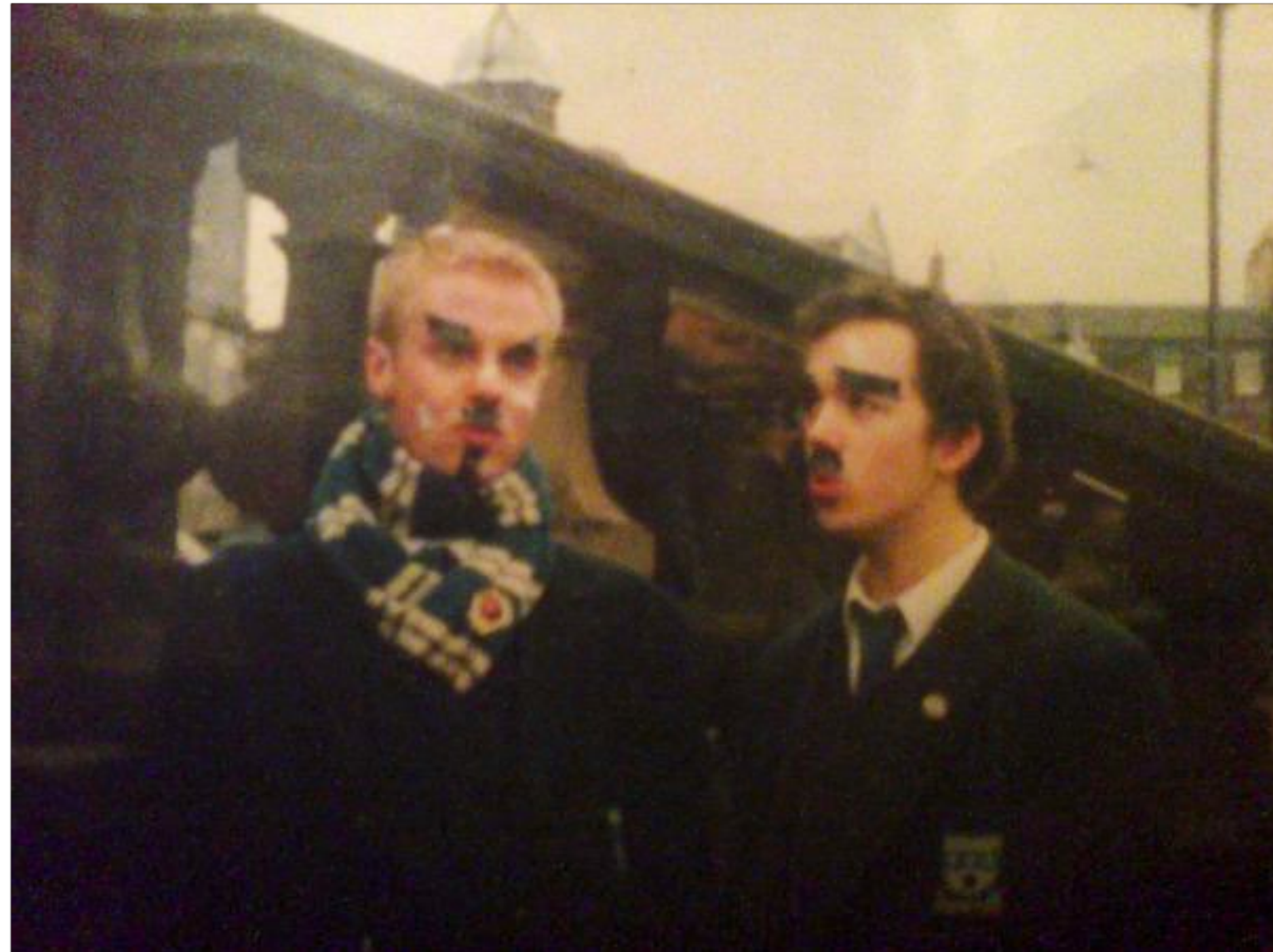


Death is the ultimate ending,
and we are not good at endings

Designing at the end

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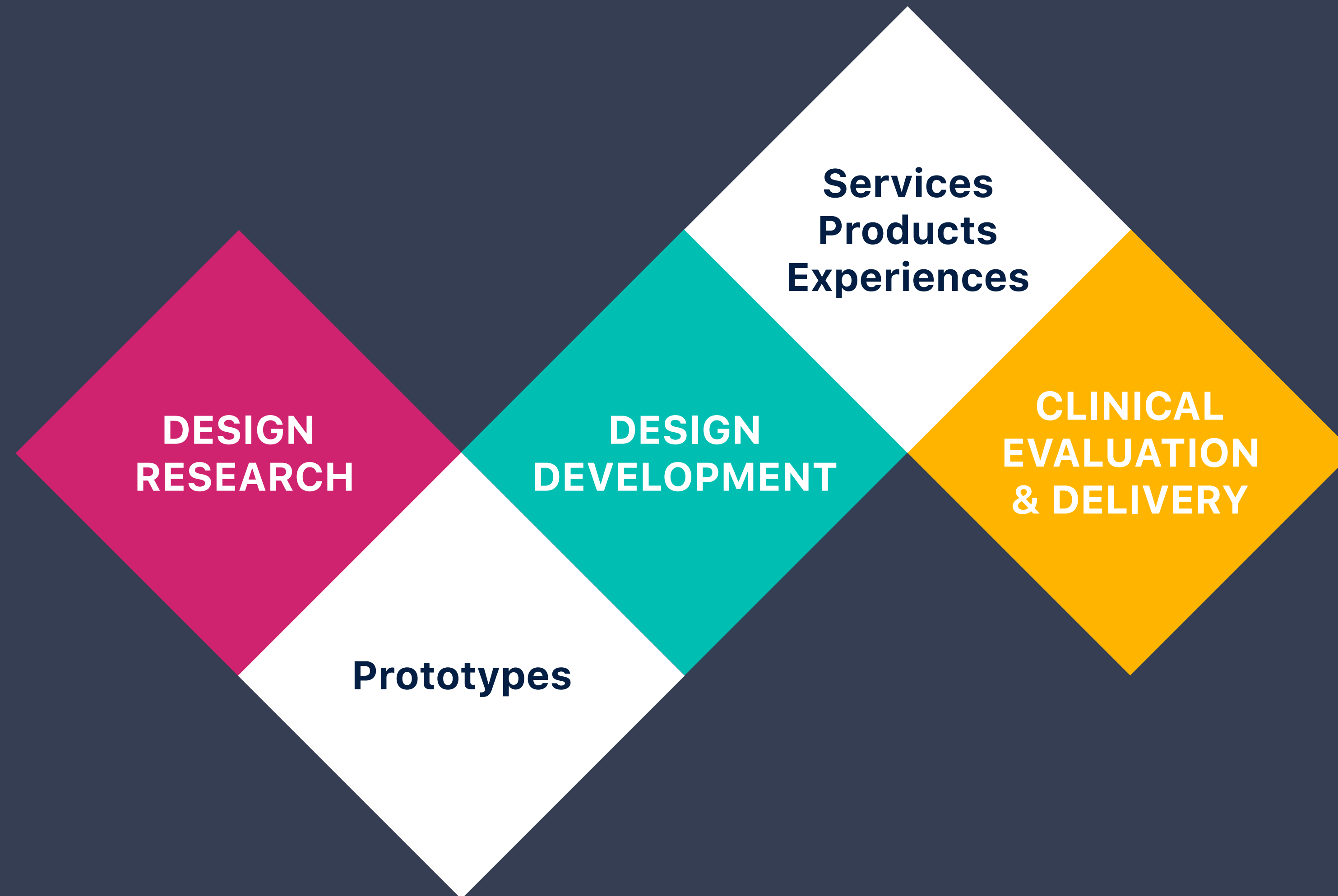


