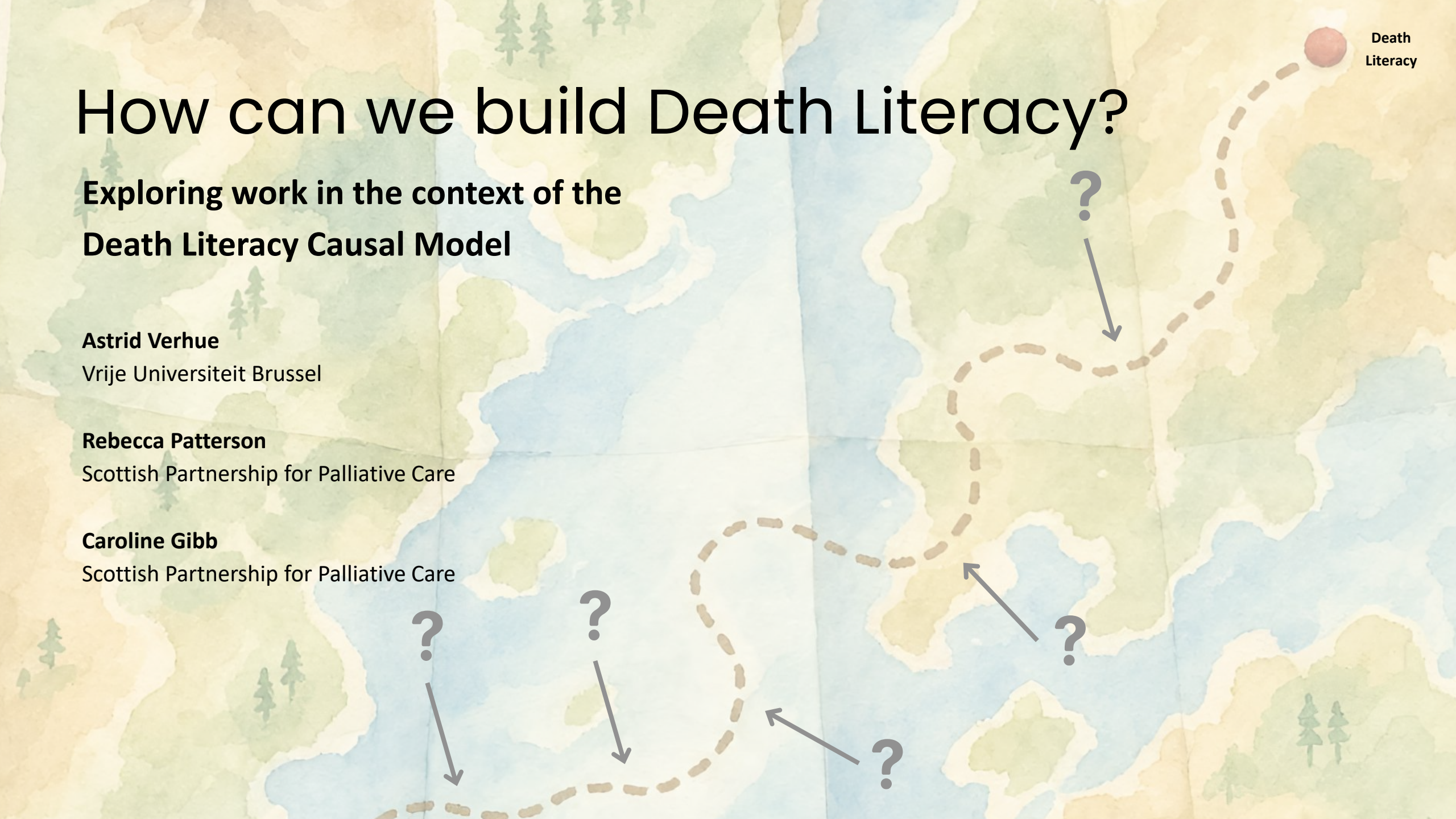


How can we build Death Literacy?

Exploring work in the context of the Death Literacy Causal Model

Astrid Verhue
Vrije Universiteit Brussel

Rebecca Patterson
Scottish Partnership for Palliative Care

Caroline Gibb
Scottish Partnership for Palliative Care

good life good death good grief

"We want to make Scotland a place where everyone knows how to help when someone is caring, dying or grieving."

Good Life, Good Death, Good Grief
Est 2011

Rebecca Patterson

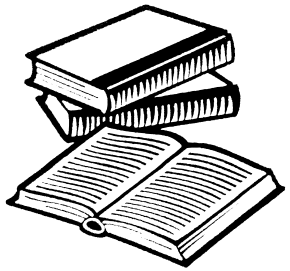
Director of Good Life, Good Death, Good Grief



Hosted by:

Scottish Partnership for Palliative Care

WORKS TO ENCOURAGE



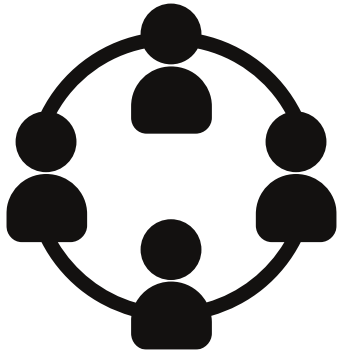
Opportunities

to talk about, to plan ahead for, give support and receive support relating to death, dying and bereavement.



Knowledge & Skills

to enable people to deal with these issues themselves and offer support to others.



Supportive environments

within communities and institutions, that enable people to learn about these issues and support eachother.

A network

to connect with others, share learning and work together

A voice

to advocate for change.

good life good death good grief

Resources

innovative ideas and practical tools you can use for free

Projects

that lead change and support community-led action



Coming Up...

What is “Death Literacy”?

Explaining the Interactive Map

Introducing the Death Literacy Causal Model

Interactive session: How does your work fit into the Causal Model?

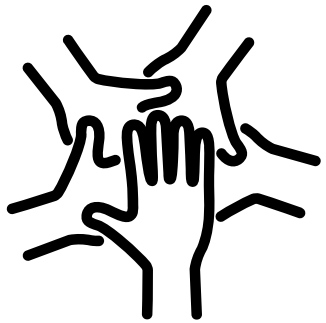
Measuring Death Literacy

What is death literacy?

“Death literacy is defined as a set of knowledge and skills that make it possible to gain access to, understand and act upon end-of-life and death care options. People, and communities, with high levels of death literacy have context-specific knowledge about the death system and the ability to put that knowledge into practice.”

Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2016). Developing death literacy. *Progress in Palliative Care*, *24*(1), 31–35. https://doi.org/10.1080/09699260.2015.1103498





ACTION



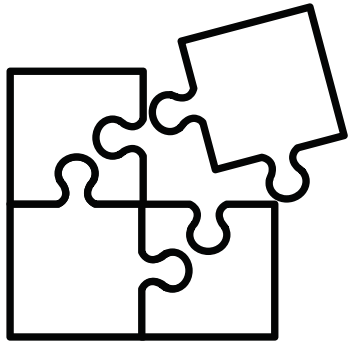
FACTUAL KNOWLEDGE

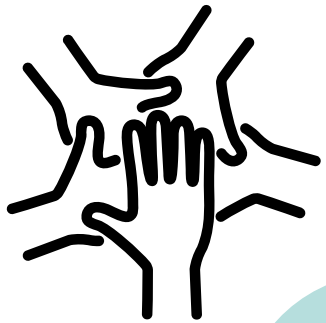


SKILLS

EXPERIENCE







I can mobilise relevant community groups and networks when there's the need.

