

EASE

END OF LIFE AID SKILLS

FOR EVERYONE

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EASE is...

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

Coming up

- Intro and welcome
- Why do we need public education around serious illness, dying, loss and care?
- What do people want to know?
- Developing the course – a thorough process.
- Aims and content of the course
- Short film – Being There
- Communities leading - the snowball delivery model
- Feedback
- What next?





Why do we need public education around serious illness, dying, loss and care?

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.

A taboo?

or...

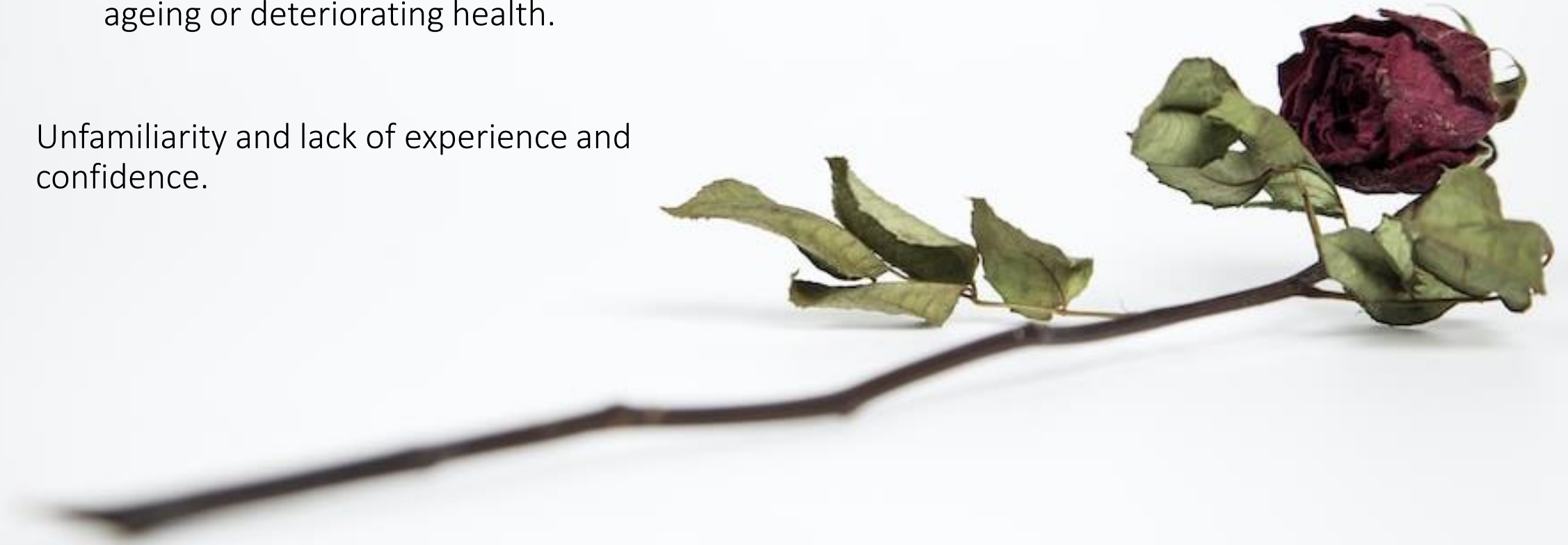


Discomfort talking about future death of people we care about.

Awkwardness around bereavement.

Reluctance to make practical plans for ageing or deteriorating health.

Unfamiliarity and lack of experience and confidence.





"We want to create a Scotland where everyone can help when someone is caring, dying or grieving."



Grief Literacy

- The capacity to access, process, and use knowledge regarding the experience of loss.
- This capacity is multidimensional: it comprises knowledge to facilitate understanding and reflection, skills to enable action, and values to inspire compassion and care.
- These dimensions connect and integrate via the interdependence of individuals within socio- cultural contexts.