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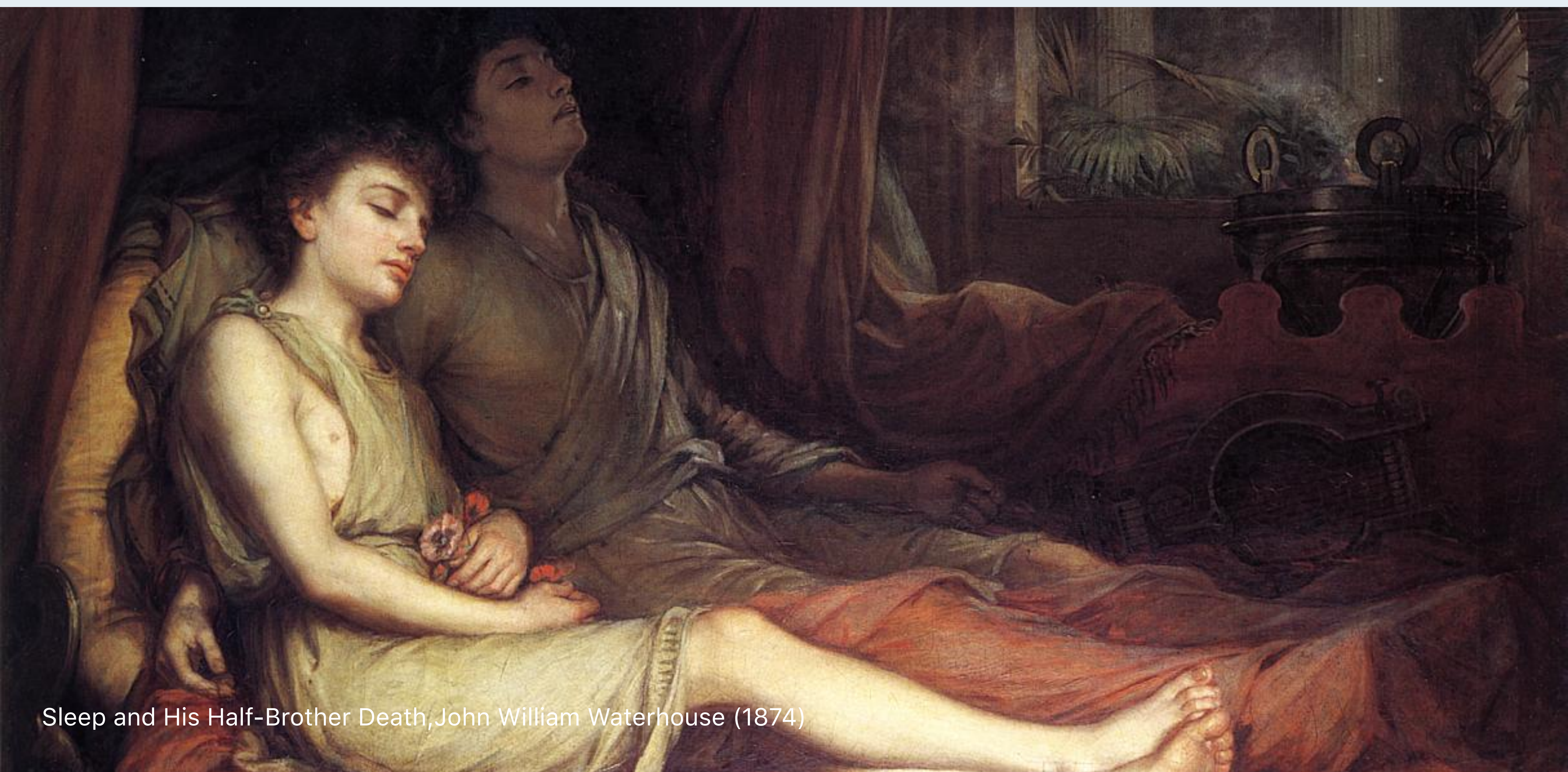
From research to delivery



What is end-of-life care?

End-of-life care involves treatment, care and support for people who are nearing the end of their life.

The aim is to help you to live as comfortably as possible in the time you have left. It covers all aspects of you, your life and those around you.

