ENABING PEOPLE TO LEARN ABOUT LIVING WITH SERIOUS ILLNESS, DYING AND BEREAVEMENT



Mark Hazelwood CEO Scottish Partnership for Palliative Care













Where are the mainstream, accessible opportunities to learn about and be more prepared for living with serious illness, dying and bereavement??





Death Literacy

Leonard, R., Noonan, K., Horsfall, D., Psychogios, H., Kelly, M., Rosenberg, J., Rumbold, B., Grindrod, A., Read, N., and Rahn, A. (2020). Death Literacy Index: A Report on its Development and Implementation. Sydney: Western Sydney University. https://doi.org/10.26183/5eb8d3adb20b0

Grief Literacy

Palliative Care

J Breen, L., Kawashima, D., Joy, K., Cadell, S. Roth, D. Chow, A. & Macdonald M.E. (2020) 'Grief literacy: A call to action for compassionate communities', Death Studies. DOI:10.1080/07481187.2020.1739780)

End of Life Literacy

Rebecca M. Patterson, Mark A. Hazelwood "Developing End of Life Literacy Through Public Education" (2022) Chapter 13 Oxford Textbook of Public Health Palliative Care



BUILDING COMFORT AND CONFIDENCE TO SUPPORT PEOPLE THROUGH DYING, DEATH AND BEREAVEMENT



Caroline Gibb Community Development Lead Scottish Partnership for Palliative Care



EASE is...

- a public education course
- designed for members of the public
- delivered free of charge by volunteer facilitators



People usually want to do the right thing when someone they know is affected by ill health, death or grief.

But sometimes other things get in the way.



The EASE course aims
to enable ordinary people to be
more comfortable and confident
supporting family, friends or
community members with issues
they face during dying, death
and bereavement



Key Messages

We all have an innate ability to support and care for each other through difficult





Planning ahead can help



Looking after yourself is important



Course Ethos

- Peer sharing and discussion is as important as formal course materials
- It should empower communities rather than be professional-led
- It should focus on learning and working together - every participant on the course brings valuable experience



EASE Course Content

Module 1: An introduction to death in Scotland

Module 2: Serious Illness and Frailty

Module 3: The Reality of Dying

Module 4: Caring for the Carer



How does EASE work?

EASE Face to Face

- 4 weekly 2-hour sessions
- Participants join sessions in person
- Activities are worked through in groups

- Reading
- Case studies
- Films
- Activities
- Quizzes
- Group discussion & reflection



EASE Online

- Participants work through 4 weekly modules on online platform Moodle
- Meet weekly on zoom for group discussion

Who are EASE facilitators?

- Anyone who's completed an EASE course
- You don't need previous experience or clinical expertise
- We welcome and encourage people from all backgrounds and experiences to become EASE facilitators



What about the experts?

- Professionals not the sole repository of expertise
- EASE doesn't rely on busy palliative care specialists
- Participants don't need particular education or skill

However:

- EASE still imparts knowledge, experience and expertise
- Features input from health and social care professionals, palliative care doctors and nurses, professionals with expertise in grief and bereavement and more



Who are EASE participants?

- Anyone who wants to be able to support someone with issues they face relating to death, dying and bereavement
- Participants bring different backgrounds, perspectives and experience which can help to enrich the course for everyone



The Story So Far

21 online courses (2021-23)

> 4 pilot f2f courses (2019, 2022-3)

