled. It would, however, be possible to reduce variability across calls, and across call-takers, by implementing some more systematic and extensive training. It would also be possible to improve the service overall by having call-takers share good practice: each call-taker exhibits particular strengths from which others could learn. There are also some particular issues and some particular items on the Advance Decision template that cause recurrent problems, and I address these further below (in 6.2.1.2; and 6.2.2.5 and 6.2.2.6).

- *6.2.1.2 Suggestions for revising template and notes:*

In late 2012, *Compassion in Dying* began the process of reviewing the wording of its the Advance Decision template and guidance notes. As part of this process, based on the interim analysis of the first 120+ calls (together with involvement in an ESRC-funded seminar which examined the strengths and weaknesses of various Advance Decision templates: see Wilkinson, 2012), I was able to identify aspects of the template and notes that were proving particularly problematic for callers (plus issues which were addressed more effectively in other templates), and to suggest particular changes (see Appendix C). I was very pleased to see that three of the four proposed changes were incorporated into the early 2013 revision of the template and guidance notes, which is in the process of being implemented.

On the basis of the analysis of all 227 calls, it appears that some aspects of the template and notes remain problematic (see Section 5.3.4 above for callers' concerns). Further, since making my original suggestions, I have also had the experience of running 'Advance Decision Writing Clinics', alongside a member of *Compassion in Dying* staff, at the public engagement event, *Before I Die: A Festival for the Living About Dying*, held at Cardiff University, 11-20 May 2013 (see www.cardiff.ac.uk/beforeidie for details). These 'clinics', which took the form of one-on-one sessions providing practical help in completing an Advance Decision for members of the public, were immensely rewarding – but also revealed an additional problem with the Advance Decision template (see 6.2.2.5 below for details and new suggestions).

6.2.2 New feedback:

My analysis of the full sample of 227 calls suggests the following issues which could usefully be addressed in order to improve the service offered by the End-of-Life Rights Information Line:

(A) Conceptual issues:

- Confusion between *Compassion in Dying* and *Dignity in Dying* [6.2.2.1 below];
- Not understanding the law [6.2.2.2];

(B) Practical issues:

- Problems with 'updating' and successive versions of forms [6.2.2.3];
- Problems with multiple copies of forms [6.2.2.4];

(C) Interactional issues:

- Callers' difficulties with particular items on the Advance Decision template [6.2.2.5];
- Call-takers' difficulties with enquiries about assisted suicide [6.2.2.6].

• 6.2.2.1 *Confusion between Compassion in Dying and Dignity in Dying:*

The existence of two organisations - *Compassion in Dying* and *Dignity in Dying* – both involved in end-of-life issues, and with very similar names, is a recurrent source of confusion for callers. This is despite the fact that publicity materials consistently emphasise that *Compassion in Dying* is involved in providing information, research and education around existing end-of-life rights, while *Dignity in Dying* is involved in campaigning to extend and defend end-of-life rights. The confusion is exacerbated by the fact that it is only relatively recently that *Compassion in Dying* became a separate organization, and the two organisations share an office, and also some staff. Further, the distinction between the two organisations is not only opaque to helpline callers, it is also apparently opaque to the wider public, including the media (e.g. the Saga magazine article which prompted the big ‘spike’ in calls wrongly referred to *Dignity in Dying*). This confusion matters for the *Compassion in Dying* helpline because callers not infrequently raise matters related to *Dignity in Dying* (e.g. membership subscriptions, newsletters, current campaigns), and these take time to disentangle and explain, which is evidently frustrating for both caller and call-taker. It may be worth considering a name-change for the End-of-Life Rights Information Line (and possibly for *Compassion in Dying* itself) which distinguishes it more clearly from the work that *Dignity in Dying* is doing.