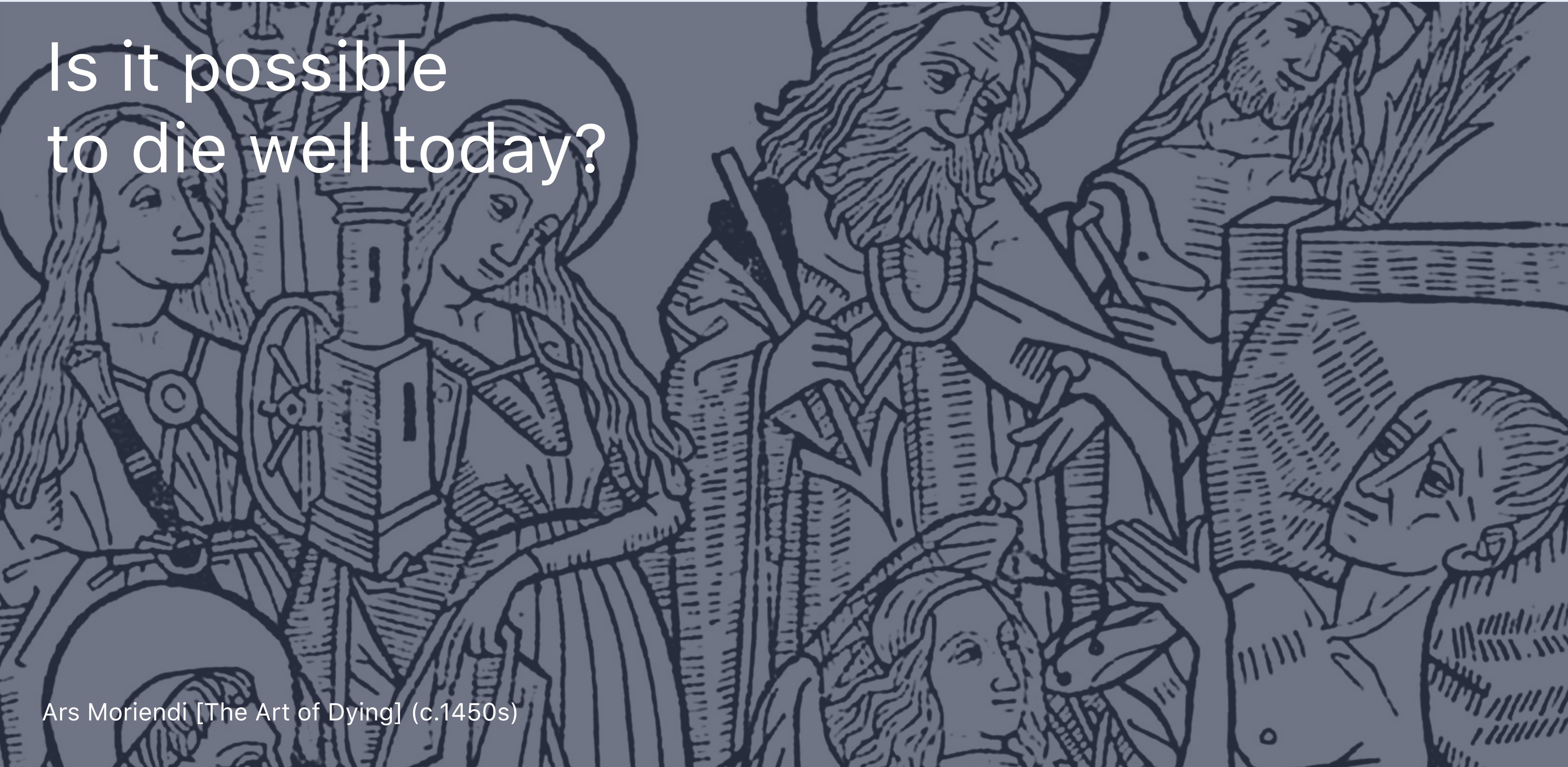


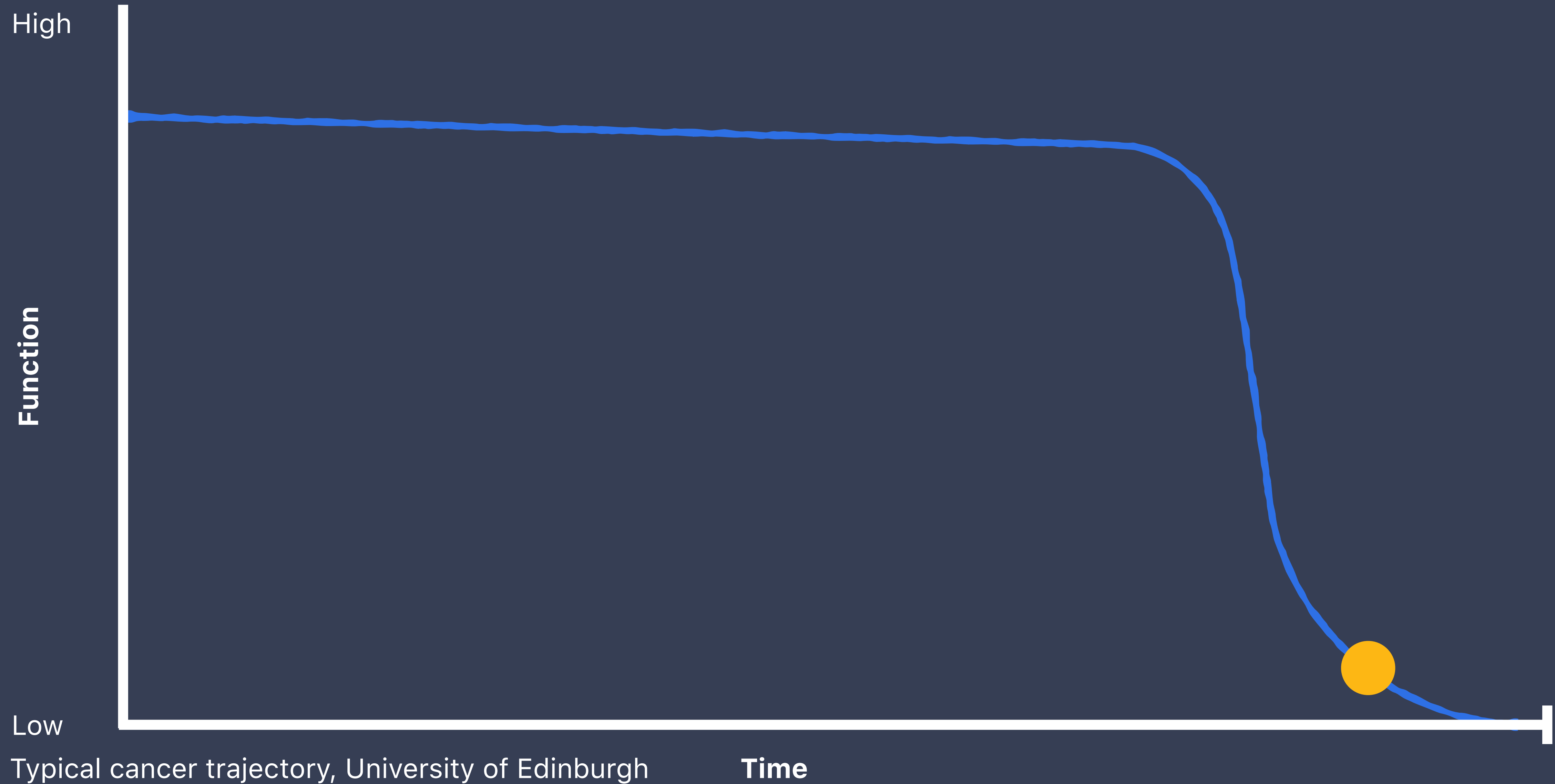
Sleep and His Half-Brother Death, John William Waterhouse (1874)

A modern death is
often complicated,
sometimes messy
and usually involving
lots of strangers