I can access relevant services.

I know how to make decisions about care.



I know how to navigate palliative care.

I know how to plan for the end of life.



I am confident to talk with friends and family about dying, death and loss.

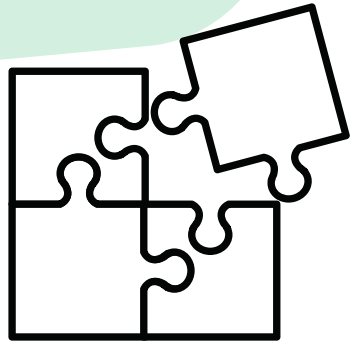
I have been bereaved.

I have supported someone towards the end of life.

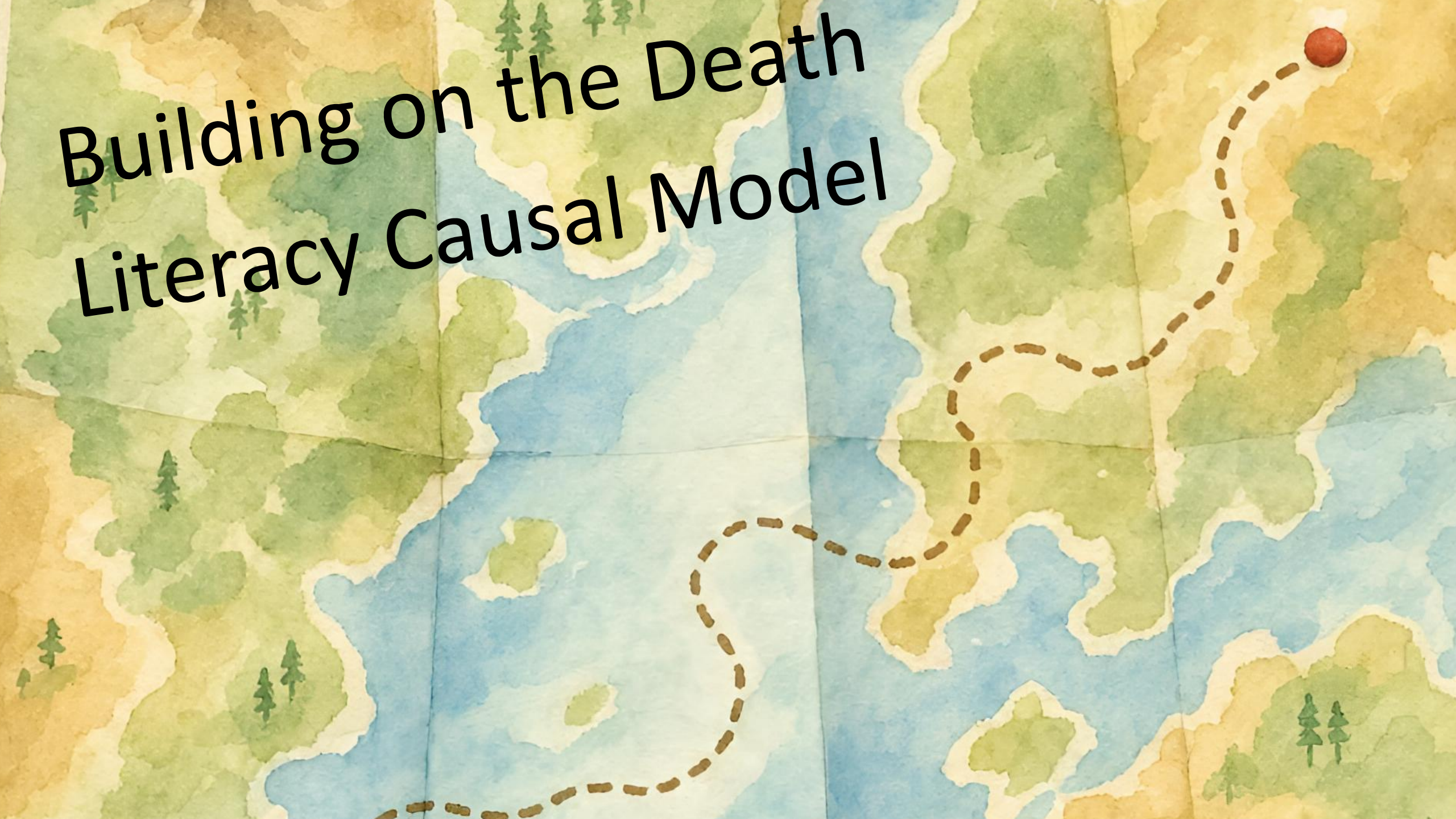
I can provide hands-on care.

These experiences have grown my knowledge and wisdom.





Building on the Death Literacy Causal Model



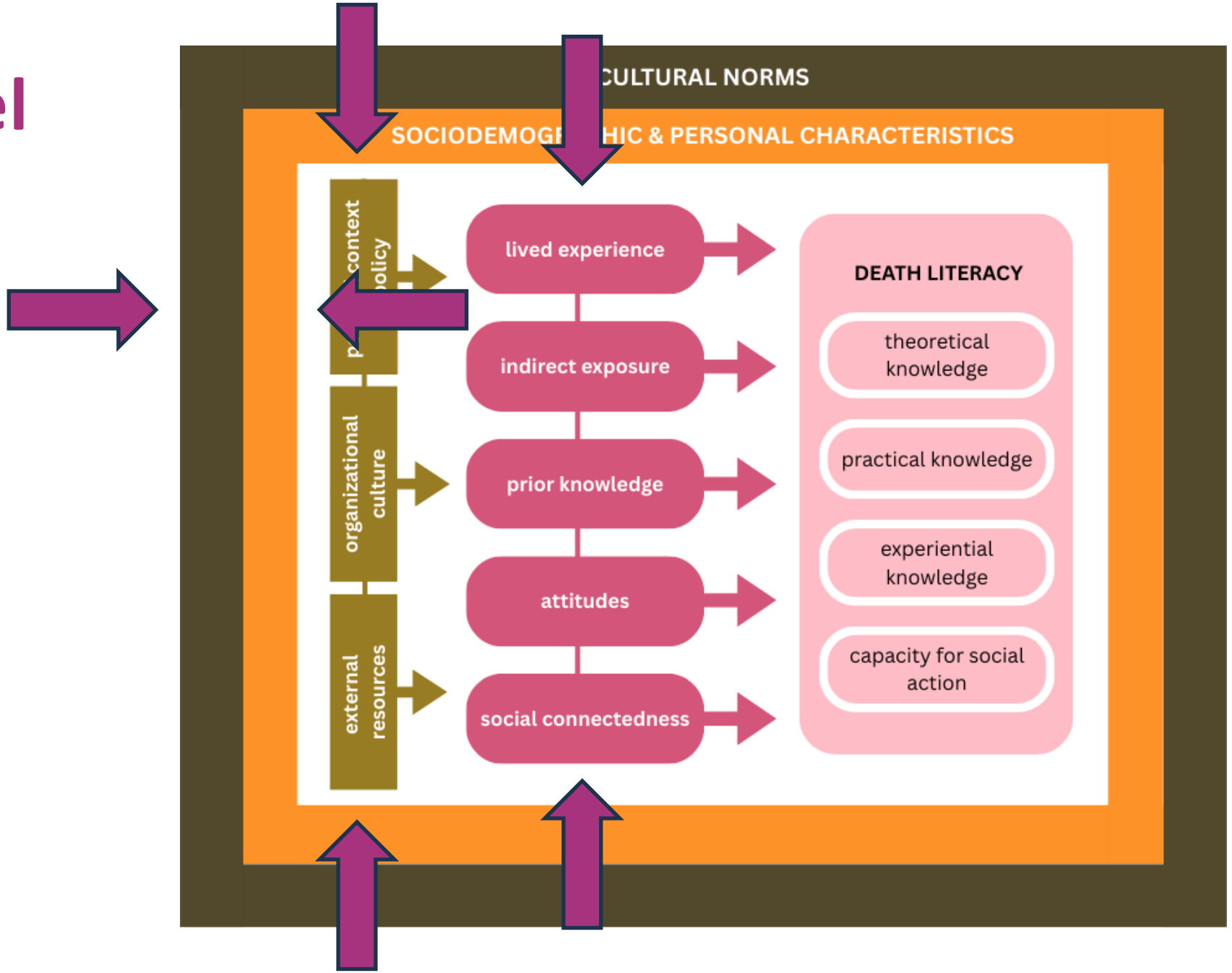
Building on the Death Literacy Causal Model

