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# Fit for their futures? How palliative care disables people with life-limiting illness

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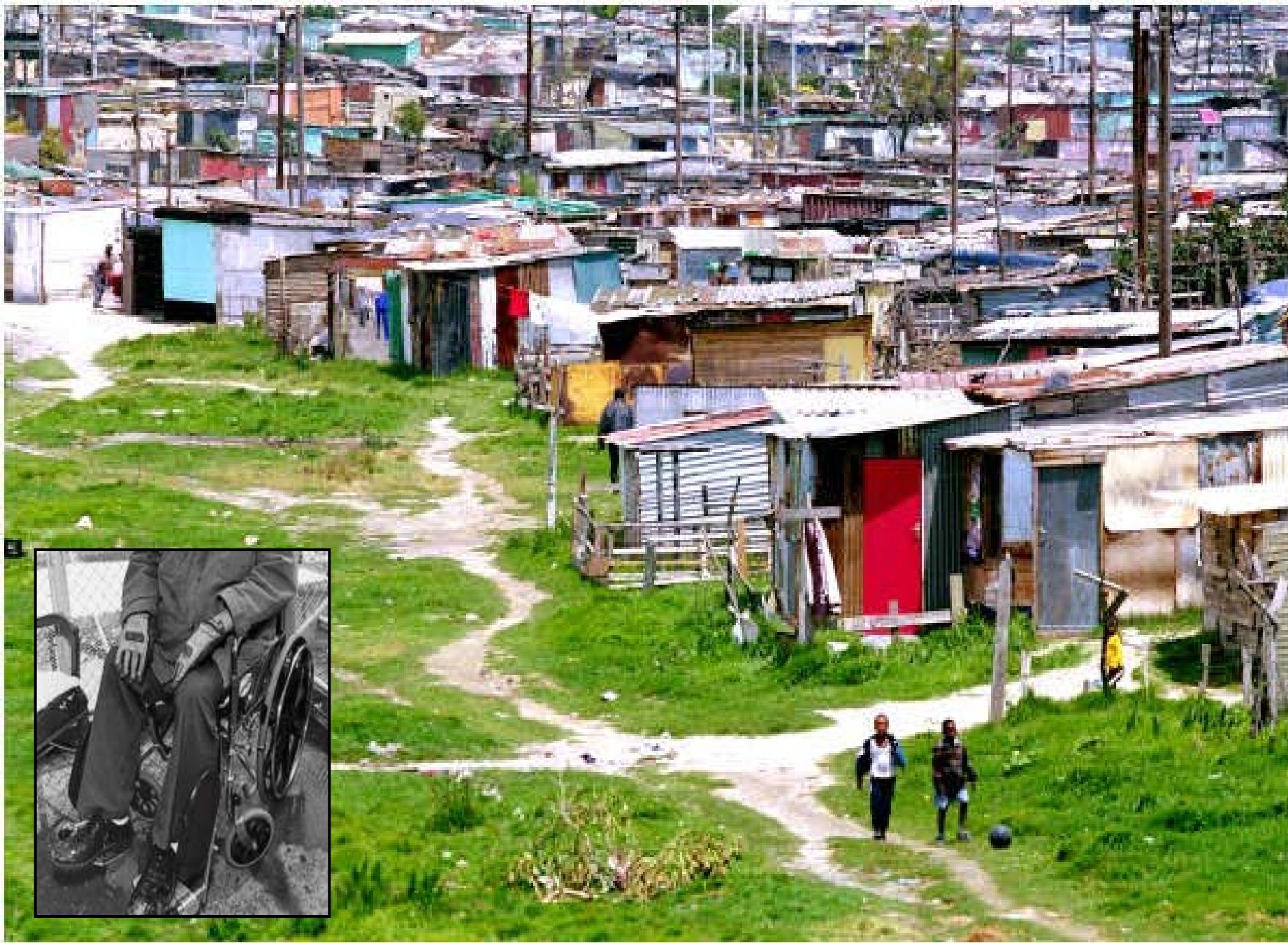
**Dr Gail Eva**