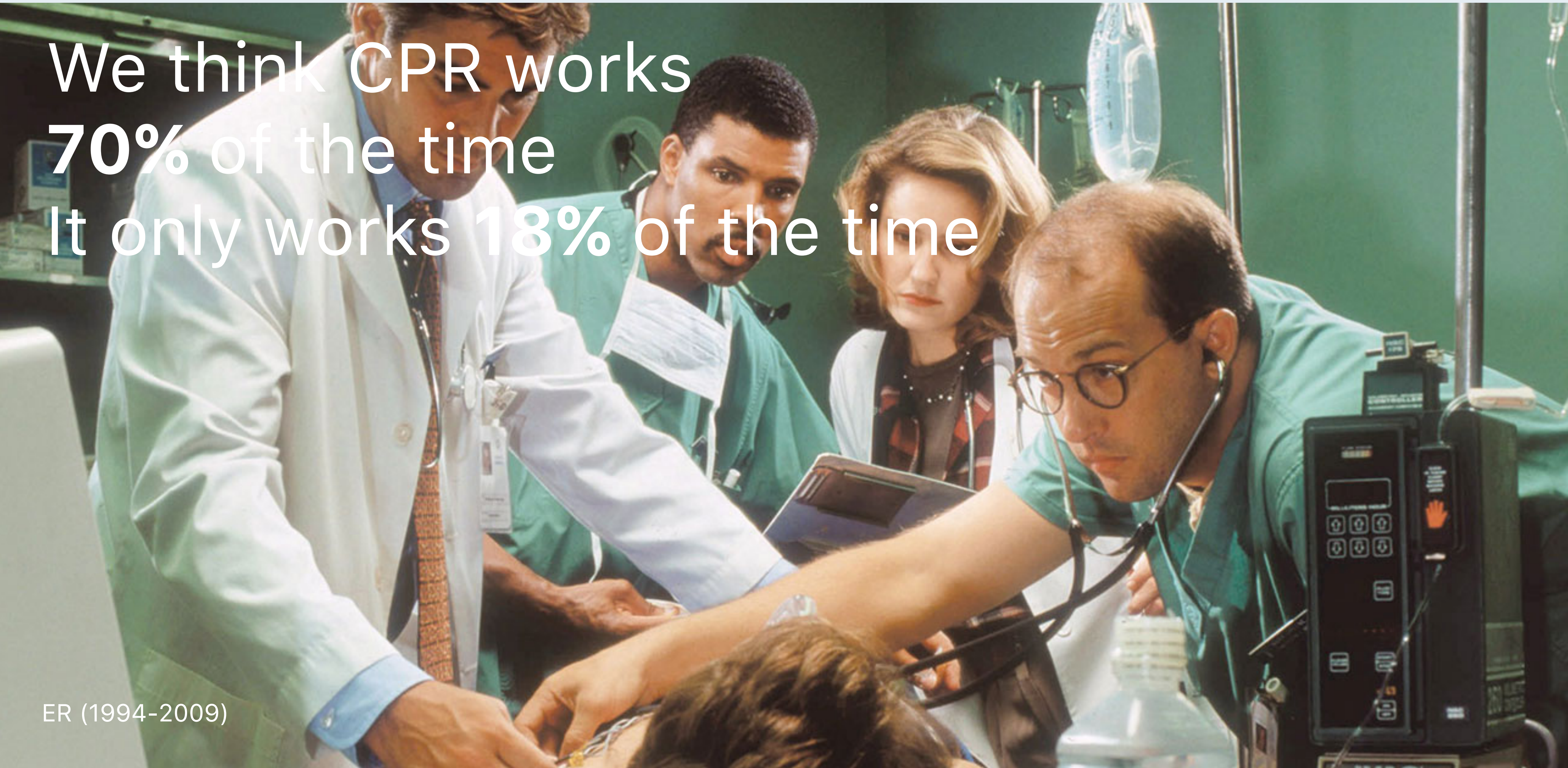


Is it possible
to die well today?



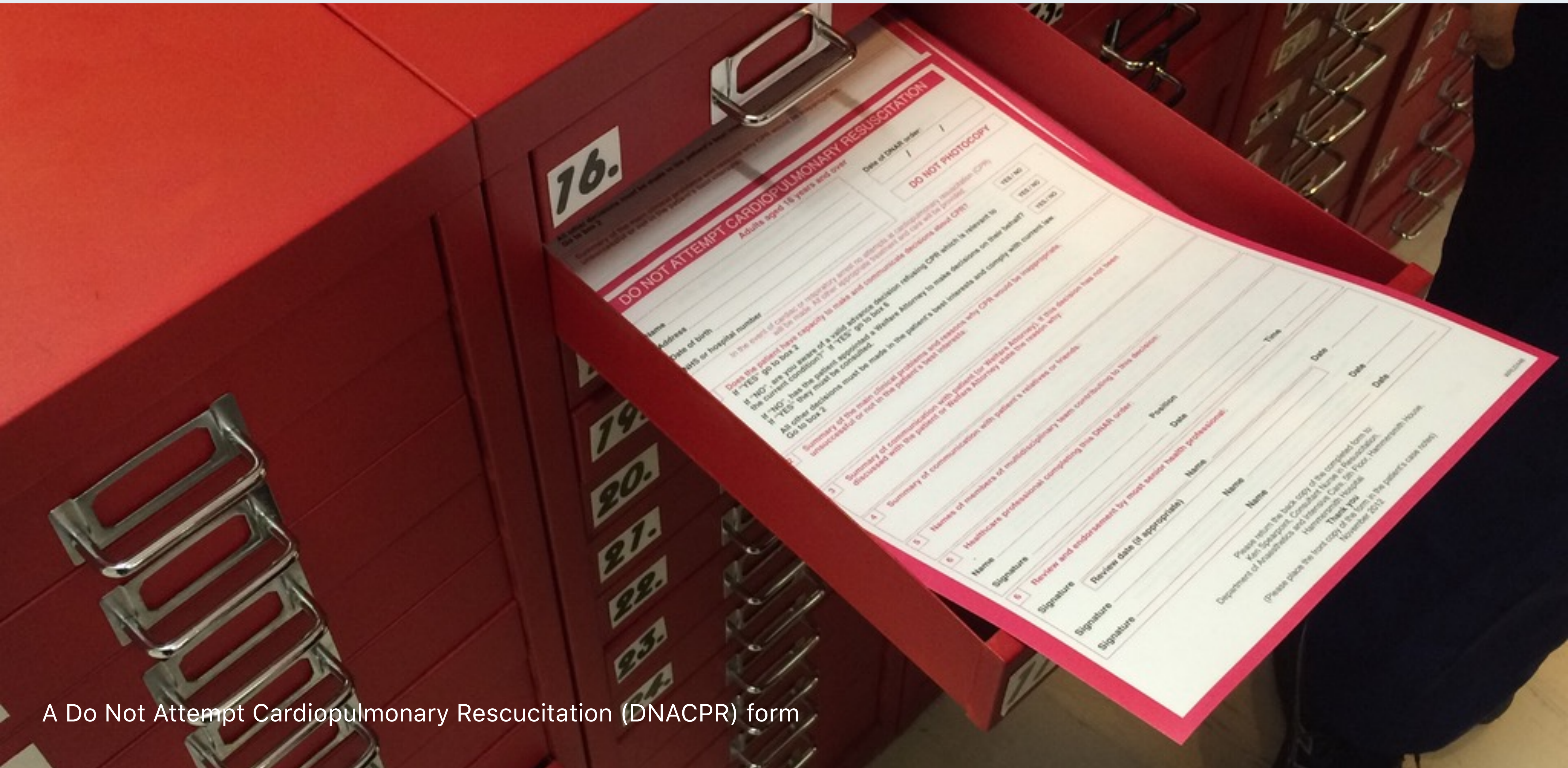


We think CPR works
70% of the time
It only works **18%** of the time



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A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

3. Personal preferences to guide this plan (when the person has capacity)

How would you balance the priorities for your care (you may mark along the scale, if you wish):



Considering the above priorities, what is most important to you is (optional):

