COMPASSION IN DYING

SUPPORTING YOUR CHOICES AT THE END OF LIFE

East London age UK

End-of-life Rights Community Advocacy

Danielle Hamm

Compassion in Dying

LOTTERY FUNDED

BIG LOTTERY FUND

In association with Daily Mail

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***Vision**: a world in which everyone has access to the care and support that is right for them at the end of life.*

***Mission**: to support people to have what they consider to be a good death by providing information and support around their **rights and choices** at the end of life.*

- Information and advice
- Research
- Training and advocacy

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Mental Capacity Act 2005

- Maximise capacity

- Advance Decision and Lasting Power of Attorney

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82% have strong wishes regarding their end of life

3% have communicated these wishes in an Advance Decision

53% wrongly believe that they have the legal right to make treatment decisions on behalf of their loved ones, if their loved ones lose capacity

35% of GPs have not initiated a discussion with a patient about their end of life wishes

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Information service

- Advice Line
- Factsheets and Rights Guides
- Advance Decisions

"I started to think about this when I was in my early eighties & had brought my will up to date & made a 'wish list' consulting my family. Making Power of Attorney and later an Advance Decision seems a logical, and kind, act to avoid distress to one's family."

"It has been only through Compassion in Dying that I have once again been able to regain some sort of control over my life."

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Feedback

- 78% are over 65
- 31% would like face-to-face advocacy
- Most don’t have access to internet/printer

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End-of-Life Rights Advocacy

- Raise awareness of end-of-life rights
  - -Older people
  - -Service providers

-Advocacy to support older people exercise their end-of-life rights

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Advocacy

- Befrienders and advocates recruited locally by Age UK EL
- Compassion in Dying trains the advocates
- Advocates deliver support
- Information Line

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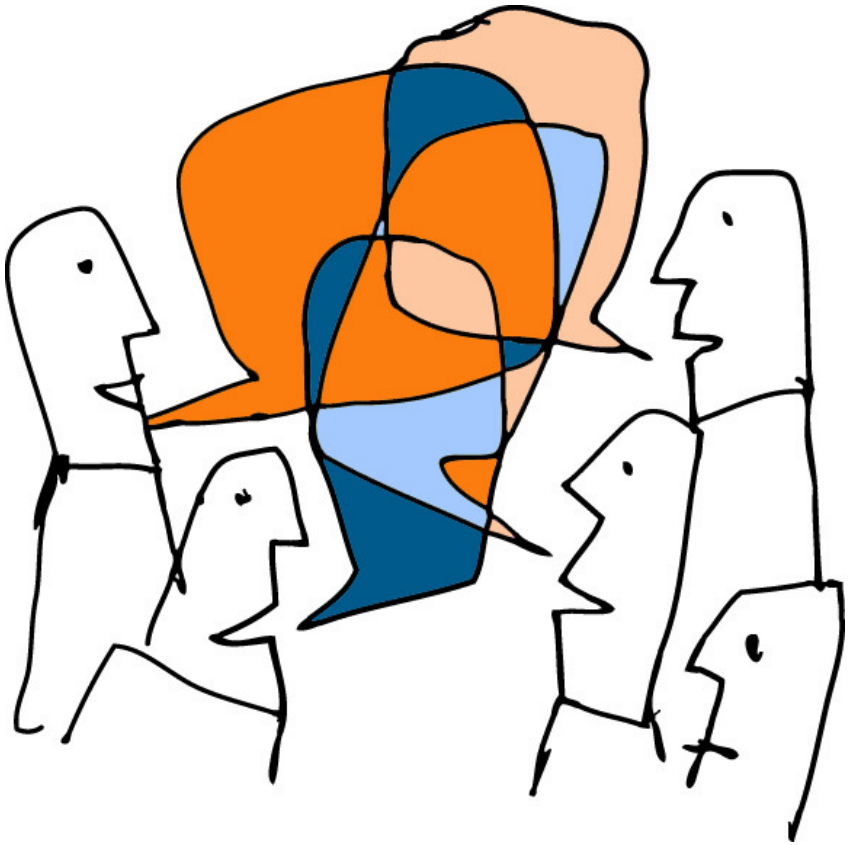
Community

- Information materials
- Training
- Referral to advocacy service
- Information line



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Pre-launch

- Involvement of older people
- Language
- Barriers to discussing end of life
- Promotional material
- Developing partnerships
  - Coordinate My Care
  - Older People's Advocacy Alliance

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3 weeks in:

- 9 advocates trained
- 15 service users signed up
- Information sent to service providers
- 5 requests for training

End of Life Rights Advocacy

82% of people in the UK have strong views about how they wish to be treated at the end of life, but only 3% have made their wishes known in an Advance Decision.

52% of people wrongly believe they have the automatic legal right to make decisions for a loved one who is seriously ill.

We can provide you with free tools to ensure you are able to inform and empower the individuals you work with to take up their legal rights at the end of life.

This includes:

- Advance Decision Toolkits for professionals
- Advance Decisions and guidance notes
- An information and Advice Line 08009992434
- Referral to independent advocacy
- Training around Advance Decisions and Lasting Power of Attorney
- Lasting Power of Attorney fact sheets

To take advantage of this service please email:
endofliferights@compassionindying.org.uk

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Funded by the Big Lottery Fund, the End-of-Life Rights Advocacy (ELRA) project is an 18-month pilot to ensure that vulnerable older people in East London have the support to make informed advance decisions about their treatment at the end of life.

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What next?

- Pilot, ongoing monitoring and evaluation
- Developing partnerships
- National roll-out

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www.compassionindying.org.uk

http://endofliferightsadvocacy.wordpress.com/

THE END-OF-LIFE RIGHTS INFORMATION LINE.

0800 999 2434