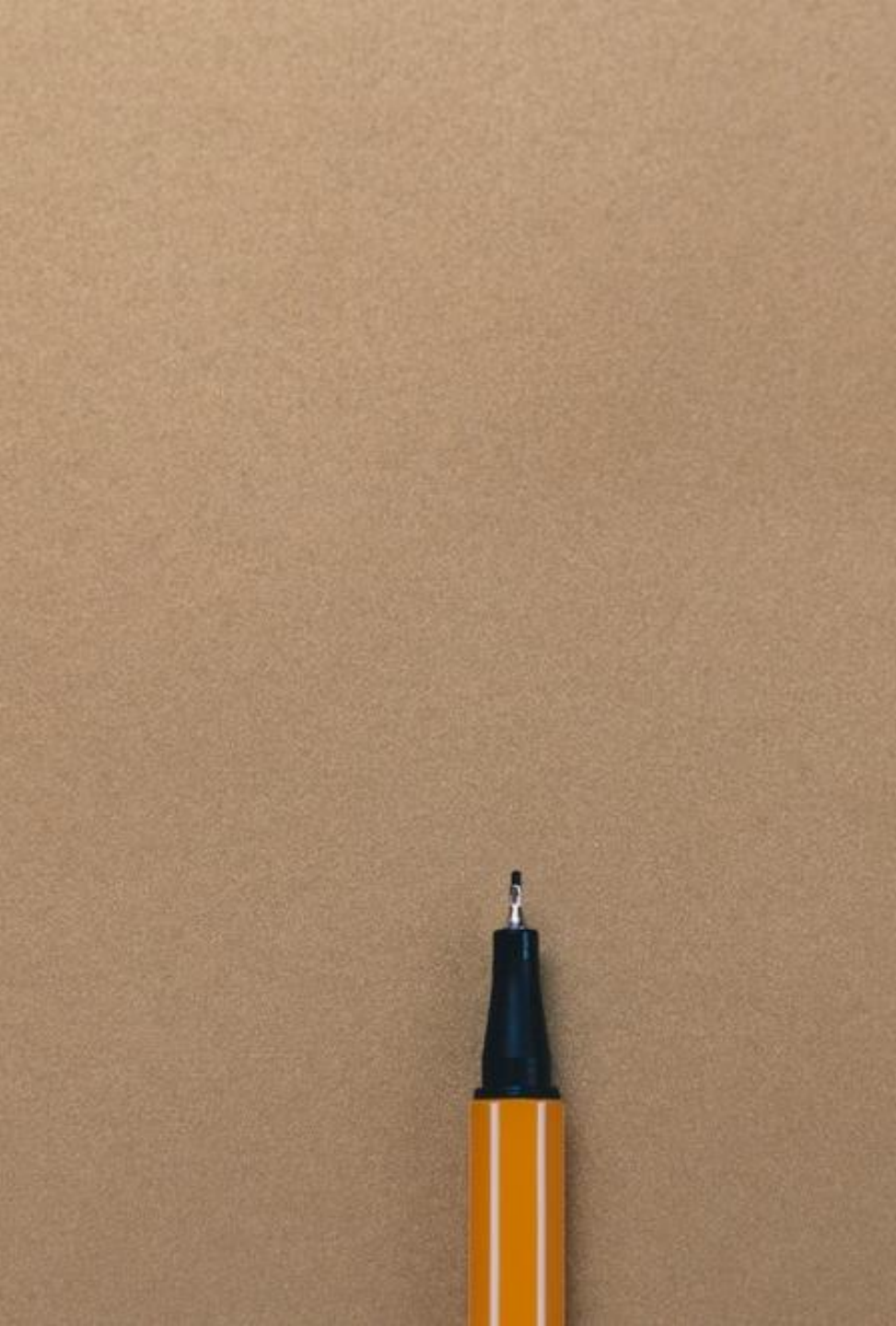
J Breen, L., Kawashima, D., Joy, K., Cadell, S. Roth, D. Chow, A. & Macdonald M.E. (2020)
'Grief literacy: A call to action for compassionate communities', Death Studies.
DOI:10.1080/07481187.2020.1739780)