4. Clinical recommendations for emergency care and treatment

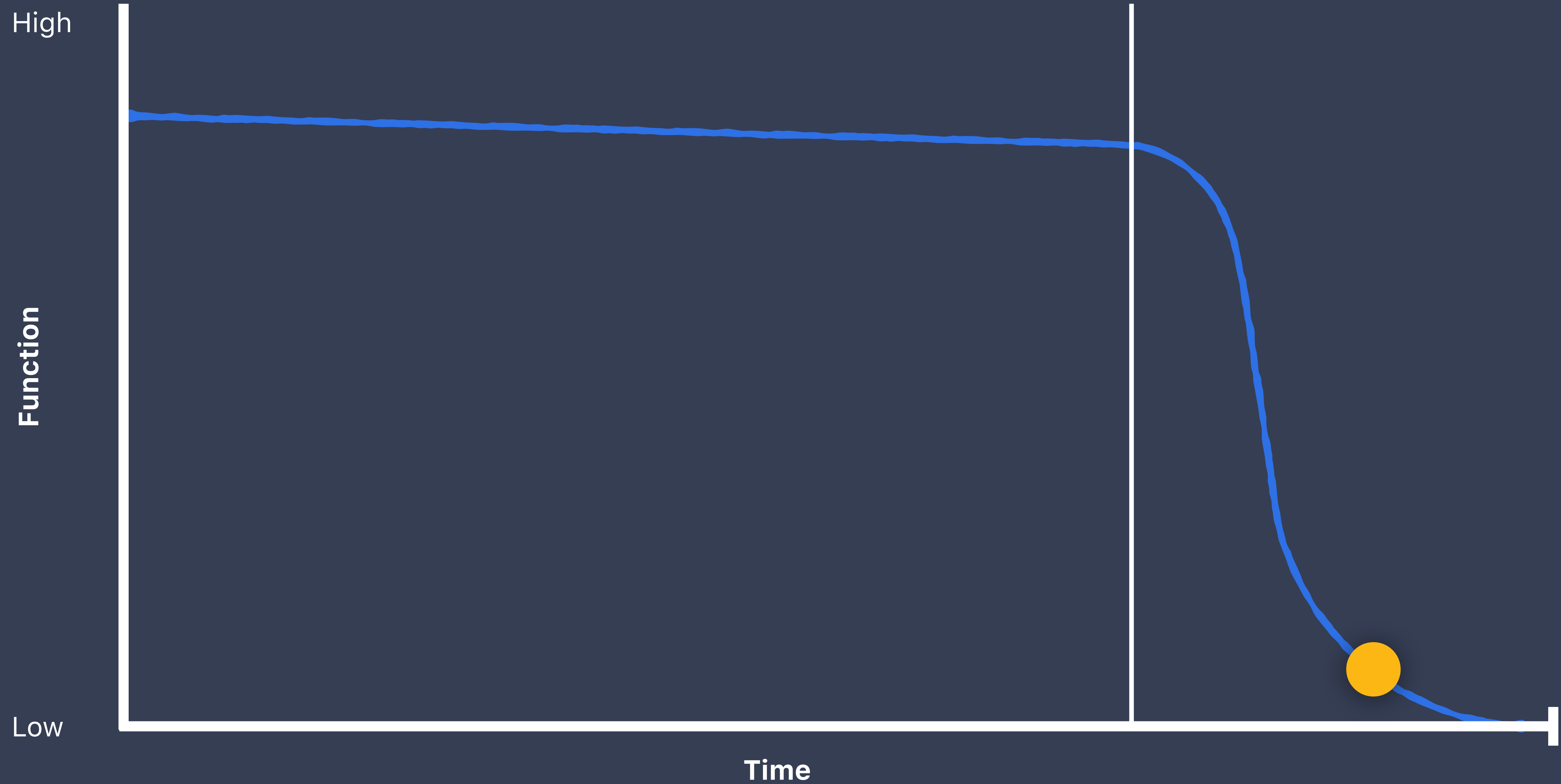
Focus on life-sustaining treatment
as per guidance below
clinician signature