Current work that increases death literacy.

Potential future activities or projects

Personal experiences that increased your death literacy

Causal model



CONTEXTUAL VARIABLES

cultural norms

sociodemographic characteristics

personal characteristics







- Rio Ferdinand – *Being Mum & Dad documentary*
- Prince William and Prince Harry – talking about their mother's death
- Greg Wise talking about his sister's death on Strictly Come Dancing
- Chris Hemsworth's Network series Limitless

CONTEXTUAL VARIABLES

cultural norms

sociodemographic characteristics

personal characteristics



CONTEXTUAL VARIABLES

cultural norms

sociodemographic characteristics

personal characteristics





If we can **understand** how socioeconomic and personal characteristics affect experiences….

perhaps we can learn how to provide better support?

EASE

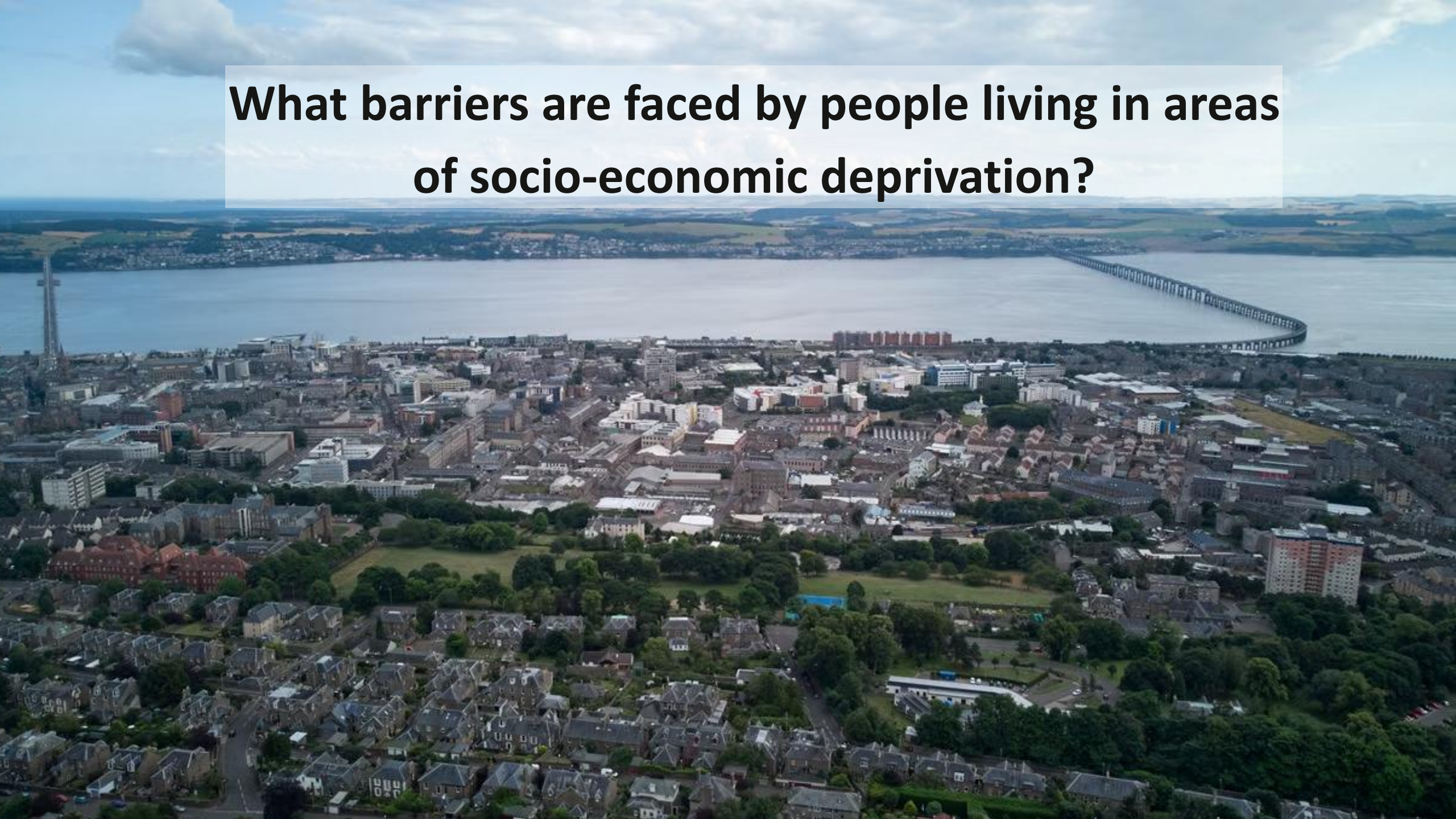
END OF LIFE AID SKILLS

FOR EVERYONE

EASE is a public education course about death, dying and bereavement.



What barriers are faced by people living in areas of socio-economic deprivation?