**13<sup>th</sup> Australian Palliative Care Conference  
Melbourne  
3<sup>rd</sup> September 2015**

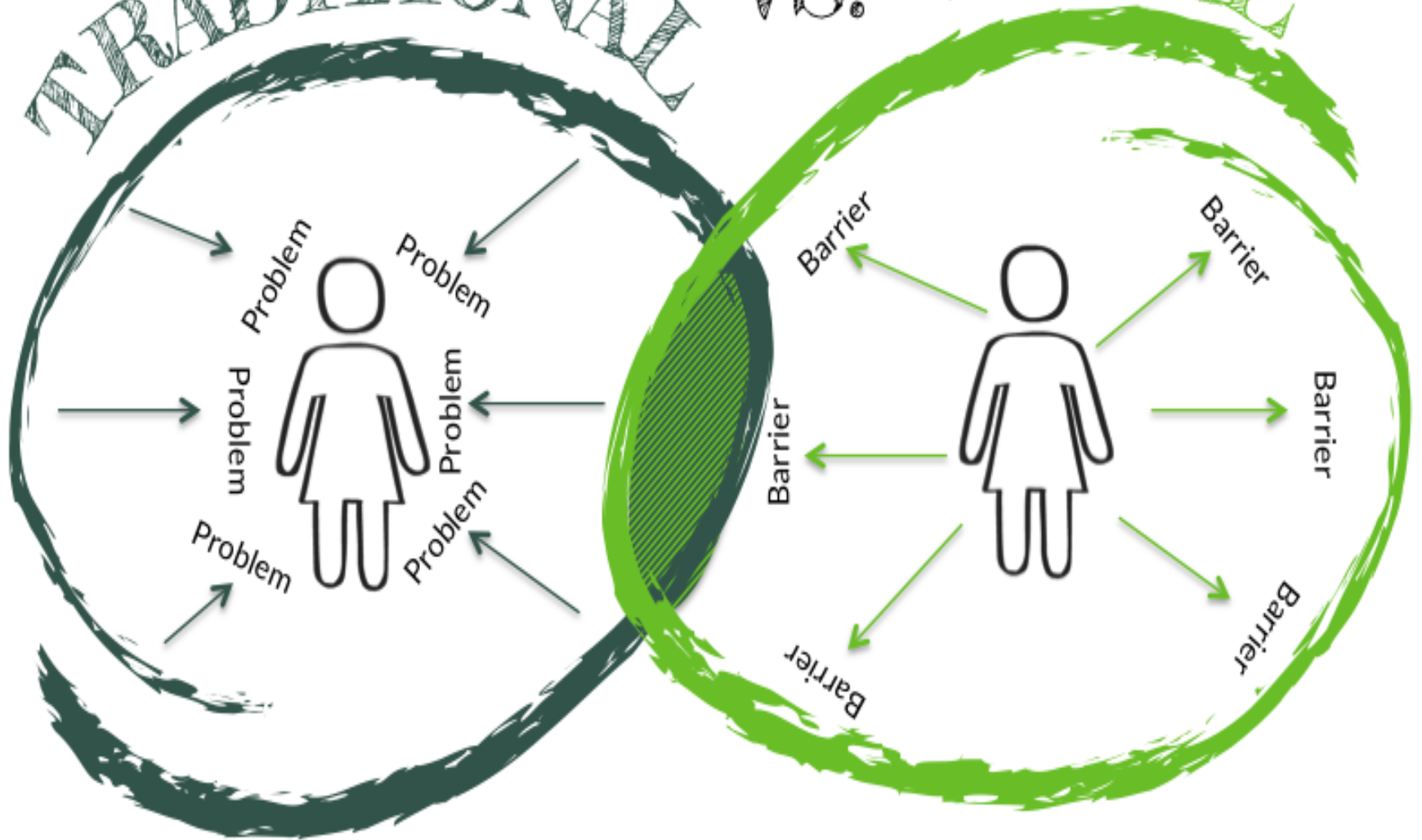








# TRADITIONAL VS. SOCIAL





# What's important to people at the end of life?



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- Having an opportunity to say goodbye and bring closure.

