

COMPASSION

IN DYING

**SUPPORTING YOUR CHOICES
AT THE END OF LIFE**

EXECUTIVE SUMMARY

**AN ANALYSIS OF CALLS TO THE *COMPASSION IN DYING*
END-OF-LIFE RIGHTS INFORMATION LINE**

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THE STUDY:

* Research question:

“Why do people call the Compassion in Dying End-of-Life Rights Information Line, and what issues do they raise?”

Based on detailed analysis of 200+ calls to the End-of-Life Rights Information Line, recorded over a six-month period.

THE FINDINGS:

Most calls are to request an Advance Decision Information Pack, but also typically involve further discussion of end-of-life issues.

* This further discussion focuses on:

- Why callers want to write an Advance Decision
 - What they hope to achieve by doing so
 - What barriers they face
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* Callers want to write an Advance Decision because of:

- family experiences

“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...”

- media coverage
- health concerns

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

- advancing age
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* By writing an Advance Decision, they hope:

- to be prepared for the future
- to ensure quality of life

“I have secondary progressive multiple sclerosis, and basically don’t believe in quantity of life over quality of life”

- to die with dignity

“I would prefer to go with dignity than to soldier on for what might be several years”

- to protect their loved ones

“I just want to make it as easy as I can for them...”

*** Key barriers to writing an Advance Decision are:**

- not understanding legal issues
- problems with professionals

“Unfortunately, when I saw my GP to make an Advance Decision ... he didn’t want to be bothered, to be honest”

- concerns about effectiveness

“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?”

- translating their wishes into a formal document

“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 ...”

RECOMMENDATIONS:

*** (1) Outreach:**

Further educate and inform people about Advance Decisions, especially their legal aspects; and provide help with completing them - through public engagement and community outreach programmes

*** (2) Professional education:**

Consider ways in which GPs - and other healthcare professionals - could be made more aware of, and knowledgeable about, Advance Decisions; and encouraged to support their patients in writing them

*** (3) Recording systems:**

Encourage development of effective recording systems for Advance Decisions - ideally a centralized registry

*** (4) Monitor and evaluate change:**

Conduct a follow-up study of the End-of-Life Rights Information Line, to monitor the impact of external and internal change. to assess the impact of changes to institutional practices, documentation, and call-taker training.

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