Focus on symptom control
as per guidance below
clinician signature

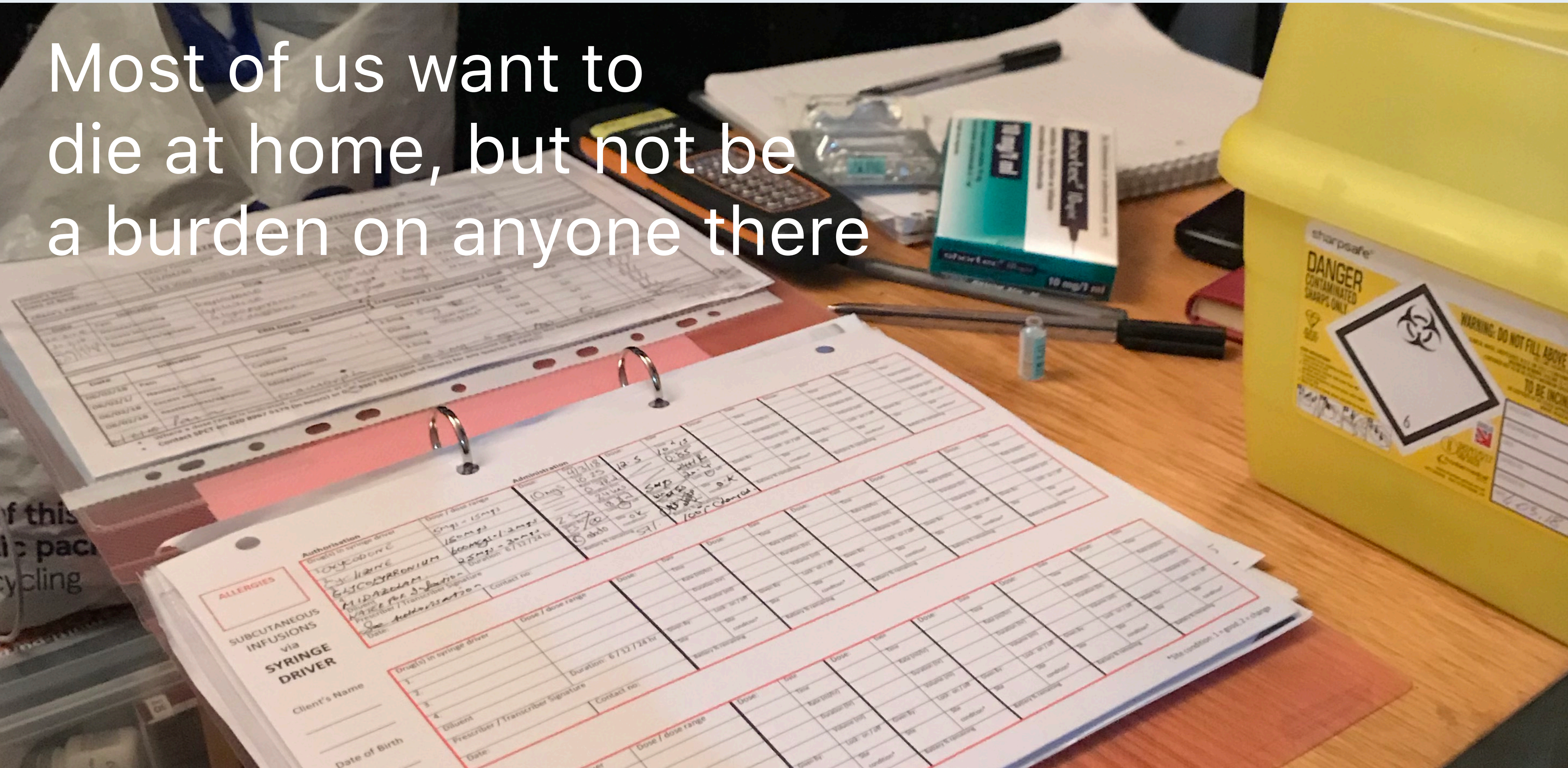
ReSPECT

ReSPECT

eSPECT



Most of us want to die at home, but not be a burden on anyone there





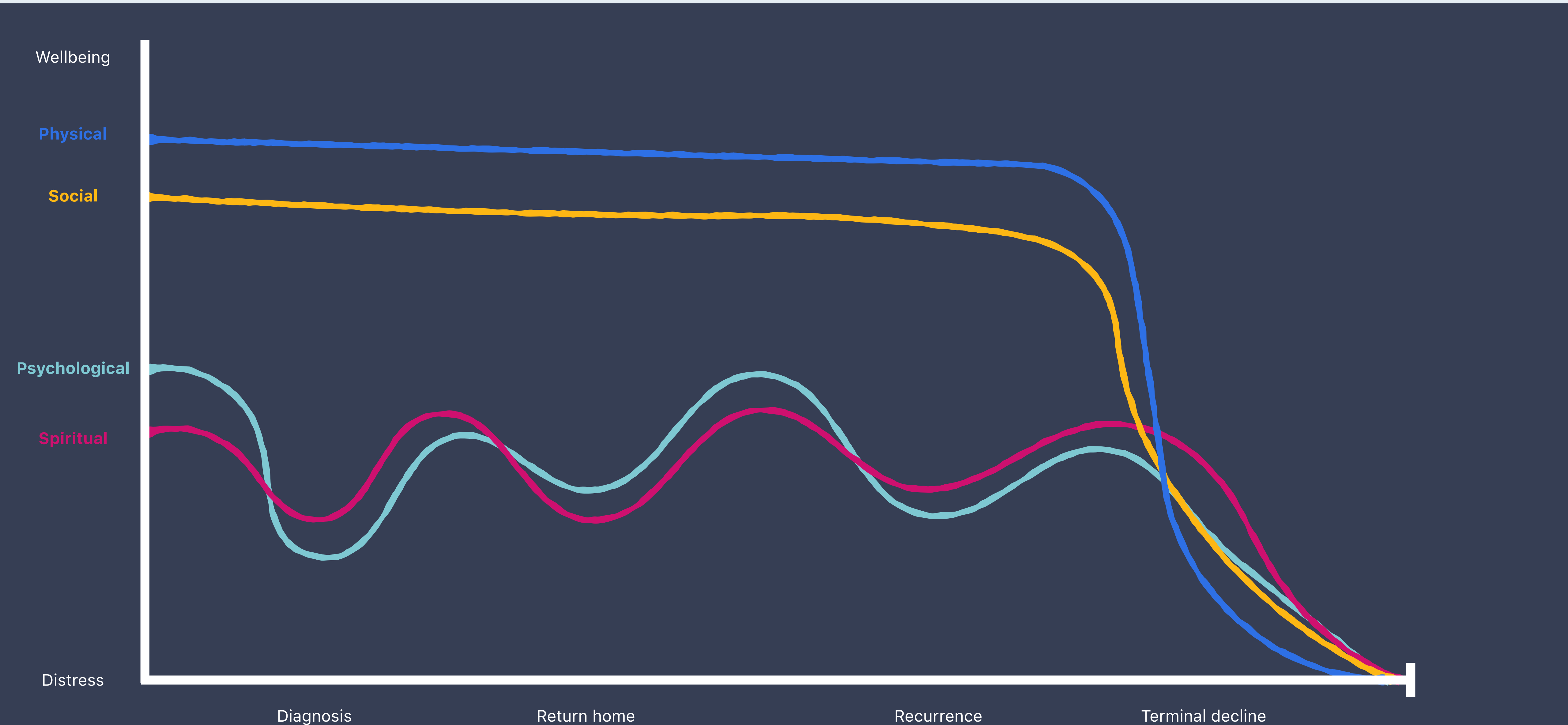
User testing session

What do we talk about when we talk about dying?

- What do you like to be called?
- Who do you want around you?
- Do you want open windows, or the A/C?
- If you had to stay in bed for a long time, what would you like to do?
- If you were permanently unconscious, would you want life-sustaining treatments?

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Amber Care Plans



ACP

HomeReview and shareContactsAccountSign out

Statement 2:
Diagnoses

This is a statement where you can customise your wishes regarding specific illnesses and diagnoses.

Use the list on the right to add or remove items to your statement or simply type your wishes directly into the box below.

You can choose to include it or skip it.

If I have any of the following diagnoses:

Severe head injury

or Terminal Cancer

and I develop an illness that is in need of urgent care with little chance of recovery to a quality of life which I consider worthwhile

then I wish to refuse the following:

If I have any of the following diagnoses:

☒ Severe head injury

☐ Heart failure

☐ Lung failure

☐ Kidney failure

☒ Terminal Cancer

☐ Dementia

☐ A disease of the central nervous system (MND / ALS, Parkinson's, MS)