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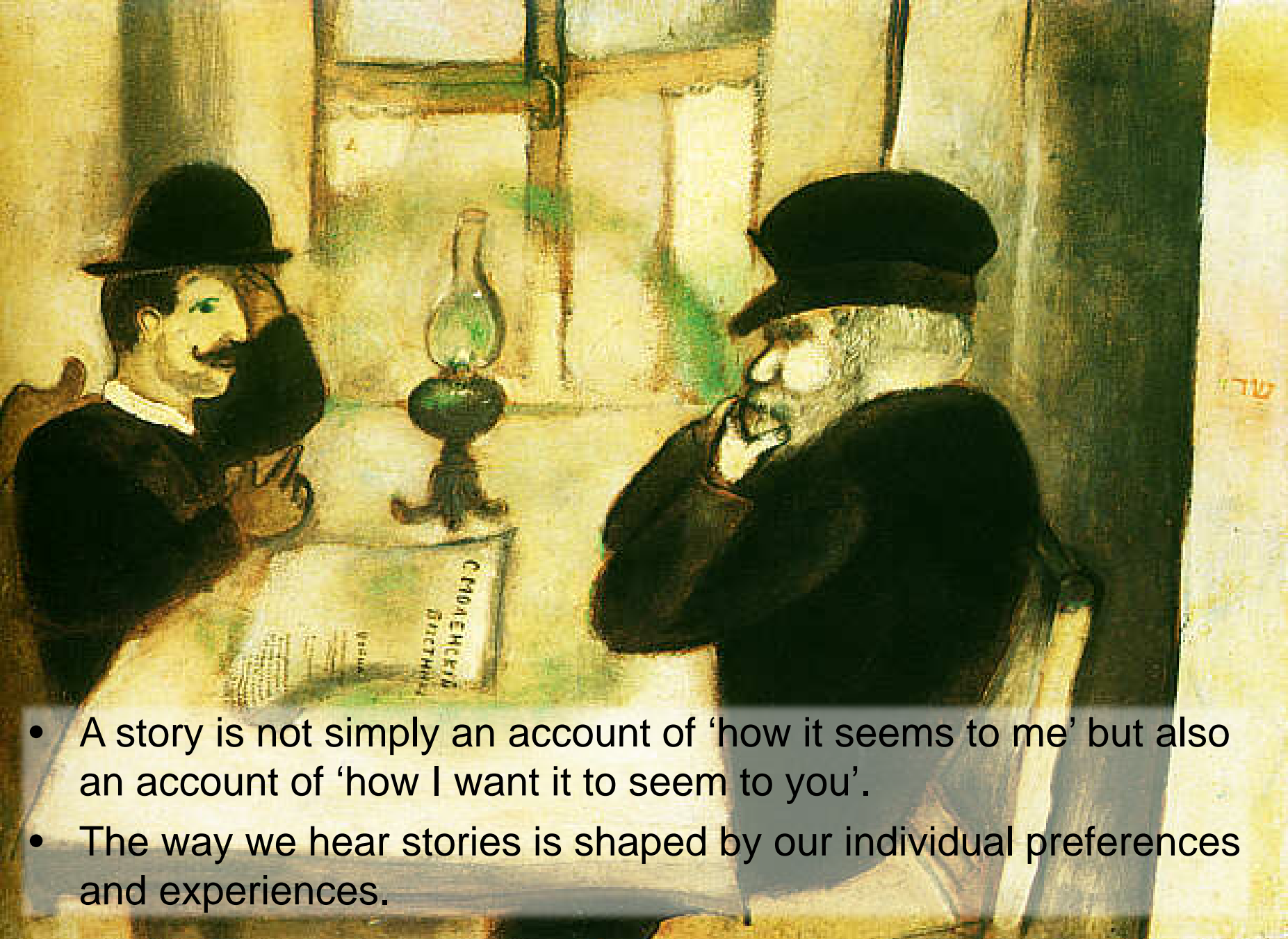
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- A story is not simply an account of 'how it seems to me' but also an account of 'how I want it to seem to you'.
- The way we hear stories is shaped by our individual preferences and experiences.



Everything has been arranged, from A to Z. I've had the funeral directors around and chosen my coffin. I did have one problem that was tricky – my mum and dad live 300 miles away from me and Graham, and it worried me: what's going to happen if I get buried here – it's too far for my mum and dad to come if they're feeling they want to grieve one day and vice versa, Graham.



So although I didn't want to be cremated, I will be, and one casket can be buried back home and one here...

I've got all of the practicalities sorted out, the hymns, the music, I've talked to the vicars about how I want the service. So if, God forbid, I take a turn for the worse, the i's are dotted the t's are crossed on what I want.

## *Occupational therapist*

Gill remained incredibly positive ... she was holding it together because that's who she is: a professional lady with a bright outlook on life.