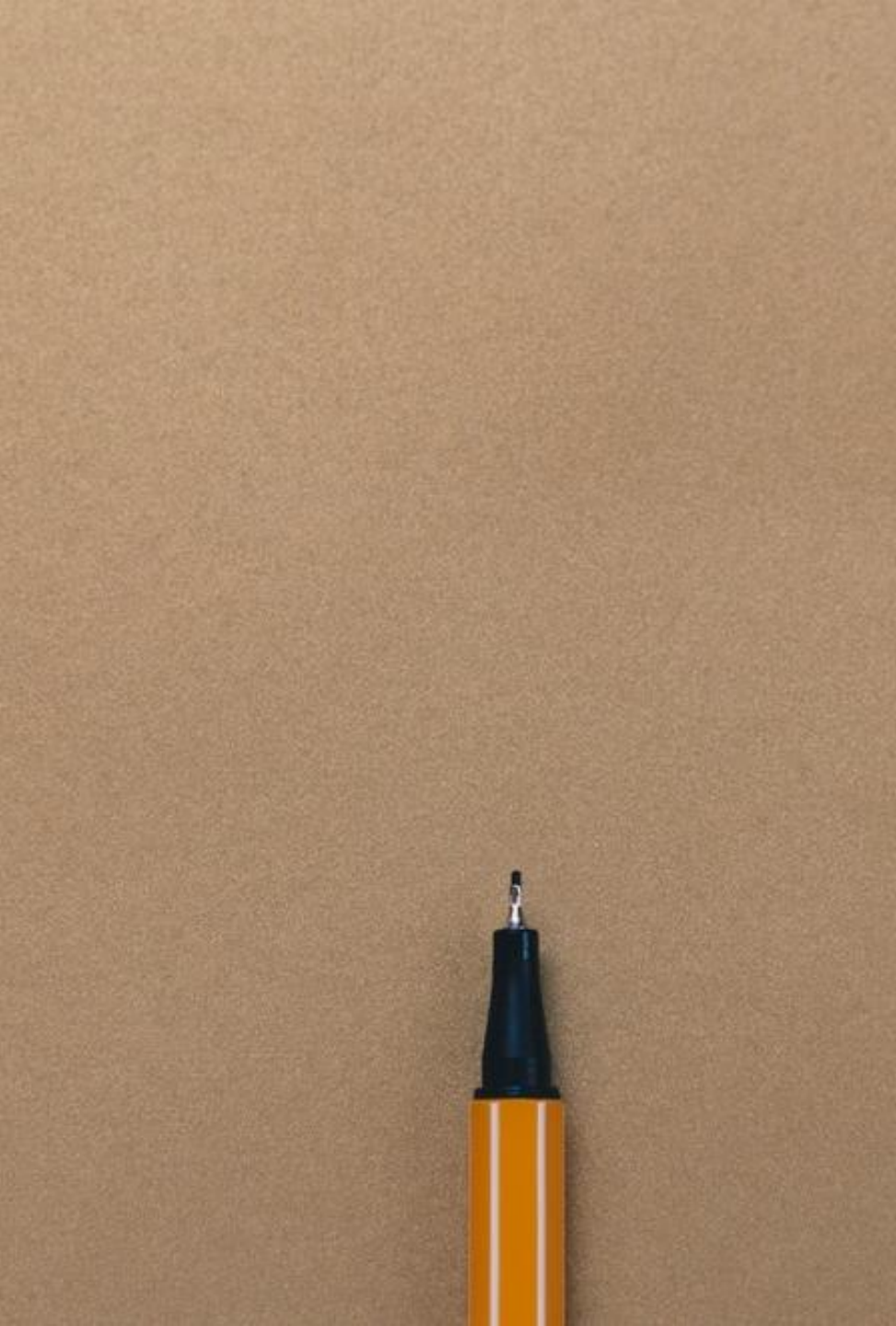


What do people want
to know?



What does the
literature say?

- 
- Planning ahead
 - Bodily changes that take place towards the end of life
 - Emotions when someone is ill, dying or caring
 - Common treatments, equipment and medications
 - Practical help and support a lay-carer can provide

- 
- Where to go for more help, information and support
 - Coping with the demands of being a carer
 - Bereavement
 - Practicalities after a death

What do members of the public want to know?

- Survey monkey questionnaire promoted via SPPC Twitter and e-bulletins
- 208 responses:
 - 80% from people who had experience of supporting someone facing the end of life
 - 20% from people who had never provided this kind of support