• 6.2.2.2 *Not understanding the law:*

Another common issue for callers – as detailed above in Section 5.3 on ‘Barriers to writing an Advance Decision’ – is difficulty in understanding the law relating to the end of life, both because of the multiplicity of documents available, and because of changes in terminology over time (e.g. from Living Will to Advance Decision). Potential confusion is increased by the widespread practice (including in the Saga article) of referring to Advance Decisions as Advance Directives. Again, this confusion matters for the helpline because of the amount of time and effort that is required to establish what the caller knows about currently-available options, and their legal status, and the relationship between them, before being able to map this onto his or her wishes for the end-of life. Often callers’ lack of knowledge or understanding does not become apparent until quite late on in the call, and may take some unpicking. Of course, *Compassion in Dying*, as an organization, cannot do very much about this, other than keeping its documentation as clear and simple as possible. (Research in the US has shown that an Advance Directive form redesigned to meet the literacy levels of most adults is evaluated more favourably than a standard form [Sudore et al, 2007].) However, my analysis of the calls suggests that Information Line call-takers could perhaps take a little more care not to assume too much knowledge on the part of callers, and to be alert for problems that may be apparent through their (mis)use of legal terminology. Given the formidable barrier that legal issues pose to the writing of

Advance Decisions, as much help as possible is needed to lead callers through the legal minefield.

- *6.2.2.3 Problems with ‘updating’ and successive versions of forms:*

A series of problems arise around the issue of ‘updating’ or making a new Advance Decision - particularly since the change in the law created by the implementation of the Mental Capacity Act in 2007. This issue arose in almost 20% of the calls – however, call-takers handled it in rather different ways. One call-taker, faced with a caller who has an ‘old’ (i.e. pre-2007) Advance Decision (often referred to as a Living Will), always suggests that the caller should make a new one. Another call-taker apparently makes a judgement call as to whether to advise the caller to complete a new Advance Decision, or to ‘update’ an existing one to comply with the requirements of the Mental Capacity Act by adding a sentence saying “The decisions in my Living Will still apply even if my life is at risk at a result”. However, this call-taker doesn’t always follow this up by saying that the additional sentence needs to be signed and witnessed. And it is not clear that, without further explanation (which is rarely offered), callers really understand the consequences of making this addition. Clearly there needs to be greater consistency in how the issue of ‘updating’ an Advance Decision vs. making a new one is handled; and any proposal that the caller might update an existing document needs fuller discussion. My suggestion is that it would be simpler to adopt as default the strategy of advising the caller to make a new Advance Decision.

These problems are compounded by the fact that successive versions of the forms are still in circulation. Callers are sometimes confused by the differences between successive versions – and a much time may be spent accounting for why particular questions have been amended, removed or added. While this issue may not be solveable (and it would be a pity not to continue to improve the template and notes), it could perhaps be ameliorated by flagging ‘post 2007’ forms more clearly as such; and by opening any discussion of the forms with a check that the caller has a ‘post 2007’ version.

- *6.2.2.4 Problems with multiple copies of forms:*

One recurrent problem – raised in about a quarter of the calls - arises from the fact that the current Information Pack includes four copies of the Advance Decision form (which the Guidance Notes suggest is in order to be able to give copies to a GP, a close relative or friend, and possibly others). However, this generates many enquiries about how the four copies are actually to be filled in. For example, callers ask questions such as: Does each copy need to be written out separately?; Should each one be signed and witnessed?; Can just one be filled in and photocopied?; Does each photocopy need to be signed and witnessed?; Can paragraphs be written out, photocopied and (physically) pasted onto the other blank forms?; Do these then need to be individually witnessed? The problem could easily be solved by simply providing one copy of the form, with instructions to photocopy it as many times as needed after it has been signed and witnessed. This solution would also have the advantage of reducing printing and mailing costs.

- 6.2.2.5 *Callers' difficulties with particular items on the Advance Decision template:*

There are two particular items on the Advance Decision template that seem to present callers with particular difficulties: these are statements 1(D) and 1(C) in the first section, 'Refusal of Treatment'. The last five quotations from callers in Section 5.3.4 of this report ('getting it down') illustrate the kinds of things they say about these two statements.