## *Social worker*

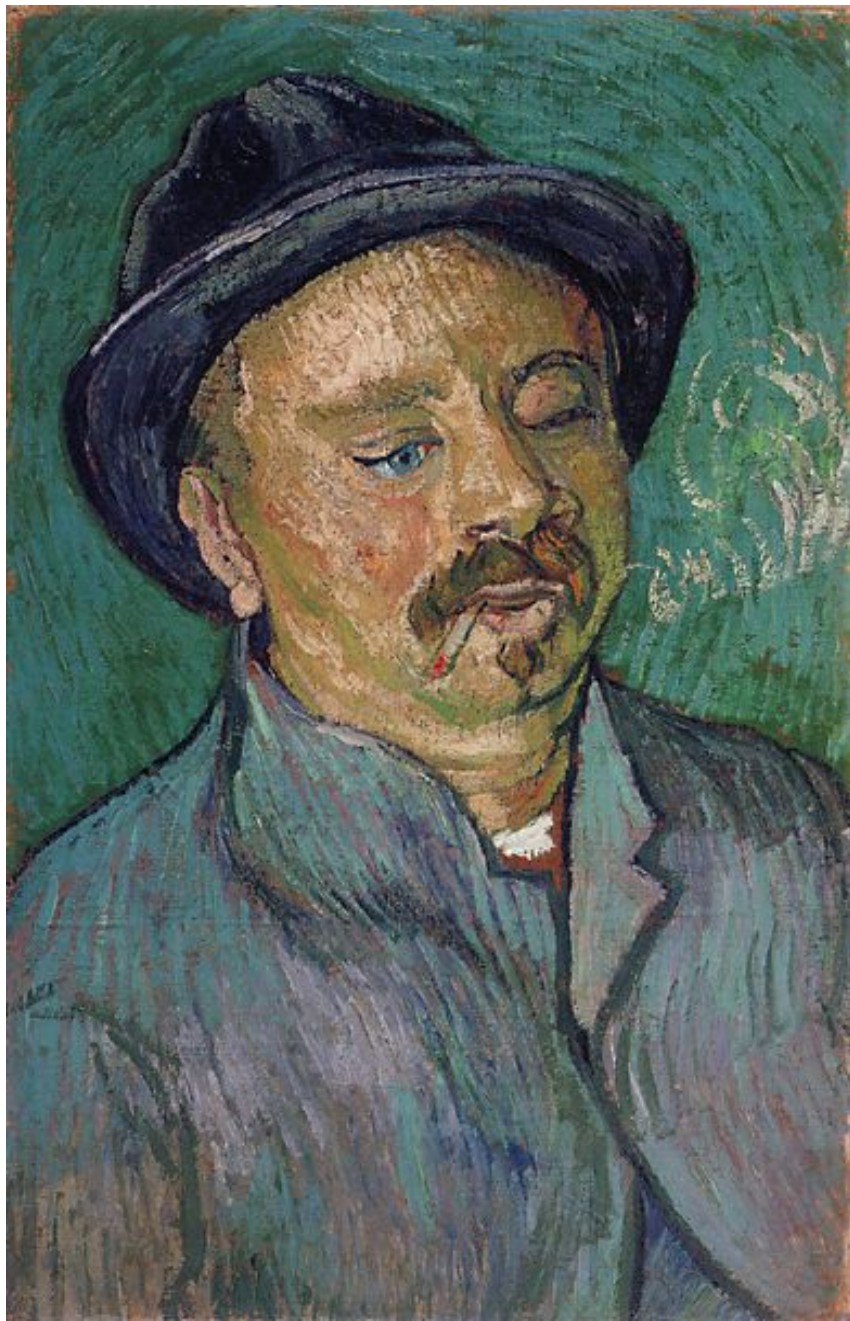
She's very competent and resourceful ... she has overcome a lot of the problems herself ... she won't sit there feeling sorry for herself.

## *Macmillan nurse*

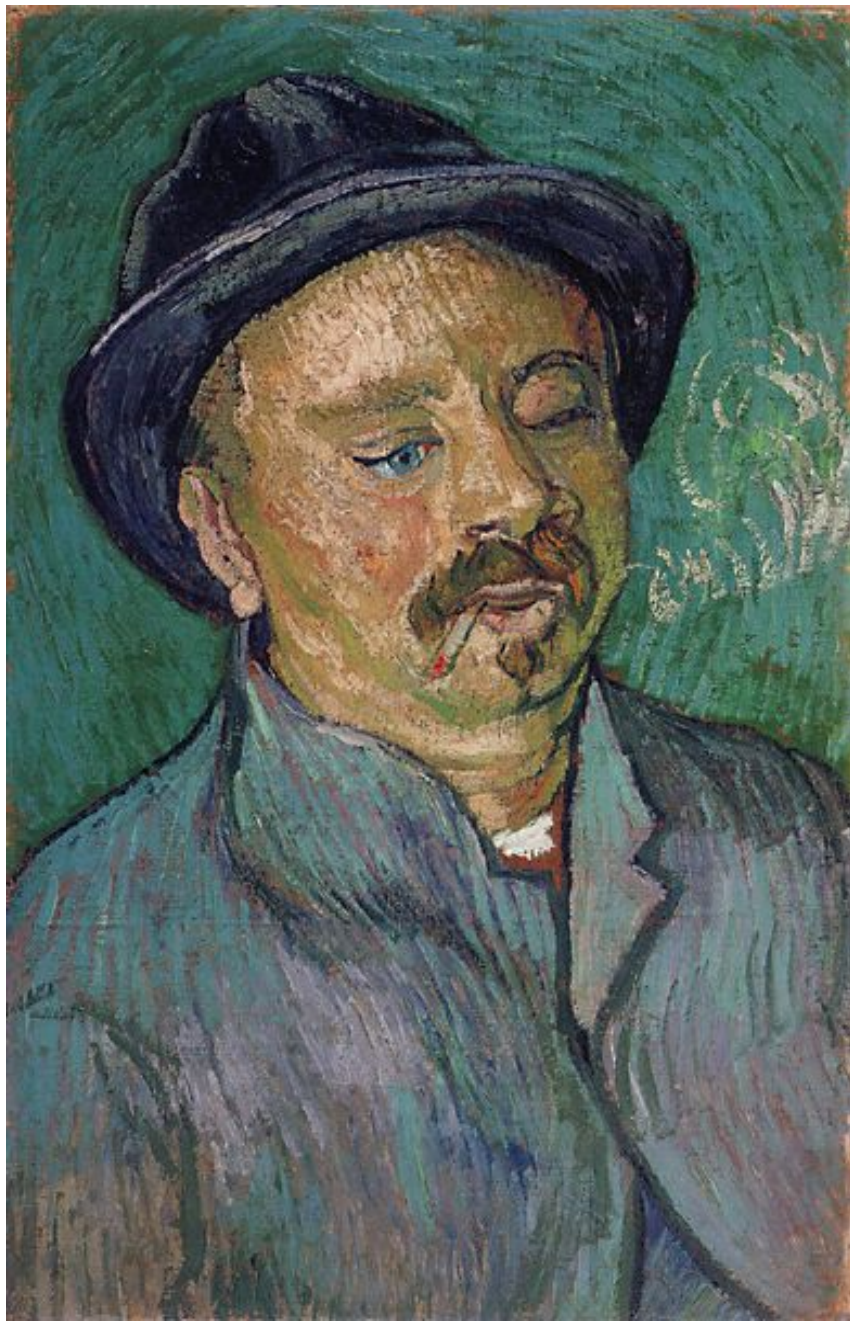
Gill's a great initiator ... knows how to take things forward ... you don't wait around for people to do stuff for you, you get on and do it yourself.