EASE
END OF LIFE AID SKILLS
FOR EVERYONE
Dundee

COMMUNITY FUND

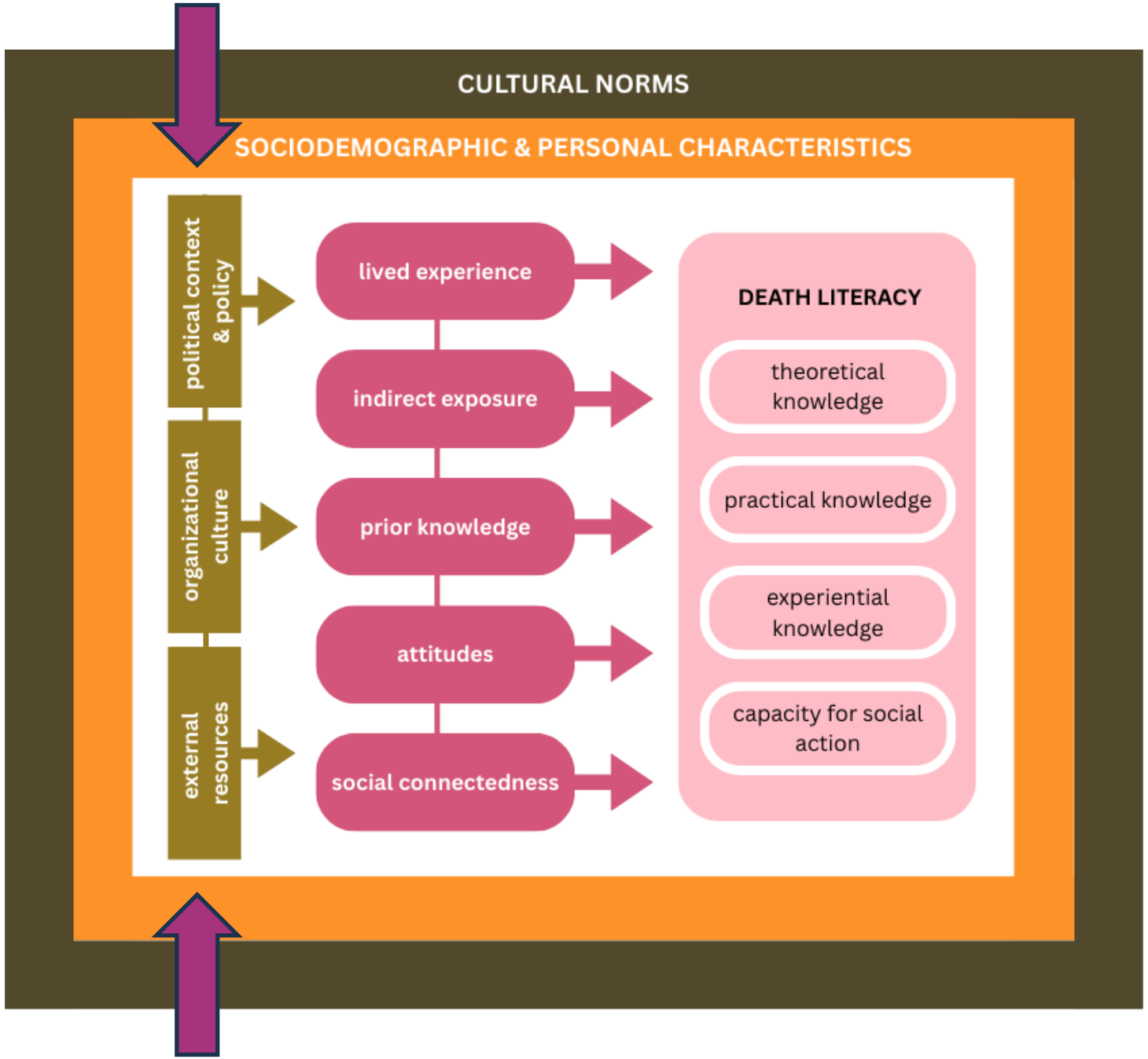
good life good death good grief

Scottish Partnership for Palliative Care

Barriers faced by people living in areas of socio-economic deprivation:

- People are worried that they won't be able to understand the course – it will be too hard for them.
- People fear unfamiliar situations, people and places.




CULTURAL NORMS
SOCIODEMOGRAPHIC & PERSONAL CHARACTERISTICS
political context & policy
organizational culture
external resources
lived experience
indirect exposure
prior knowledge
attitudes
social connectedness
DEATH LITERACY
theoretical knowledge
practical knowledge
experiential knowledge
capacity for social action

ENVIRONMENT

policy & political context

institutional culture

external resources





How do we influence the policy context?

We write reports that explain what needs to happen.

We respond to consultations by Scottish Government and Public Health Scotland.



Dying in the Margins

"For people on low incomes, terminal illness plunged them further into hardship"

A 4-year research project (2019-2023) examined people's experiences of home dying in the context of financial hardship and deprivation in the UK.

University of Glasgow

Marie Curie

Marie Curie

Nobody should die in poverty

It shouldn't be harder to make ends meet at the end of your life. But many people are pushed into poverty when they're diagnosed with a terminal illness.

Marie Curie are calling on government to...

- Give dying people their State Pension
- Protect dying people from soaring energy bills
- Support dying parents with childcare costs
- Strengthen the rights of terminally ill tenants, their families and carers.

ENVIRONMENT

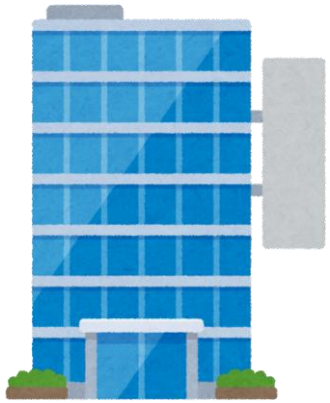
policy & political context

organizational culture

external resources







The Bereavement Charter Mark provides a framework and resources to help communities become more supportive of bereaved people

Organisational Culture

In workplaces:



In schools



ENVIRONMENT

policy & political context

institutional culture

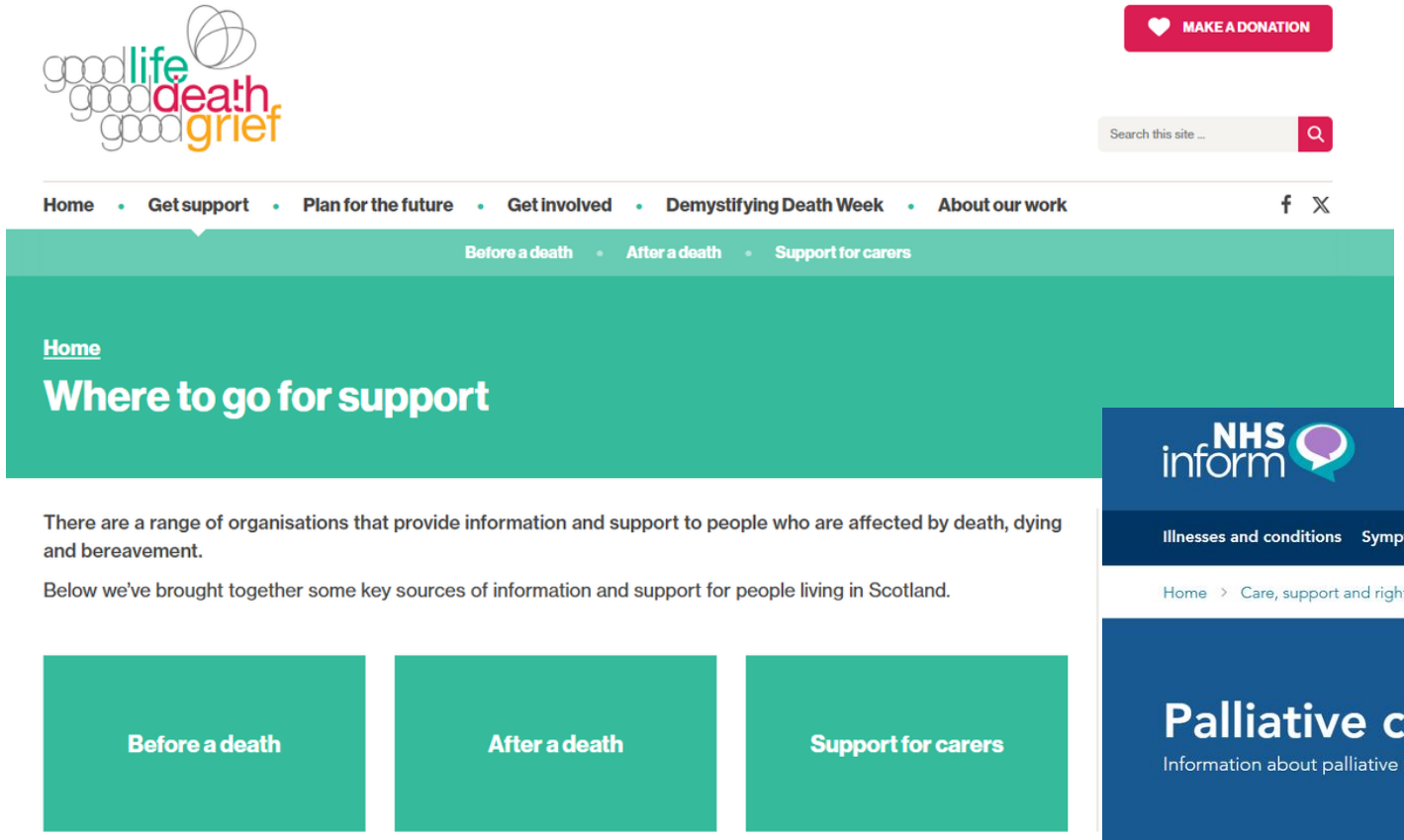
external resources

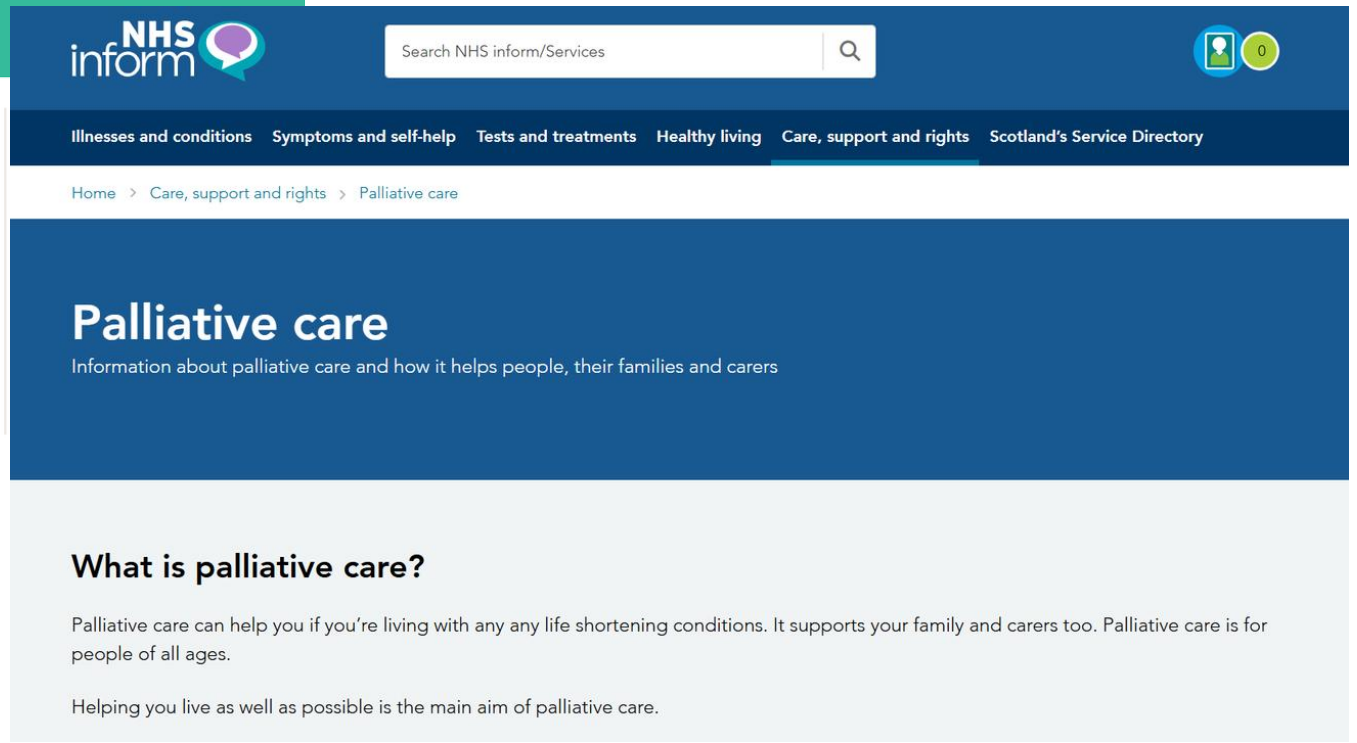


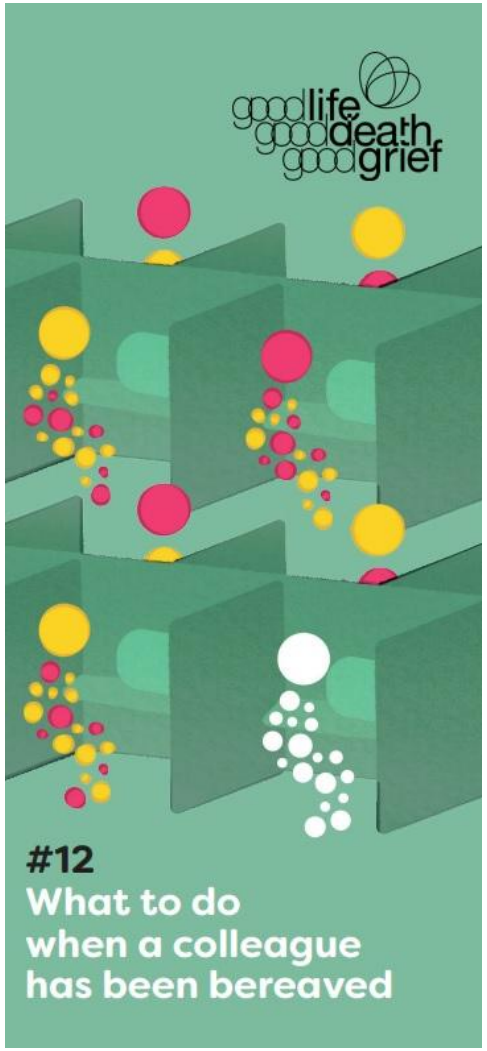


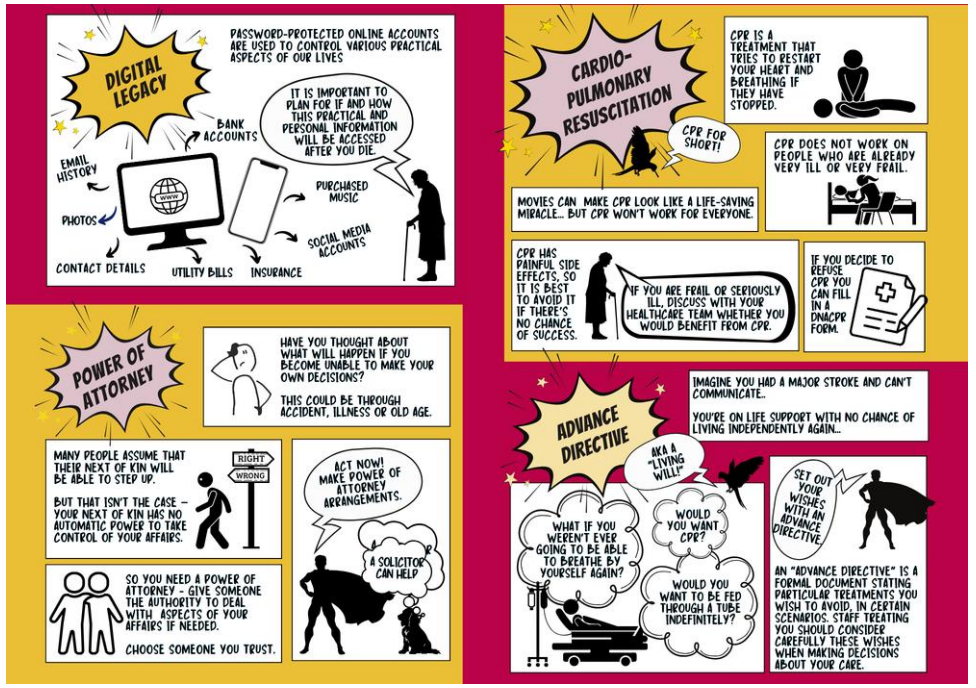


Websites


MAKE A DONATION
Search this site ...
Home • Get support • Plan for the future • Get involved • Demystifying Death Week • About our work
Before a death • After a death • Support for carers
Home
Where to go for support
There are a range of organisations that provide information and support to people who are affected by death, dying and bereavement.
Below we've brought together some key sources of information and support for people living in Scotland.
Before a death
After a death
Support for carers


NHS inform
Search NHS inform/Services
Illnesses and conditions
Symptoms and self-help
Tests and treatments
Healthy living
Care, support and rights
Scotland's Service Directory
Home > Care, support and rights > Palliative care
Palliative care