In relation to 1(D), callers recurrently indicate that they want to 'cover everything', rather than to list particular situations in which they refuse treatment. This problem has already been addressed, following my November 2012 recommendations, in the January 2013 revision of the template and guidance notes. Specifically, the guidance notes have now been amended to emphasise that statements (A), (B) and (C) are designed to cover refusal of treatment (should someone lose capacity) in virtually any situation; and to highlight that individuals can specify that they wish to refuse all life-prolonging treatments in every situation they list in 1(D). It remains to be seen, when the new materials come on stream, whether these changes address callers' concerns about 1(D).

In relation to 1(C), callers recurrently indicate that they do not have any basis for deciding how many weeks of unconsciousness would be acceptable to them. This problem is compounded by the fact that call-takers regularly deal with this problem by saying this is 'a personal decision', which does not really help, nor is there currently anything in the guidance notes which addresses this. One solution would be to put a 'default' number of weeks into the statement, with an explanation in the guidance notes, together with a note indicating that the figure could be amended, should an individual so wish. It would be prudent to wait for Royal College of Physicians' review of the management of disorders of consciousness, due for publication in Autumn 2013, (and which will offer definitive guidelines) before deciding what this figure should be.

There is a further problem with 1(C), which came to the fore during the course of the 'Advance Decision Writing Clinics' at the Cardiff University *Before I Die* festival earlier this month. Several members of the public who came to these clinics had also attended the 'expert panel' event the evening before (see Wilkinson, 2013d), in which several presentations had referred to the 'minimally conscious state' (Giacino, Ashwal, Childs et al, 2002), in which unconsciousness is punctuated with brief, occasional, and fragmented moments of consciousness. They were particularly concerned about the recent case of 'M' (W v M & Ors [2011]), in which treatment-withdrawal from a minimally conscious woman (without a valid and applicable Advance Decision) was refused on the grounds of 'sanctity of life'. In working through the Advance Decision template in the Writing Clinics, then, these people commented that 1(C) only covers unconsciousness – yet in some ways minimal consciousness could be seen as a 'worse' condition (see Wilkinson and Savulescu, 2012). This is so both for the minimally conscious individual, to the extent that they may be fleetingly 'aware' of their situation, in a way the persistently unconscious individual is clearly not, and for their families - for some of whom 'minimal consciousness' is a 'fate worse than death' (Kitzinger and Kitzinger, 2012). Consequently, clinic attendees wanted to discuss ways in which the Advance Decision could be amended to cover this eventuality. Again, however, it would be prudent to wait for the Royal College of Physicians' report in a few months time for guidance as to how this might most appropriately be done.

- 6.2.2.6 *Call-takers' difficulties with enquiries about assisted suicide:*

There are a number of calls in the sample in which callers ask questions about assisted suicide – in particular, about the logistics and cost of going to the Dignitas clinic in Switzerland. This creates a very particular set of difficulties for the helpline call-takers, who are well aware (as callers often are not) that providing information about Dignitas could be construed as assisting a suicide, and that in the UK – under the Suicide Act, 1961 - assisting a suicide is illegal and could result in prosecution. *Compassion in Dying's* policy is clearly not to provide this information. Call-takers are therefore faced with the challenging interactional task of refusing to provide information that has been requested without alienating the caller. I have run two 'expert' workshops involving a detailed analysis of these challenging calls (Wilkinson, 2013a,b). Analysis shows that there is great variability in how the task is handled by call-takers: (e.g. by claiming they 'do not know'; by declaring they are 'not allowed' to say; by explaining that providing this information is illegal) and in call-takers' reactions to this (ranging from acceptance, to surprise, to anger). Perhaps not surprisingly, in general these calls are not handled well. I suggest that call-takers need some clear advice on how to handle 'the Dignitas question', and, preferably, training in how they might best do so.