## *Occupational therapist*

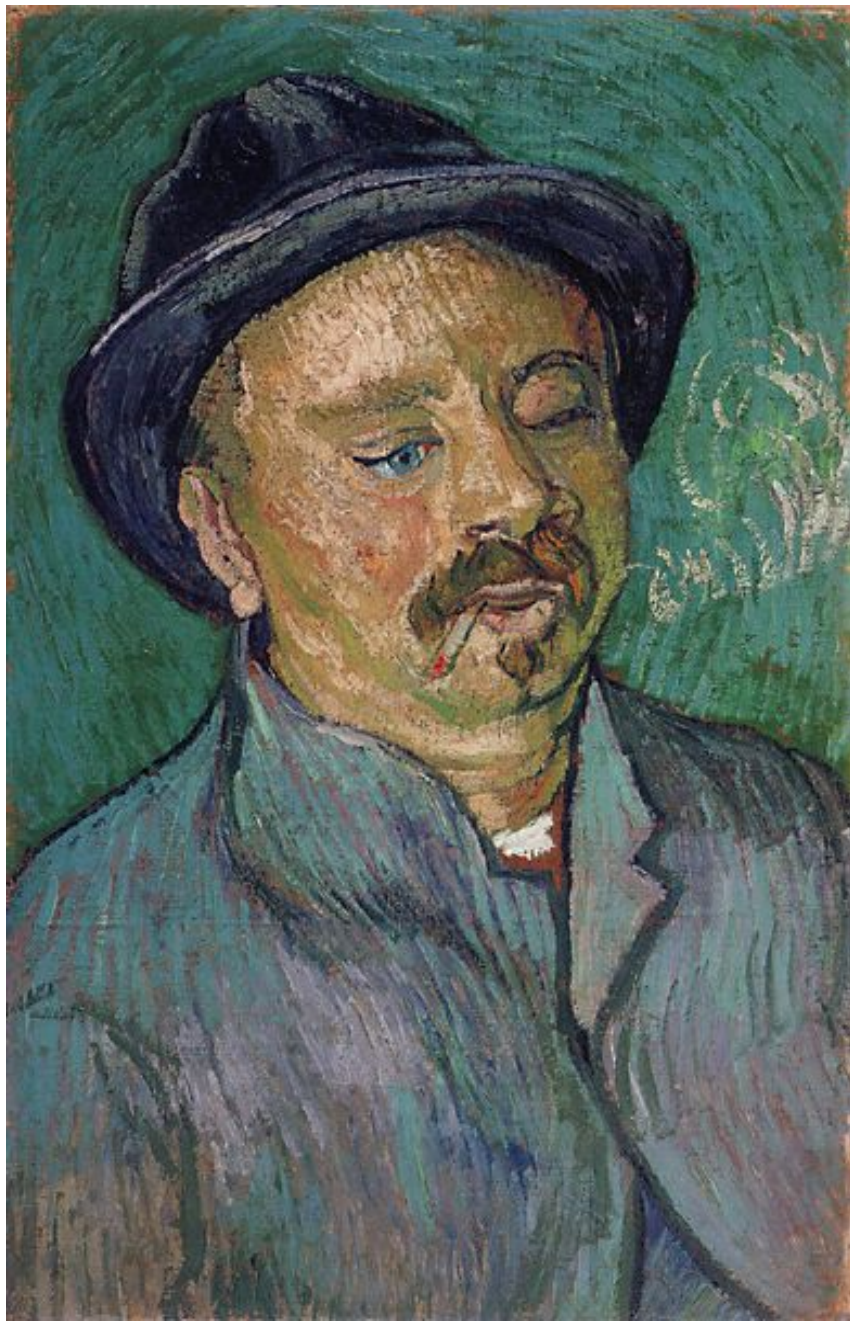
Gill went home adamant that she wanted to be upstairs, which we completely went with because that was her wish. The bath was highly important to her and there was no way of having a bath downstairs, and she felt that was a better option.