Information about palliative care and how it helps people, their families and carers
What is palliative care?
Palliative care can help you if you're living with any any life shortening conditions. It supports your family and carers too. Palliative care is for people of all ages.
Helping you live as well as possible is the main aim of palliative care.



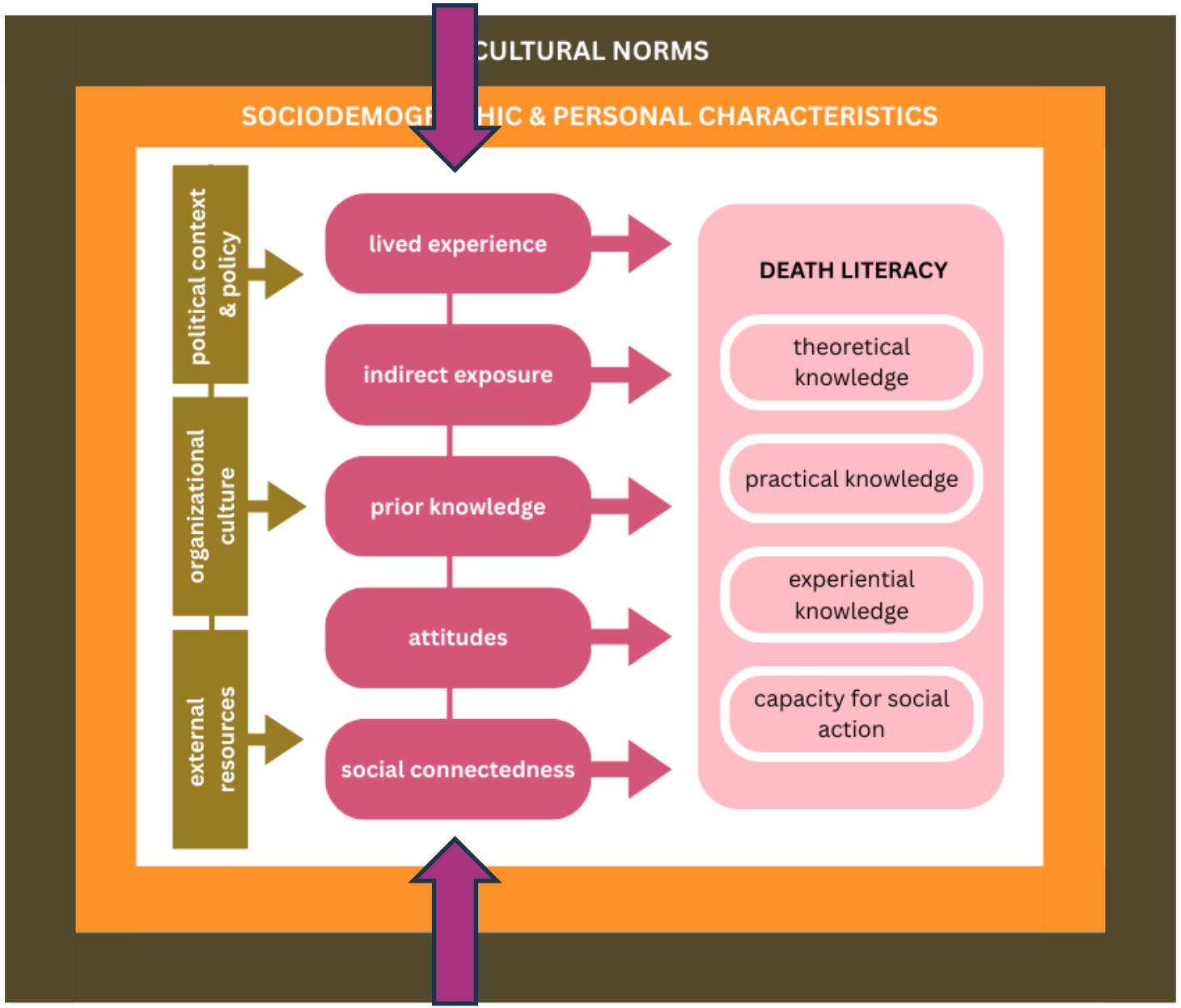




Information leaflets

&

Short films


CULTURAL NORMS
SOCIODEMOG HIC & PERSONAL CHARACTERISTICS
political context & policy
organizational culture
external resources
lived experience
indirect exposure
prior knowledge
attitudes
social connectedness
DEATH LITERACY
theoretical knowledge
practical knowledge
experiential knowledge
capacity for social action

INDIVIDUAL LEVEL

lived experience | indirect exposure | prior knowledge | attitudes | social connectedness







No-one Dies Alone



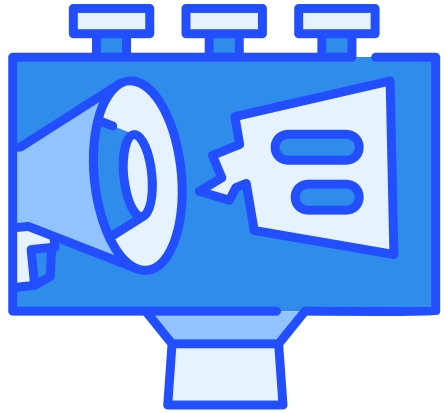
In Inverclyde and Ayrshire, volunteers and hospitals work together so that people dying in hospital have company.