(7) Relationship between this study and other aspects of *Compassion in Dying*'s work:

In this - penultimate - section of the report, I briefly reflect on the relationship between the present study and two other, related, aspects of *Compassion in Dying*'s work: the current pilot community 'outreach' project, seeking to raise awareness and uptake of Advance Decisions among vulnerable older people in East London [7.1]; and the ongoing collection of monitoring data from helpline callers, through the voluntary completion of follow-up questionnaires [7.2].

7.1 Outreach:

This analysis of helpline calls provides a rich source of evidence that can be used to document the need for *Compassion in Dying* to engage in outreach. Around 10% of callers report problems in accessing or completing Advance Decisions, for the following main reasons:

- Difficulties with hearing or vision:
(e.g. *Say again. I'm a little deaf. Sorry, say again dear.*)
- Lack of IT skills (or no computer):
(e.g. *I'm learning my computer but my computer and I seem to disagree on a variety of things and my computer always wins.*)
- On own at home – lack of mobility and/or support:
(e.g. *I live on my own and I'm suffering from arthritis. And life is not easy.*)

As we have seen – in Section 5.3 - there are significant barriers to putting an Advance Decision in place. These kinds of challenges constitute further barriers for a proportion of older adults, who may well need additional help and support to complete an Advance Decision – the kind of help and support that can be provided through a community outreach programme.

A different form of community outreach work - one-on-one 'Advance Decision Writing Clinics' for members of the public - was pioneered at the Cardiff University *Before I Die* Festival (see section 6.2.1.2 above). These 'clinics' were very successful and much appreciated by attendees, and could usefully be repeated at other public events.

7.2 Monitoring:

The data from my telephone recording study provide a valuable complement to *Compassion in Dying*'s monitoring data, collected via follow-up surveys. Data triangulation across different methods of investigation can increase confidence in the robustness of findings.

Here, not only do the methods of the two studies differ, so too do the two samples. The main difference between them is that the sample of recorded calls is more representative of the range of callers to the helpline than is the sample of voluntarily-returned questionnaires. This is especially the case given that the response rate for the questionnaire

study, and the total number of questionnaires received, are both quite low. [NB I only have the collated questionnaire data to January 2012, representing a total of 126 questionnaires.] Other differences between the two data samples are that there are more men in the questionnaire study than in the recorded calls (38% as against 16%); and the questionnaire respondents are younger than the telephone callers (around 40% are under 60, as against 11%).

Despite these sample differences, I have found convergence between the two studies in three particular findings:

(i) 'Problems with professionals':

- 16% of questionnaire respondents said their doctor had not heard of Advance Decisions before; and 3 had had a negative reaction from their doctor.
- This accords well with my finding that 'problems with professionals' is a barrier to writing an Advance Decision [Section 5.3.2], and highlights the need for education and training of doctors in this area.

(ii) 'Concerns about effectiveness':

- Only 64% of questionnaire respondents answered 'yes' to the question 'Do you feel more confident that your wishes for treatment at the end of life will be respected?' 36% answered 'no or 'don't know'.
- This accords well with my finding that 'concerns about effectiveness' is a barrier to writing an Advance Decision, including concerns about whether it will be respected [Section 5.3.3]

(iii) 'Getting it down':

- Only 51% of questionnaire respondents were 'very satisfied' with the Information Pack, while 35% were 'quite satisfied' and 13% 'neither satisfied or dissatisfied.
- This accords well with my finding that 'getting it down' (translating end-of-life wishes into a formal document) is a barrier to writing an Advance Decision [Section 5.3.4]; and supports my assessment that the Advance Decision template and guidance notes could still be improved [see Section 6.2.2.5 for specific suggestions].

The fact that the findings of these two – very different - studies converge in these areas suggests that these findings are robust.