I had a happy childhood. I'd go watch the blacksmith pump his bellows when I was 7. I learned so much that when I got a job at the factory at 14 I knew more than the other young starters so I did really well. Fortunately – everything is just fortunately – I met a good gang of kids. The chaps at work, I always met the best ones. I don't know why, but everything seemed to work out right for me. A friend of a friend in the Merchant Navy helped me to get a job there. The blokes on the ship were really good fellows, took care of me. I've been to practically every country in the world.



Three o'clock this morning, I'm wide awake and my head's going round thinking about what I'm going to do. How I'm going to get my rice pudding from the kitchen to my table. Now, see, I've got the problem solved. I've got this tea trolley I made years ago. It's got four castors, but if I take the back two off, build it up with a bit of wood, like, so it doesn't slide. There's plenty of timber down the shed. And I'll put on handles, screw them into the side, I can hold on and walk round with my tea trolley, push, stop, push, stop, like so. I'm looking forward to going home. It'll be an adventure!



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## *Occupational therapist*

At first, he was realistic, saying he didn't think that he would cope at home.

But he didn't improve much with radiotherapy and he got more and more frustrated with us saying you're not ready to go home. The more we talked to him the less he seemed to understand what we were getting at, that he wouldn't go back to how he was.

Eventually, we said you've got options: go home as you are but agree not to undertake any kitchen activities.

He said he just needed a rail on the work surface, things that we thought weren't so appropriate because work surfaces aren't meant for such weight bearing activities.

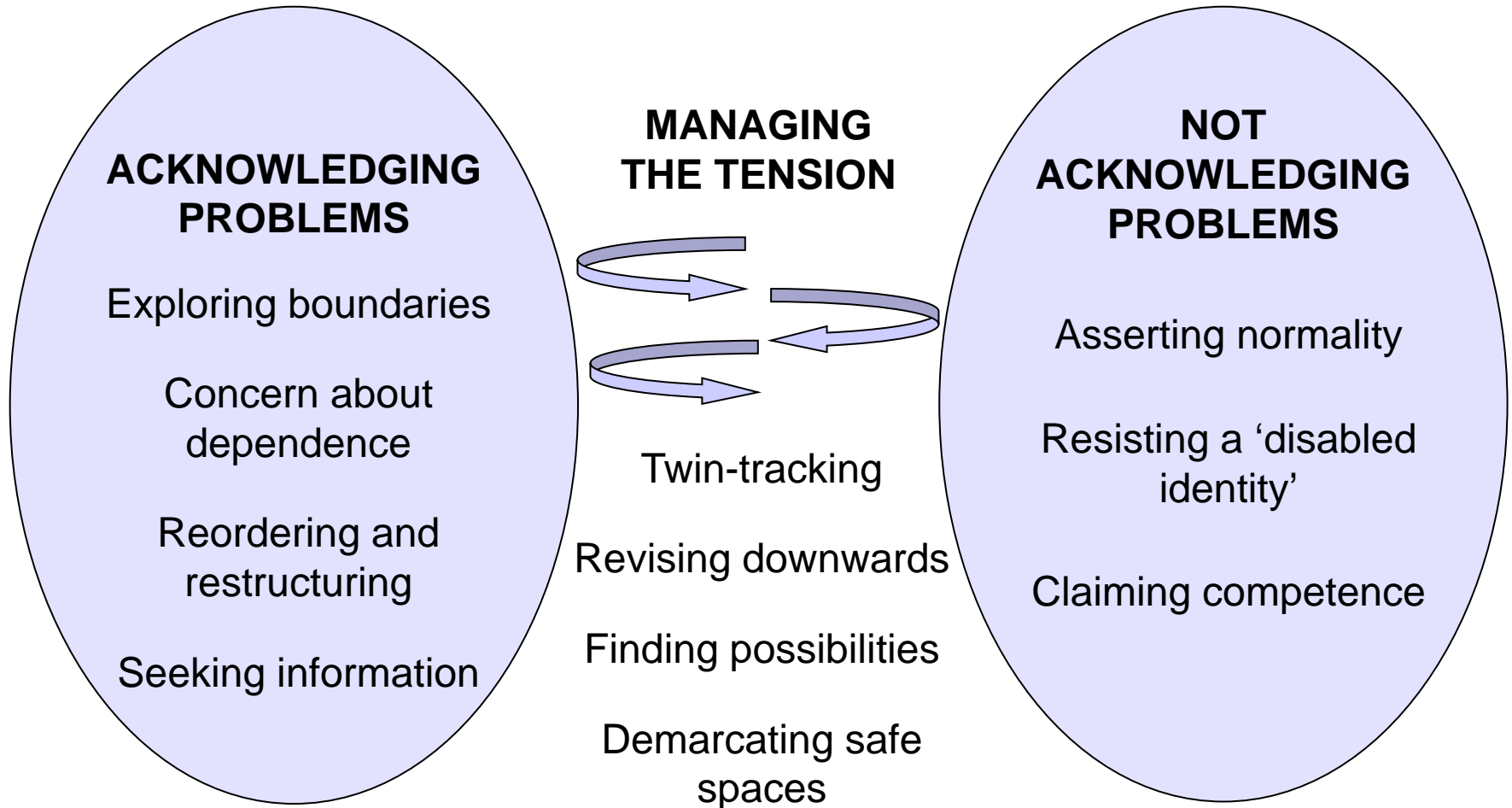
We had to be quite assertive with him to make him understand where we were coming from and why we were saying what we were saying and that it wasn't to take away his independence.