INDIVIDUAL LEVEL

lived experience | **indirect exposure** | prior knowledge | attitudes | social connectedness







EASE

END OF LIFE AID SKILLS

FOR EVERYONE

An education course for people who who want to be better equipped to help friends or family who are caring, dying, or grieving.



good life good death good grief

POWERS, PUZZLES & PRESCIENCE

A SUPERHERO HAS GONE MISSING. CAN YOU SOLVE THE MYSTERY AND UNLOCK THE WISDOM OF FORESIGHT?



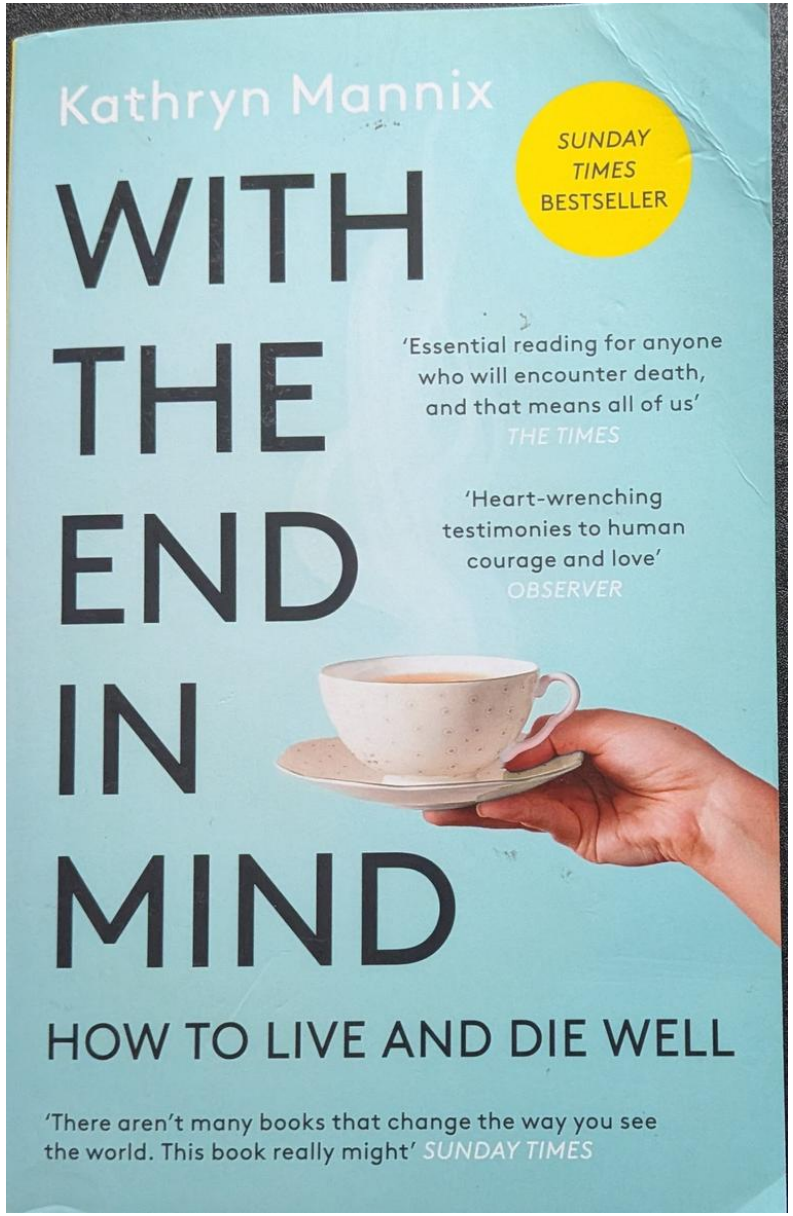


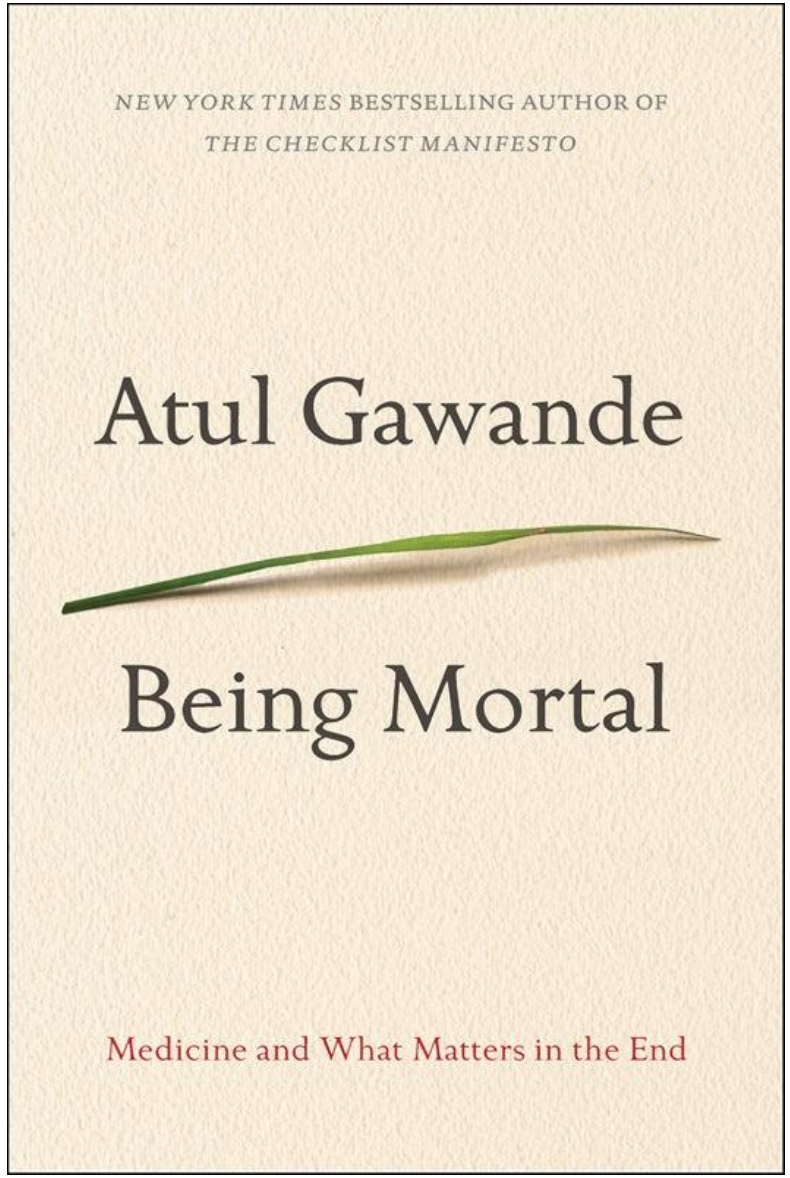


Demystifying death week

Bringing dying into the limelight

Demystifying Death Week is about
shining a light on death, dying and bereavement in Scotland.