(8) Conclusions and key recommendations:

This study of calls to the *Compassion in Dying* End-of-Life Rights Information Line has identified key reasons why callers want to write Advance Decisions; what they hope to achieve by so doing; and barriers to putting an Advance Decision in place.

It has also shown that the Information Line is very effective, in terms of numbers of people reached, the scope of the service, and the praise and appreciation it attracts. I am confident that, overall, the service provided by *Compassion in Dying* is a very good – and very important – one.

I have nine recommendations which could improve the service still further. The first four relate to practical and organizational issues; the last five to training, education and outreach, together with a follow-up study.

(A) Recommendations concerning practical and organizational issues:

- **Recommendation 1:**

Consider ways of differentiating *Compassion in Dying* more clearly from *Dignity in Dying* (e.g. a name change for the Information Line and/or the organization).
[See 6.2.2.1]

- **Recommendation 2:**

Consistently advise callers to complete new Advance Decisions, rather than ‘updating’ old ones – and ensure that post-2007 forms are always used.
[See 6.2.2.3]

- **Recommendation 3:**

Provide only one copy of the Advance Decision template (not 4) in the Information Pack, together with instructions to photocopy as required after signing and witnessing.
[See 6.2.2.4]

- **Recommendation 4:**

Seek advice on two further revisions to the Advance Decision Template (and guidance notes), in order to amend statement 1(C) in the following two ways (and to explain the amendments):

- (i) To offer an appropriate ‘default’ figure for the period of unconsciousness.
- (ii) To cover minimal consciousness, as well as unconsciousness.

The Royal College of Physicians’ forthcoming report on the management of disorders of consciousness will help with deciding how best to make these changes. This report is currently out for consultation with interested organisations, and I recommend that *Compassion in Dying* asks for a copy. (I would be happy to do this on your behalf, if you so wish.)
[See 6.2.2.5]

(B) Recommendations for training, education and outreach, and a follow-up study:

• Recommendation 5:

Training: Provide call-takers with specific advice and training in relation to the following issues:

- (i) Being alert to problems in callers’ knowledge and understanding of the law, particularly not assuming too much knowledge and understanding.
[See 6.2.2.2]
- (ii) How to handle queries about assisted suicide, and Dignitas.
[See 6.2.2.6]

• Recommendation 6:

Training: Consider implementing further training, in the form of workshops in which call-takers learn from each other by sharing good practice (and also discuss problems).
[See 6.2.1.1]

• Recommendation 7:

Outreach: Run regular one-on-one ‘Advance Decision Writing Clinics’ at public events. (I would be happy to continue to be involved in these, whenever possible.)
[See 6.2.1.2]

• Recommendation 8:

Education: Consider ways in which GPs could be made more aware of, and knowledgeable about, Advance Decisions; and encouraged to facilitate their patients’ putting them in place.

Clearly working with GPs would be a longer-term strategy for *Compassion in Dying*, with considerable resource implications. (I am currently collaborating with Celia Kitinger, at the University of York, to set up a pilot study with two interested GPs, with whom we have developed links.)

[See 5.3.2 and 7.2]

- **Recommendation 9:**

Follow-up study: Conduct a follow-up study to determine whether the changes that have been made to the Advance Decision template and guidance notes have reduced callers' difficulties with the particular items that have been changed. This could be done, once the new documentation is fully implemented, by recording and analyzing a further sample of calls - possibly from 'new' call-takers, which would also allow for the possibility of providing them with feedback/further training.

[See 6.2.1.2]

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Legal cases:

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W v M & Ors [2011] EWHC 2443 (Fam)

Appendices:

A. Biographical note

Sue Wilkinson, BSc, PhD, CPsychol, CSci, FBPsS

Sue Wilkinson is Professor of Feminist and Health Studies in the Department of Social Sciences at Loughborough University. She is a Chartered Psychologist, Chartered Scientist, and Fellow of the British Psychological Society.