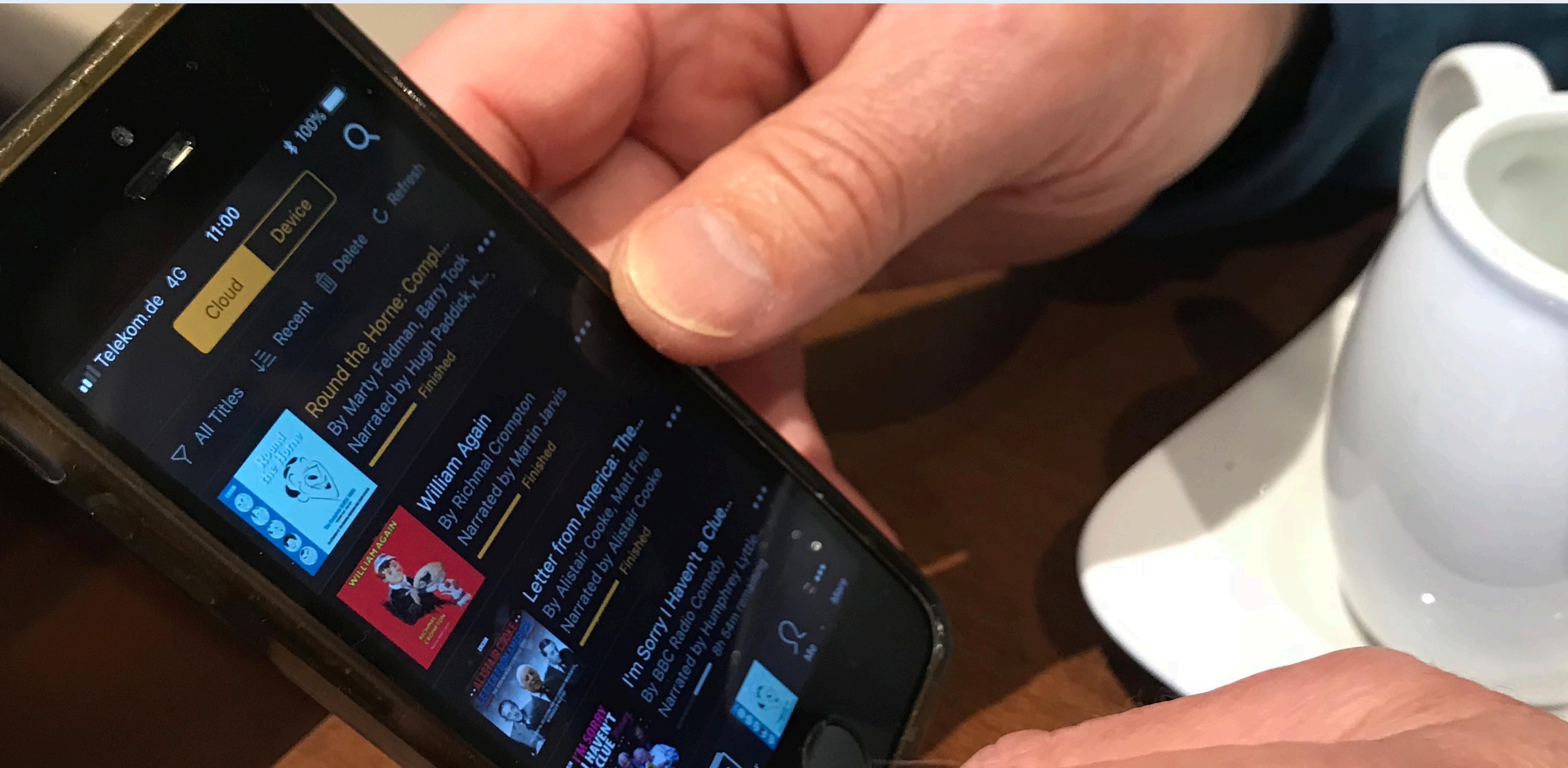
and I develop an illness that is in need of urgent care with little chance of recovery to a quality of life which I consider worthwhile

then I wish to refuse the following:

☒ All medical treatments aimed at prolonging or artificially sustaining my life

Designing at the end

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Designing at the end

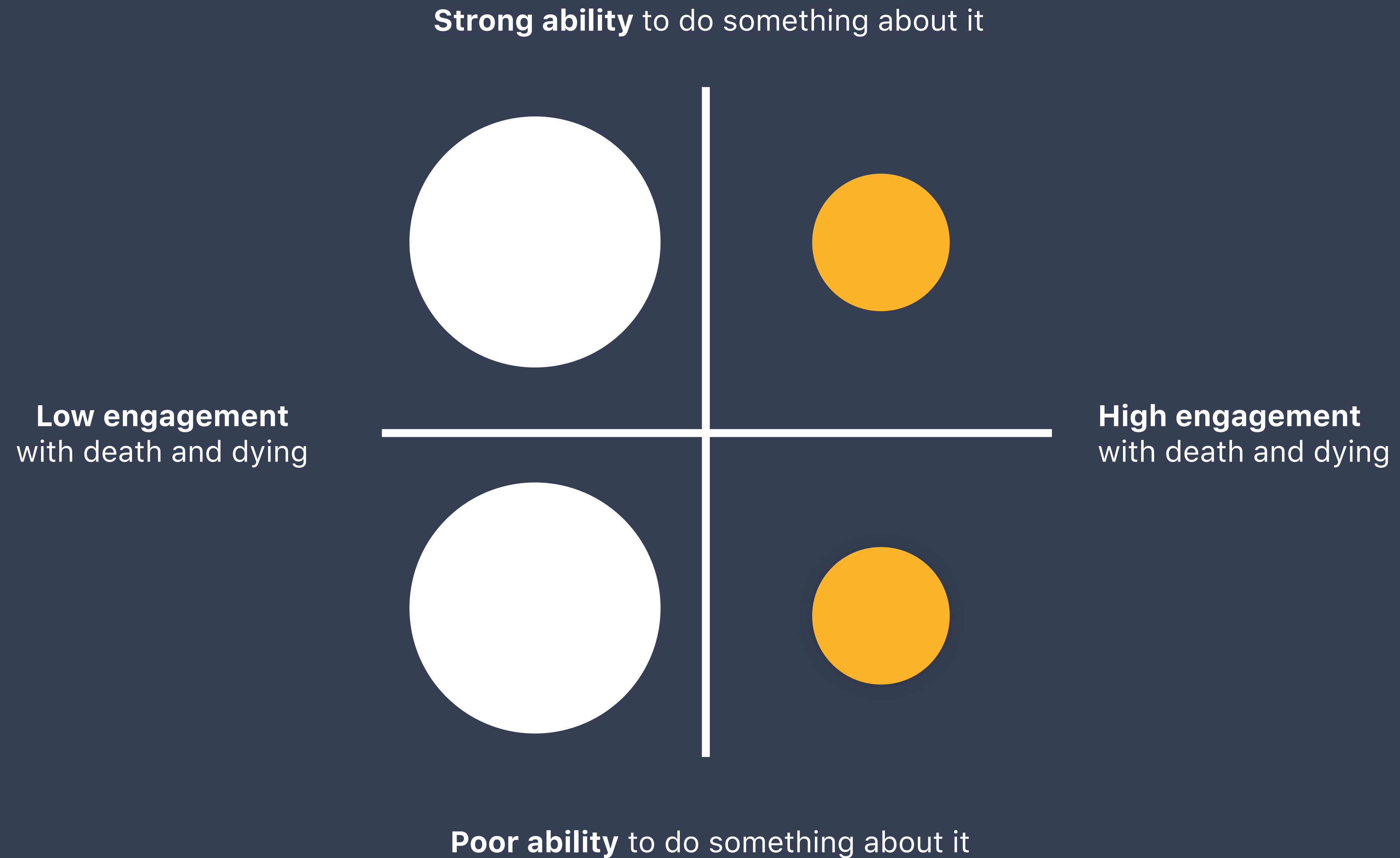
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Nope end...

The idea of death,
the fear of it, haunts
the human animal
like nothing else

Thinking about and preparing for death is really difficult, unless you...

- Have experienced death at an early age
- Have experienced a traumatic or difficult death
- Are faced with a life-limiting or terminal diagnosis
- Care for people near the end of their lives





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We die the same
way we lived



"Are you at peace?"

1. I wish I'd had the courage to live a life true to myself, not the life others expected of me
2. I wish I hadn't worked so hard
3. I wish I'd had the courage to express my feelings
4. I wish I had stayed in touch with my friends
5. I wish that I had let myself be happier

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How might we end things better?