Gill went home adamant that she wanted to be upstairs, which we completely went with because that was her wish.



The first time I used it, it was the wrong move really, because we went to Tesco and it was busy, and there I was down, you know, in this wheelchair and I just felt all these people coming towards me. And it was like – oh, I had no control. It was terrifying, absolutely terrifying and I just wanted to get out.

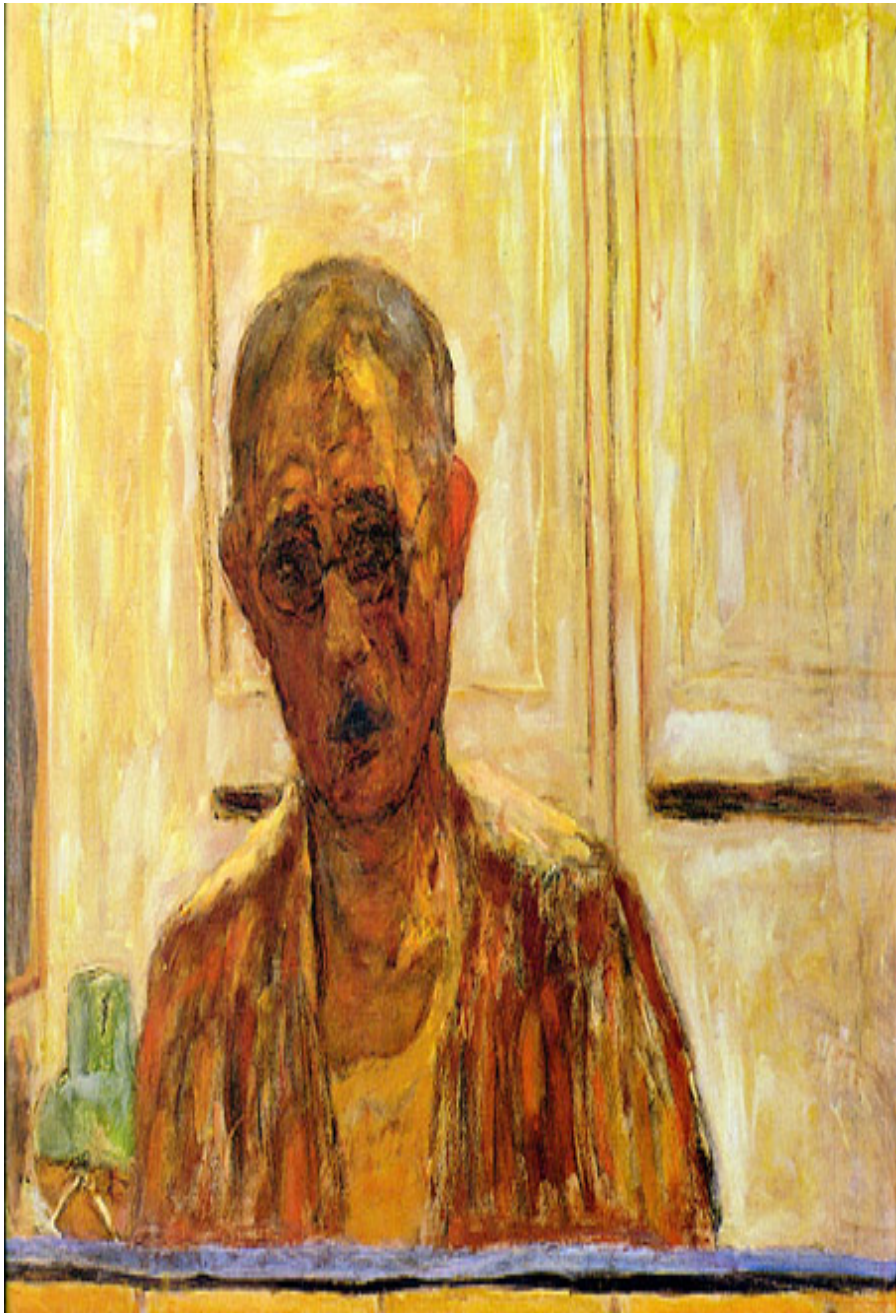
# How do people with cancer manage disability?



Eva G, Paley J, Miller M, Wee B (2009) Patients' constructions of disability in metastatic spinal cord compression. *Palliative Medicine* **23**: 132-140 .