She is a founding member of the Loughborough University Helplines Research Unit – a group of scholars with special expertise in the analysis of telephone helpline interaction. Between them, they have worked to study and evaluate (to date) eleven telephone helplines, including the Fibromyalgia Association (UK), Macmillan Cancer Support, Mind Info Line, the NSPCC helpline, and Kids helpline. The Loughborough University Helplines Research Unit also collaborates with other scholars working on helpline interaction both nationally (University of York) and internationally (Queensland University of Technology, Australia; Victoria University of Wellington, New Zealand).

Sue is a specialist in qualitative methods, and her research interests are in the areas of communication, health, and end-of-life issues. She is an invited member of the ESRC-funded initiative on Advance Decisions, and has contributed to seminars, workshops, conferences and an expert panel on this topic (see references, above).

B. Acknowledgements

I am very grateful to the four *Compassion in Dying* helpline call-takers, and the 227 helpline callers who gave their consent to be recorded for this project.

I would also like to acknowledge helpful feedback on parts of this report from members of the ESRC-funded seminar series on Advance Decisions; and from the audience at the expert panel on Advance Decisions at the Cardiff *Before I Die* festival (see references for details).

Data transcription and coding for this project was supported by funding from Loughborough University.

Many thanks to Louise Bradley and Joanne Meredith for their assistance with data coding.

C. Copy of email of 25 Nov 2012, suggesting changes to Advance Decision template & guidance notes

To: Davina Hehir, Compassion in Dying
cc. Danielle Hamm, CiD; Sue Peters, CiD; Philip Satherley, CiD

From: Sue Wilkinson and Celia Kitzinger

25 November 2012

Dear Davina

Feedback on Proposed Revisions to the CiD Advance Decision Template

Thanks very much for letting us have a look at the proposed revisions to the Compassion in Dying Advance Decision template.

Here, as promised, are our suggestions for a few further changes. These recommendations are based on:

- (a) My preliminary analysis of 120+ calls to the CiD Info Line, focusing on the problems callers encounter in attempting to complete the AD template; and
- (b) The work of last month's ESRC-funded seminar on Advance Decisions, (convened by Celia, who is PI for this seminar series), at which a dozen or so of us (lawyers, ethicists, neurologists, intensivists, GPs, palliative care specialists, charity representatives (including Phil) as well as academics) spent the afternoon researching the pros and cons of various AD templates, including one drafted by a leading barrister.

Recommendations:

(1) Review dates (revised AD template p.1):

The person completing the form needs to ensure that there is no possibility of the "review" or "confirmation" dates being treated as "valid until" or "expiry" dates. A warning to this effect was issued by the judge in the recent High Court case of X Primary Care Trust v XB and YB ([2012]EWHC 1390 (Fam)).

Recommendation:

- *Add a sentence saying (something like) "This document is intended to apply indefinitely unless I specifically revoke it".*

(2) Refusal of treatment (revised AD template p.2, statement 1(B): "I suffer serious impairment of the mind or brain with no prospect of recovery..."):

Celia's research interviews with clinicians suggest that, given the degree of medical uncertainty around brain injury, and documented evidence of very late recoveries, it's

unlikely that clinicians would ever agree conclusively that there was NO prospect of recovery. Also, the wording of this statement is inconsistent with the wording of statements 1(A) and 1(C), both of which say “little or no prospect of recovery”, rather than “no prospect of recovery”.

Recommendation:

- *Amend the wording of 1(B) (currently “no prospect of recovery”) to “little or no prospect of recovery”.*

[NB Wording would also need to be changed in the Guidance Notes (Section 1) to match this.]

(3) Value statement (revised AD template p.5: “...what you consider to be an acceptable quality of life or recovery (for example, in relation to the statements made on page 2).”):

“Quality of life” is a contested and hard-to-define concept; and because quality of life is partly subjective, the validity of assessment of other people’s quality of life has been widely debated in the scholarly literature. Also, the statements on page 2 do not actually refer to “quality of life”, only to “recovery”.