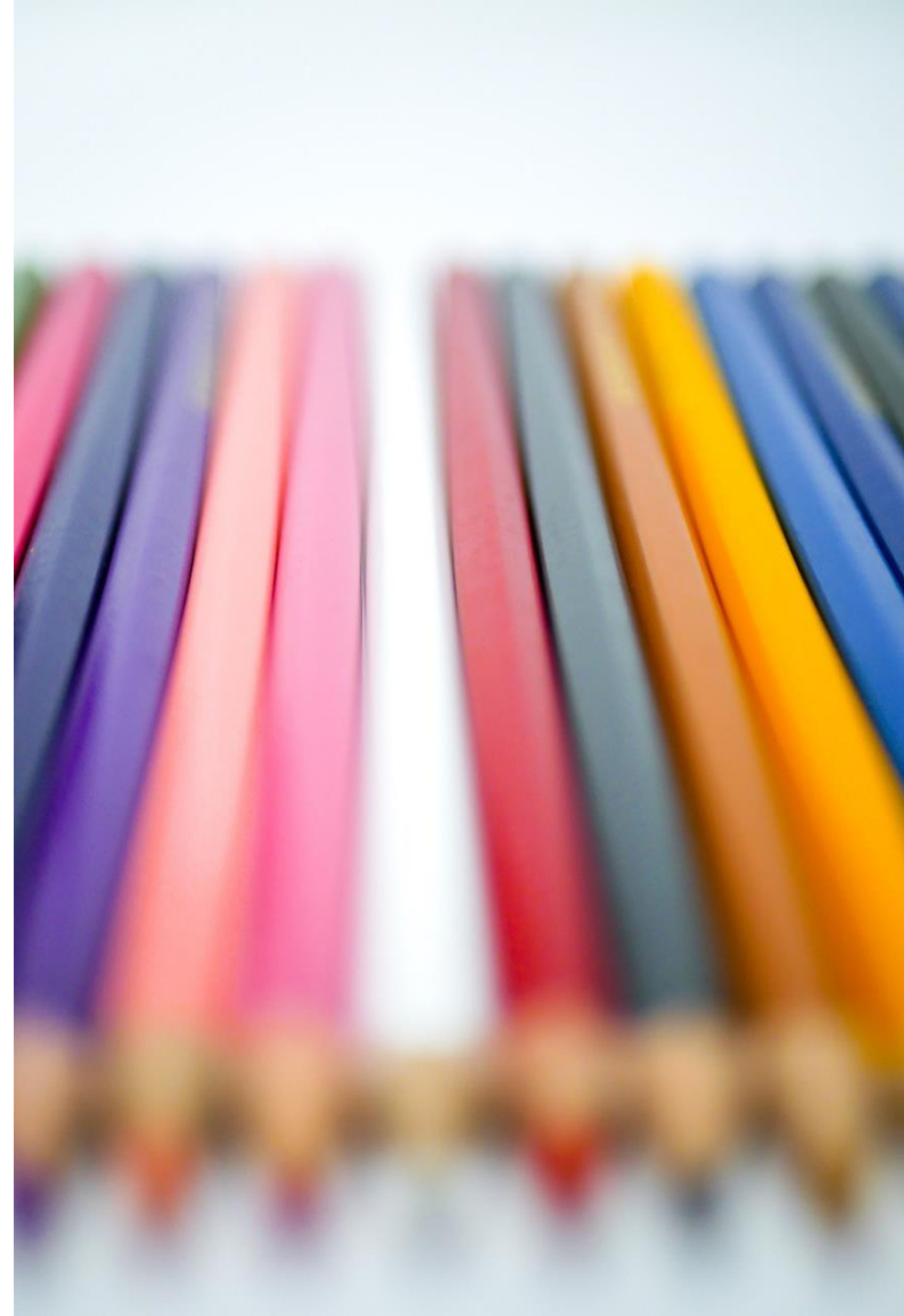


ALSO...

Lack of familiarity with some of the issues that commonly arise

Navigating the health and social care landscape

- What formal health & social care support is available (and what isn't)
- How the health and social care system is structured
- Rights to access support or to refuse medical intervention
- Advocating for someone who is ill



Learning outcomes: (Knowledge and Understanding

On completion of this course I will know about:

- the common patterns of how people die in Scotland.
- the roles different professionals and institutions play in supporting individuals and their families and carers towards the end of life.
- what planning people can undertake to prepare for the end of life.
- some of the emotional responses that are common when someone is dying.
- Some of the rights of individuals and carers.
- some of the bodily changes that we often go through in the last days of life.
- The kind of treatments, equipment and medications that are commonly used by healthcare staff towards the end of someone's life.
- some of the emotional and physical responses that are common when we are caring for someone who is dying, and when we are bereaved.