Go beyond human-centred design

No one exists in isolation: design for relationships, communities and ecosystems

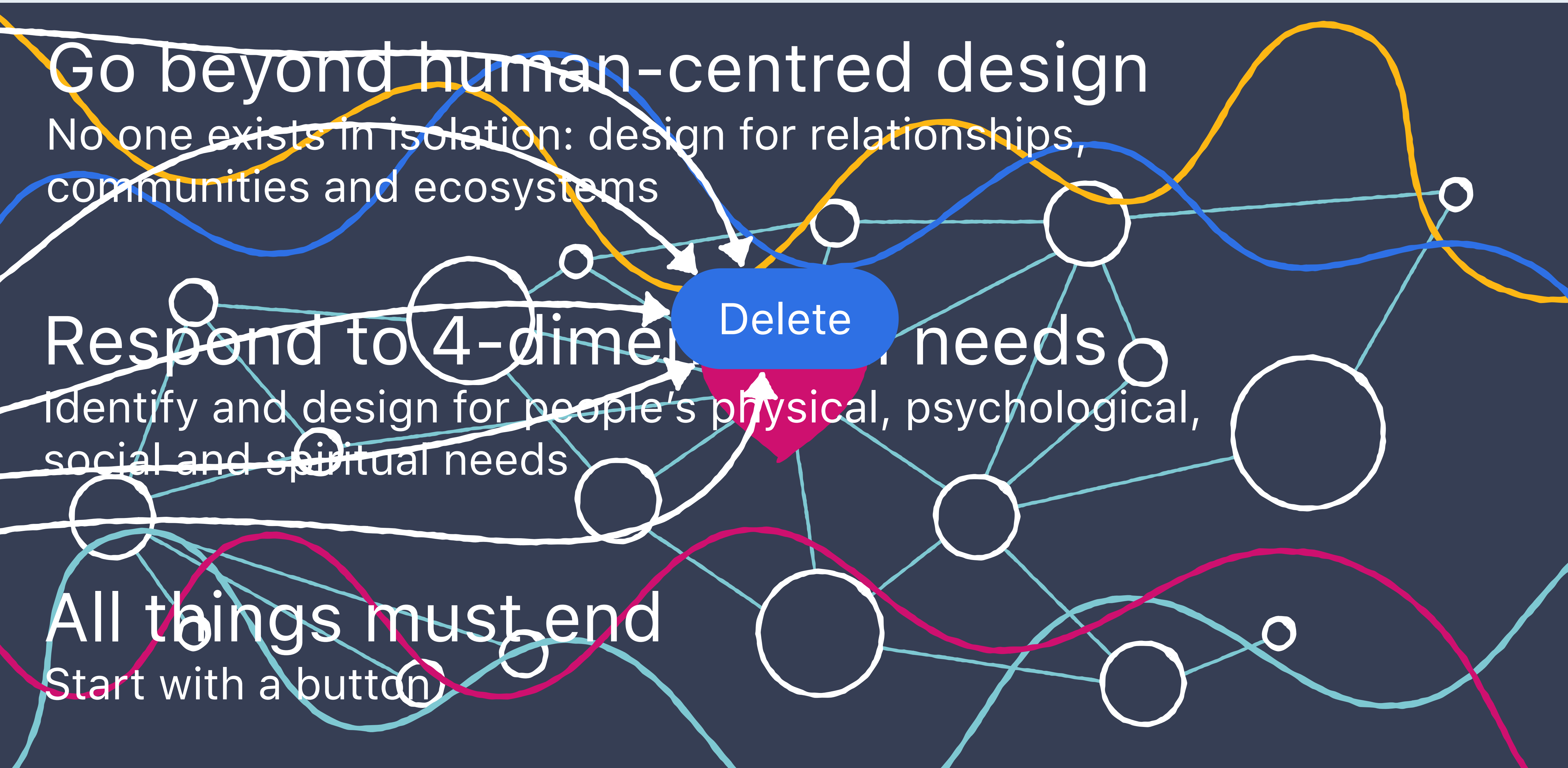
Respond to 4-dimensional needs

Identify and design for people's physical, psychological, social and spiritual needs

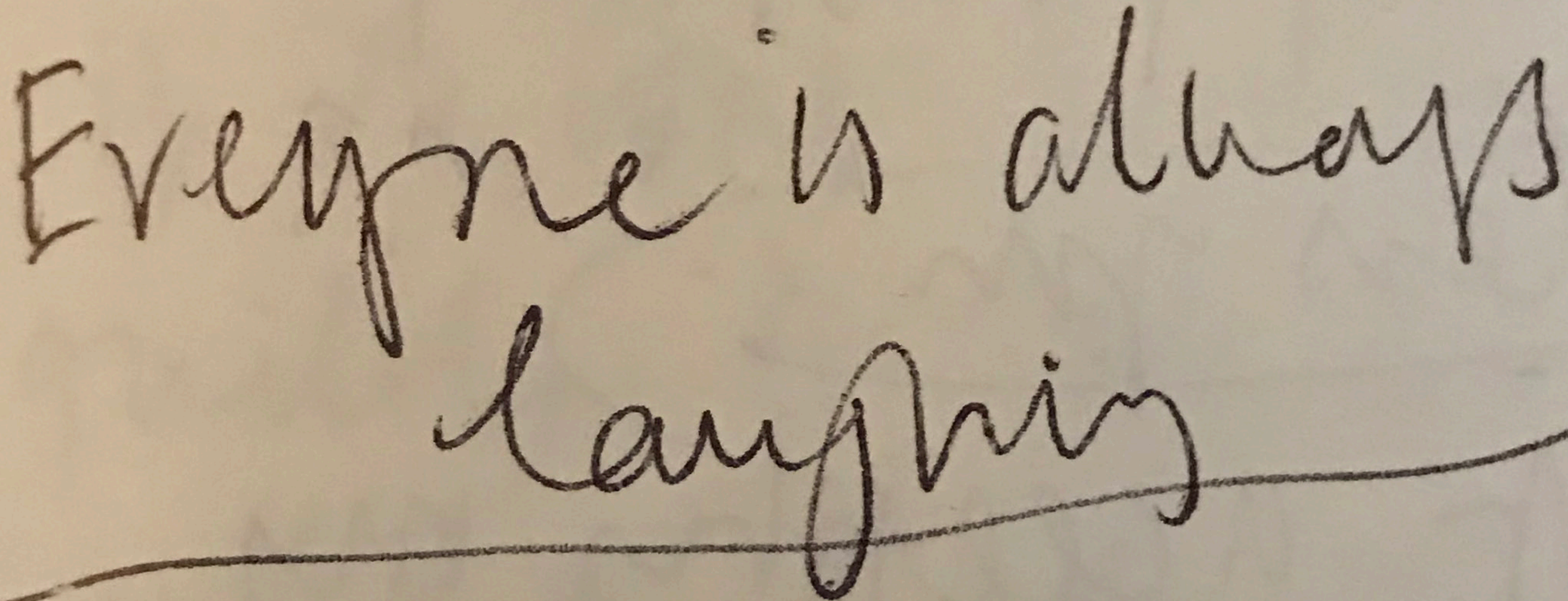
All things must end

Start with a button

Delete



If we can accept the end,
we can enjoy the rest of the journey

A handwritten note in dark ink, enclosed within a hand-drawn rectangular border. The text is written in a cursive, flowing script. The first line reads "Everyone is always" and the second line reads "laughing".

Everyone is always
laughing

Thank you

ivorwilliams.info
helixcentre.com