Recommendation:

- *Delete the words “quality of life or”, so that the statement reads “... what you consider to be an acceptable recovery (for example in relation to the statements made on page 2).”*

[NB Wording would also need to be changed in the Guidance Notes (Section 4) to match this.]

(4) Refusal of treatment (current Guidance Notes, Section 1, notes for statement 1(D) – NB we haven’t seen the revised version of the Guidance Notes):

This raises some complex issues.

My research shows that callers to the Info Line are sometimes looking for a more ‘generic’ way of refusing treatment – i.e. without having to undertake the near-impossible task of attempting to specify the full range of medical conditions/situations to which their treatment refusal applies. They ask whether they have “forgotten anything”, or they ask (for example):

- “do you know where I could find some sort of phrasing that more or less takes care of everything”;
- “do you have a sort of a catch-all phrase that will cover more or less anything where I’m incurable, in great pain, or I’m out of it, you know, with a stroke or whatever”;

Also, for callers who want to communicate a generic overall refusal of treatment, the requirement to list specific conditions leads them to rack their brains for possibilities. They say (for example):

- “I don’t know all the sort of things I might hit”;
- “... if I’m thinking about them [specific symptoms/situations] I won’t know what to think about unless I’ve heard of them”;
- “It’s more a question of things that I don’t know about. I don’t want sort of to suddenly be hit with some sort of weird and wonderful terrible thing that I’m then, I’m not covered for”;
- “... if it could be to just say I don’t want to sort of receive treatment for these things, that would be something I’d like to put down, but I don’t know what those things are”.

We appreciate that the suggestion to specify particular conditions/situations stems from the need (under the Mental Capacity Act 2005) for an Advance Decision to be both “valid” and “applicable”. Ways of ensuring this were discussed extensively at the ESRC Seminar on ADs and our recommendations below derive from the conclusions of that meeting.

Recommendation (i):

- *Add a sentence at the end of this section of notes saying (something like) “It is also possible to refuse all life-prolonging or life-sustaining treatment should you lose the capacity to make treatment decisions”. To assist callers to do this, the guidance note could continue as follows: “Simply write on the form, ‘If I lack capacity to give, or withhold, my consent to medical treatments, then I refuse all medical intervention aimed at prolonging or sustaining my life’.” (Celia ran this wording past some senior lawyers who found it clear.)*

Alternatively, on the AD template itself, the (p.1) Refusal of Treatment statement 1(D) could be amended to become an either/or option, perhaps as follows:
 “Further to the points made above, (either) I wish to refuse all medical treatments intended to prolong my life (or) I wish to refuse medical treatments intended to prolong my life if I am in any of the following situations”.

This alternative suggestion would require some further changes to the text on p.2. I am happy to have a phone conversation with you if it would be helpful to talk these through, and/or to look at a draft rewording.

Recommendation (ii):

- *Additionally, shift the current focus from CONDITIONS for which someone might wish to refuse treatment to TREATMENTS they might wish to refuse by removing the indicative list of conditions (which – as shown above - leads people to rack their brains for others).*

I discussed this possibility with Sue in the feedback session last week (and briefly mentioned to you, Davina). For it to work, it would probably also be necessary to remind people that an AD only applies when they have actually lost capacity (I have evidence from the Info Line that people often forget this) – and it may well be that they are less concerned about what has caused the loss of capacity (e.g. an accident or a stroke or dementia) and more concerned about treatment refusal.

This second recommendation may entail more rewriting than you want to do in this revision, but if you'd like to discuss it further, I'd be happy to do so.

I hope these suggestions are useful. If it would also be helpful for us also to cast an eye over the proposed revisions to the Guidance Notes (in addition to the particular recommendations above based on the current version), we'd be very willing to do so – and we would try to do so quickly, as I know you're keen to get the final version to the designer as soon as you can.

All the best,

Sue and Celia

Sue Wilkinson
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