Learning outcomes: (communication skills)

On completion of this course I will:

- Be more confident engaging with others on subjects relating to death, dying and bereavement.
- Be more confident talking to someone about planning ahead for the end of life.
- Be able to talk with and/or listen to someone who is dying in a way that will make a positive difference, and feel more confident about doing so.
- Be able to talk with and/or listen to someone who caring or who is bereaved in a way that will make a positive difference, and feel more confident about doing so.

Learning
outcomes:
(applied
knowledge)

On completion of this course I
will:

- Be able to offer practical support which will make a positive difference to someone who is dying and feel more confident about offering such support.
- Be able to offer practical support which will make a positive difference to someone is bereaved, or who is supporting someone who is dying or bereaved, and feel more confident about offering such support.

Learning
outcomes:
(autonomy and
support)

On completion of this
course I will:

- Recognise when I need help and know how, when and where to access different kinds of help, information and support.

How was the course designed and developed?

Description

Video
module

Menu



Working group membership

Joan Adam Nurse Lecturer at St Columba's
Hospice (retired)

Russell Jones Acting Lead Chaplain,
Beatson West of Scotland Cancer Centre

Euan Paterson GP Facilitator, Glasgow
(retired)

Ruth McQuillan Master of Public Health
(online) Programme Director

Stewart Wilson Manager, North East
Edinburgh Counselling Service

Mark, Robert, Rebecca – Scottish
Partnership for Palliative Care



Designing the course

- Learning outcomes
- Logical structure
- Basic secondary education
- Pedagogy – how do people learn?
- Practicalities
- Building a safe and supportive group

“because death education programmes are typically not designed to mobilize networks or create social action they may actually promote compliance with the dominant medical approach by reinforcing the primacy of professional knowledge.

As such these traditional models of education rarely recognize, mobilize or develop the existing knowledge within communities.”

Noonan, Kerrie & Horsfall, Debbie & Leonard, Rosemary & Rosenberg, John. (2016). Developing death literacy. *Progress in Palliative Care*. 24.



Course Ethos

- It should empower communities rather than be professional-led
- Focus on learning and working together - every participant on the course brings valuable experience
- Accessible and inclusive



Piloted in Dundee and
Musselburgh.

Feedback sought from
participants and
facilitators.

External expert
feedback sought.

Changes made.

Ongoing feedback and
tweaks.



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

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

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



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 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