Kathryn Mannix
SUNDAY TIMES BESTSELLER
WITH THE END IN MIND
'Essential reading for anyone who will encounter death, and that means all of us' THE TIMES
'Heart-wrenching testimonies to human courage and love' OBSERVER
HOW TO LIVE AND DIE WELL
'There aren't many books that change the way you see the world. This book really might' SUNDAY TIMES


NEW YORK TIMES BESTSELLING AUTHOR OF THE CHECKLIST MANIFESTO
Atul Gawande
Being Mortal
Medicine and What Matters in the End

INDIVIDUAL LEVEL

lived experience | indirect exposure | **prior knowledge** | attitudes | social connectedness







EASE

END OF LIFE AID SKILLS

FOR EVERYONE

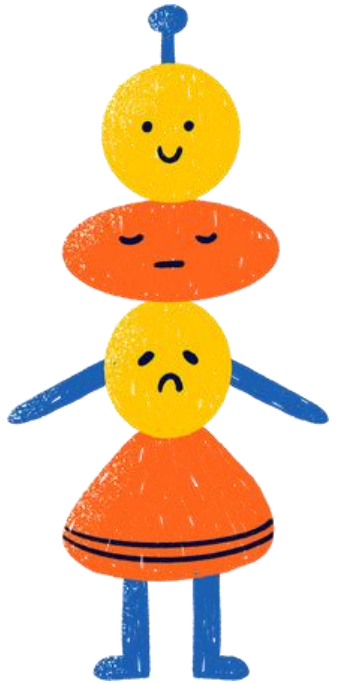
How do you navigate the healthcare system?

How do you advocate for someone who can't communicate well?



INDIVIDUAL LEVEL

lived experience | indirect exposure | prior knowledge | **attitudes** | social connectedness





It Takes A Village

A powerful series of portraits exploring the idea that as people's health deteriorates, care and support comes in many guises.

INDIVIDUAL LEVEL

lived experience | indirect exposure | prior knowledge | attitudes | **social connectedness**



to absent friends ...

a people's festival of storytelling and remembrance.





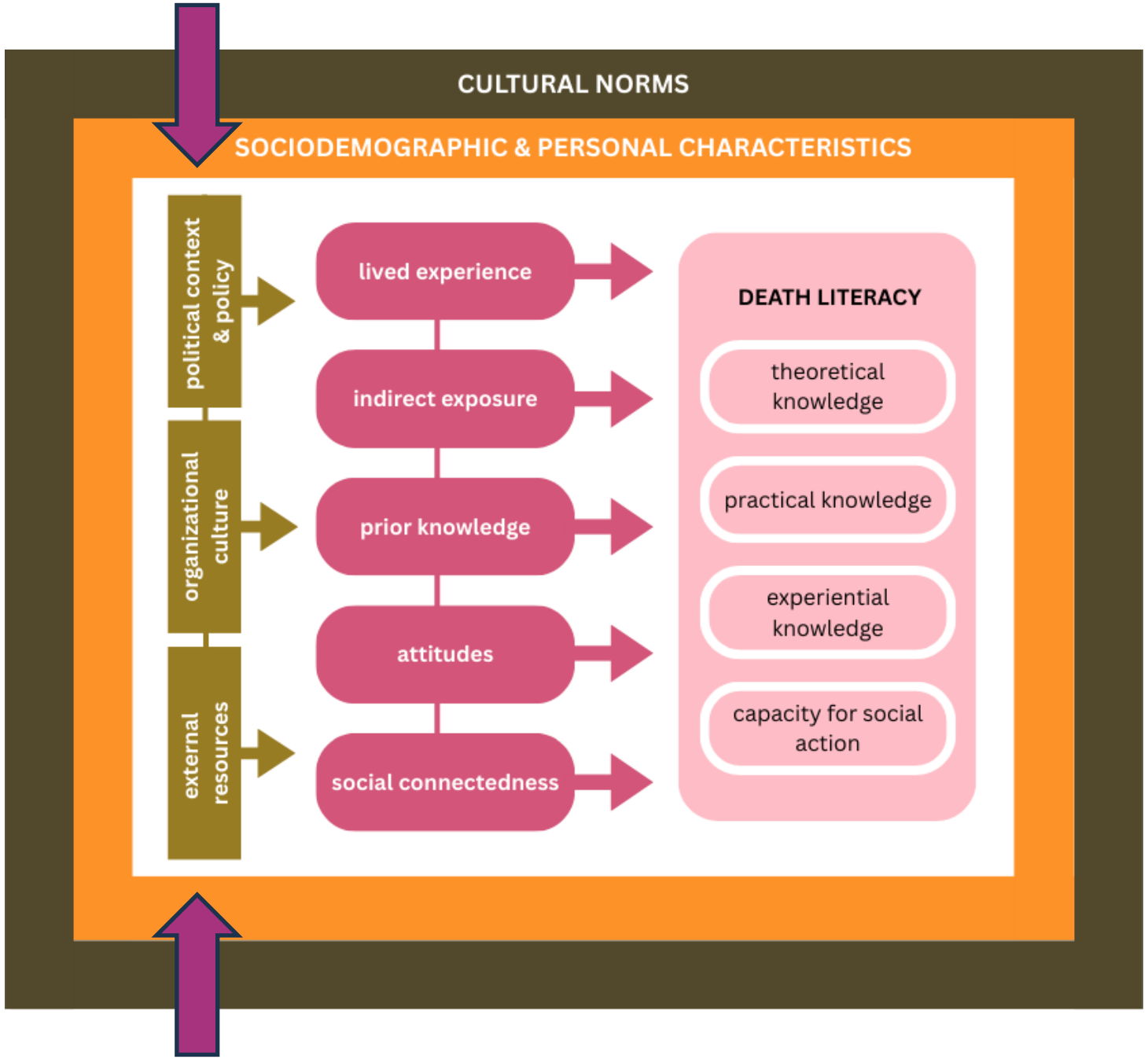


Building on the Death Literacy Causal Model

Current work that increases death literacy.

Potential future activities or projects

Personal experiences that increased your death literacy


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Can we measure Death Literacy?

The Death Literacy Index is a 29-item survey tool with four scales that provide information about:

1. Practical Knowledge (8 items)
2. Experiential Knowledge (5 items)
3. Factual Knowledge (7 items)
4. Community Knowledge (9 items)



More information

DEATH LITERACY Institute

https://www.deathliteracy.institute/death-literacy-index-questions

Palliative Care & Social Practice

Progressing the Death Literacy Index: the development of a revised version (DLI-R) and a short format (DLI-9)

Kerrie Noonan, Andrea Grindrod, Sumina Shrestha, Sora Lee, Rosemary Leonard and Therese Johansson

DEATH STUDIES
https://doi.org/10.1080/07481187.2021.1894268

Routledge
Taylor & Francis Group

Check for updates

Developing a death literacy index

Rosemary Leonard[a], Kerrie Noonan[a], Debbie Horsfall[a], Marguerite Kelly[a], John P. Rosenberg[a,b], Andrea Grindrod[c], Bruce Rumbold[c], and Alison Rahn[a,d,e]

[a]School of Social Sciences, Western Sydney University, Sydney, Australia; [b]School of Nursing, Midwifery and Paramedicine, University of the Sunshine Coast, Caboolture, Australia; [c]Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, Australia; [d]Australian Centre for Evidence Based Aged Care, School of Nursing and Midwifery, Melbourne, Australia; [e]School of Humanities, Arts and Social Sciences, University of New England, Armidale, Australia

readyCONNECT







Death literate communities: learning together, supporting each other

3 March 2027

Renfield Centre, Glasgow