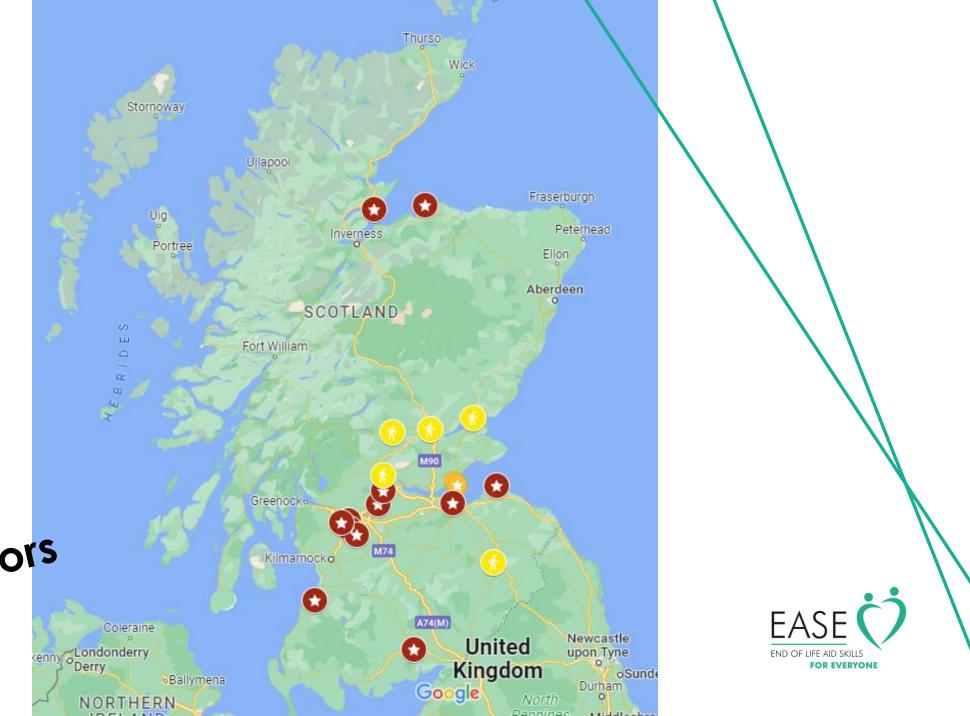


267
people
have complete d the EASE course



5
facilitator
cohorts

33 facilitators

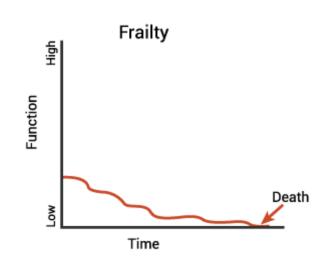


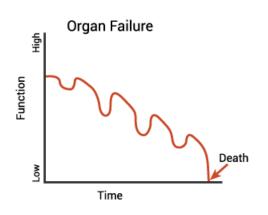
Evaluation

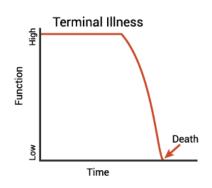
- Pre and post-course questionnaires
- Show difference in knowledge, comfort and confidence
- Open questions for more detailed feedback
- Allows for regular improvements



The stats







"I am aware of the common patterns of how people die in Scotland"

Before EASE: After EASE:

40% 100%

"I am aware of how people can plan to prepare for the end of life, and where I can get further information about this."

Before EASE: 40%

After EASE: 100%





"I am aware of the common bodily changes that people often go through in the last days of life."

Before EASE: 44%

After EASE: 100%



I feel able to offer practical support which will make a positive difference to someone who is dying.

Before EASE: 44%

After EASE: 97%



"I feel able to talk with and/or listen to someone who is dying in a way that will make a positive difference.

Before

EASE: 51%

After EASE:

95%

The Voices

"I will take away a new strength in being able to help, plan and offer support" "It has been a deeply reassuring exercise. even just to know that I am not alone and not doing the wrong thing. How to get help and how to cope. A really valuable life lesson"

"I feel more confident about discussing death, dying and bereavement now and feel I could talk to people about this more easily. It's important just to be there in a calm and supportive way."

"...the course gave a broad overview of issues relating to death, grief and caring and reflected a broad range of experiences. It was a privilege to hear from other people on the course and the facilitators supported that process very well."



What's next?

- √ Rolling out the face to face course across Scotland
- ✓ Training and supporting facilitators
- ✓ Outreach taster sessions
- ✓ Get EASE to as many people as possible!

The People

Sheila, week 1:

"I'm scared of death"



The People

Sheila, week 4:

"I'm not scared anymore"



More information

www.goodlifedeathgrief.org.uk/content/ea se/

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Film