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

Film



The EASE Snowball

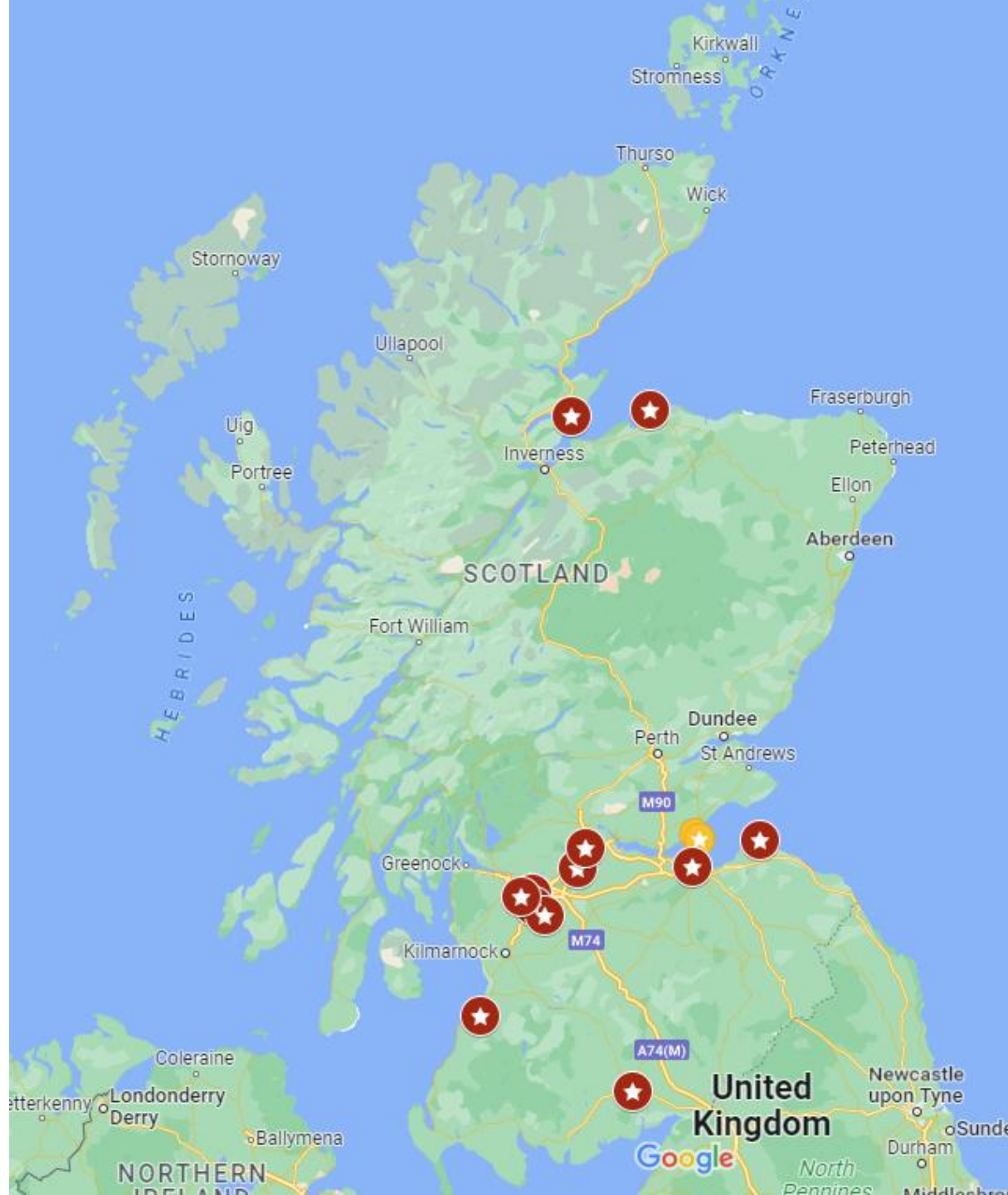
The vision: that EASE will be delivered in communities across Scotland, by people from those communities

- We started small!
- We work within our capacity and resource
- We are responsive to demand, but we are also okay with saying no – or not yet
- We evaluate as we go
- As the snowball grows and picks up pace, we check in to see if we need to slow down, redirect or change shape

The Story So Far

**26 online
courses**
(2021-23)

**8 face to
face
courses**
(2019,
2022-3)



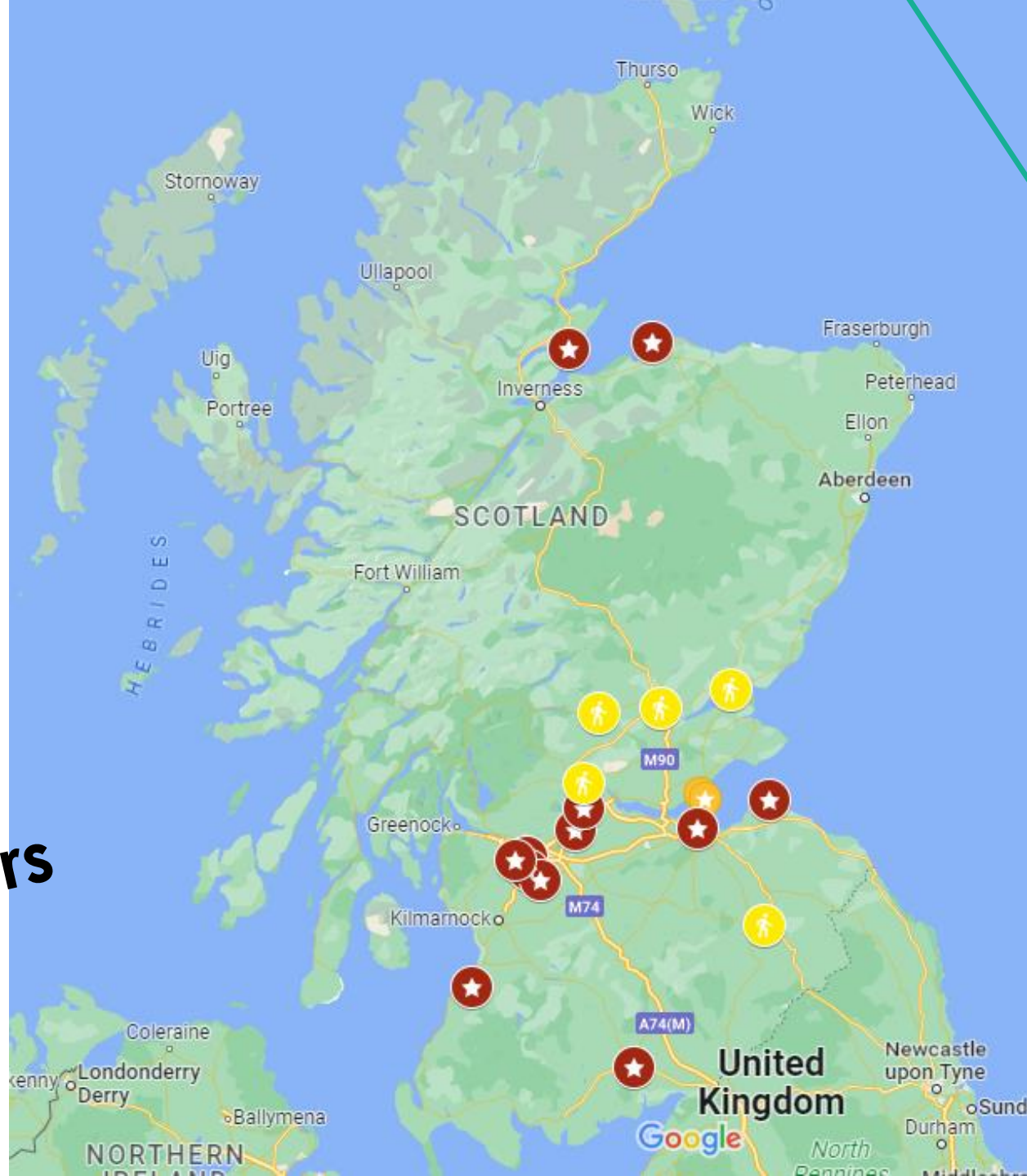
341
people
have
complete
d the EASE
course

6

**facilitator
cohorts**

55

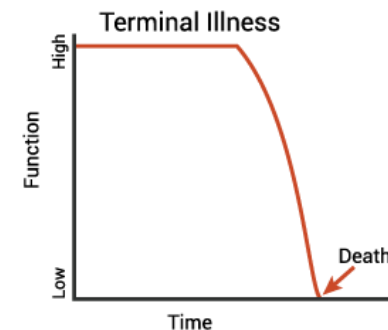
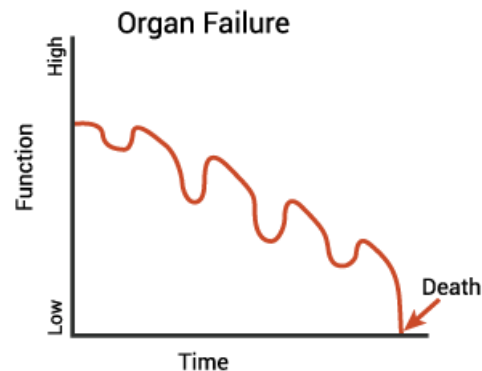
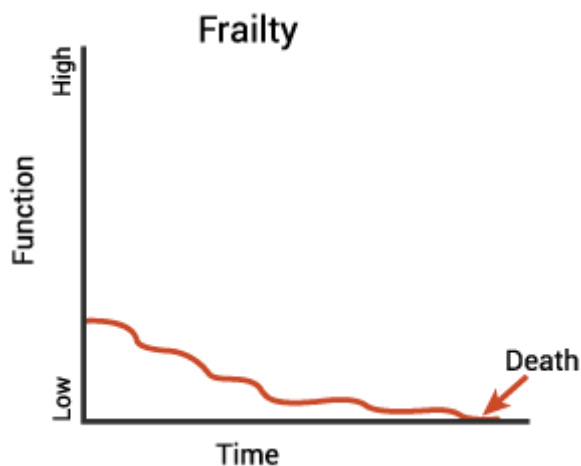
**Facilitators
trained**



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 of death
anymore”

More information

[www.goodlifedeathgrief.org.uk/content/ea
se/](http://www.goodlifedeathgrief.org.uk/content/ea
se/)

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