I've had to give up my vegetable garden, which makes me feel sad. I can't stand and move without a walking frame anymore. But I have two or three ambitions that I **will** achieve. Not a question of wanting to, I **am going** to achieve them. And the first one, it is the essence of being independent and standing alone, is I want to go and hit a golf ball. Proper swing, unaided, followed by a hole.



### *Interview 1*

I can still walk, so I'm still alright. I mean, if I had to be in a wheelchair, it would just be terrible.

### *Interview 2 (five months later)*

Because see, getting out in the wheelchair, if we discussed this last November I would have been in tears. Now it's an absolute joy to go out in a wee wheelchair. So it's just crept on me, and it's just not a big issue.

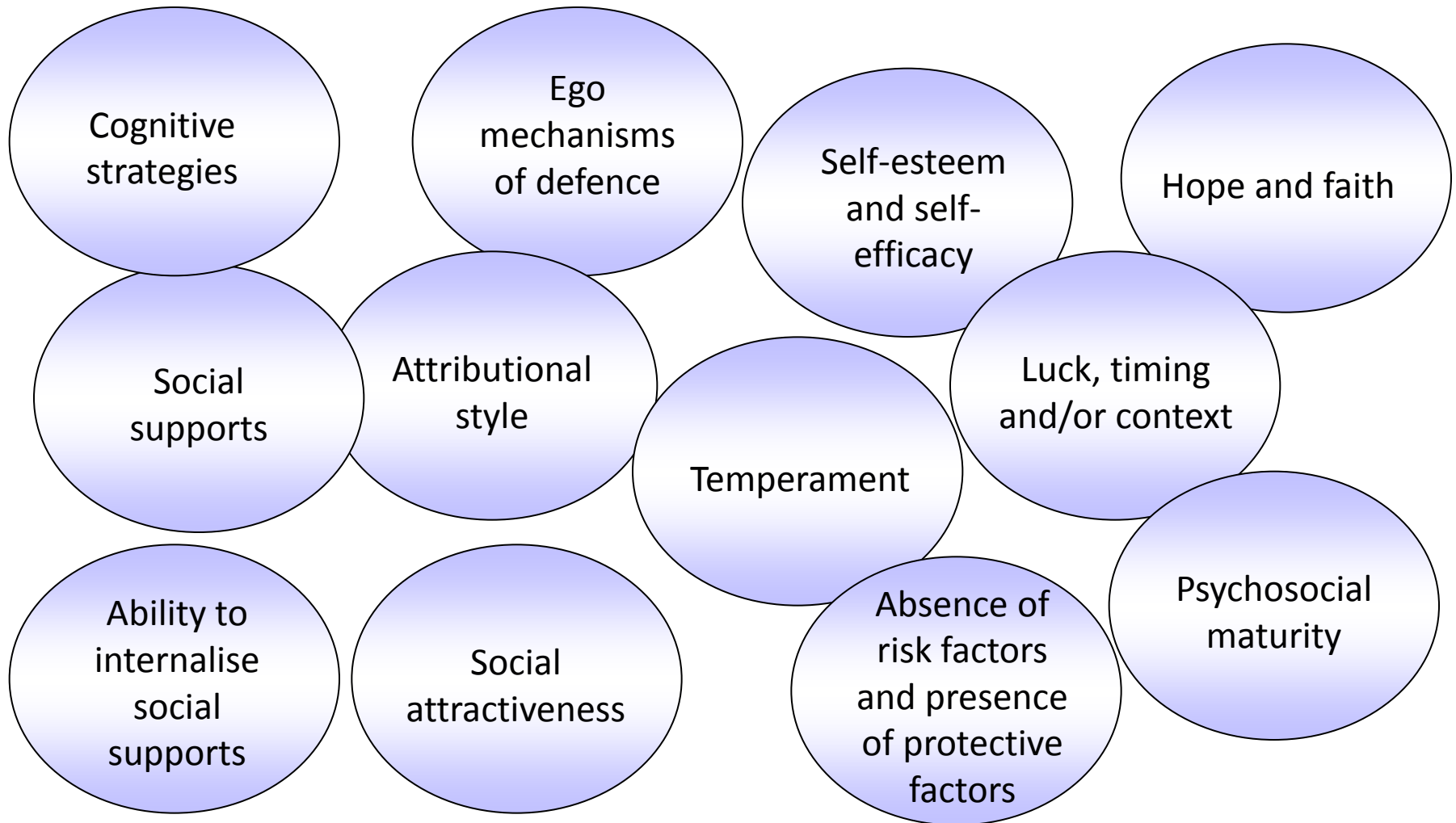
At the minute I'm walking and getting into the chair. If there was a dependence, if I couldn't get up stairs or couldn't get out of the seat, I can't imagine what that would be like.



Round up the usual suspects...



# What helps us to live well?



Vaillant GE (1993) *The Wisdom of the Ego: Sources of Resilience in Adult Life*. Cambridge MA: Harvard University Press

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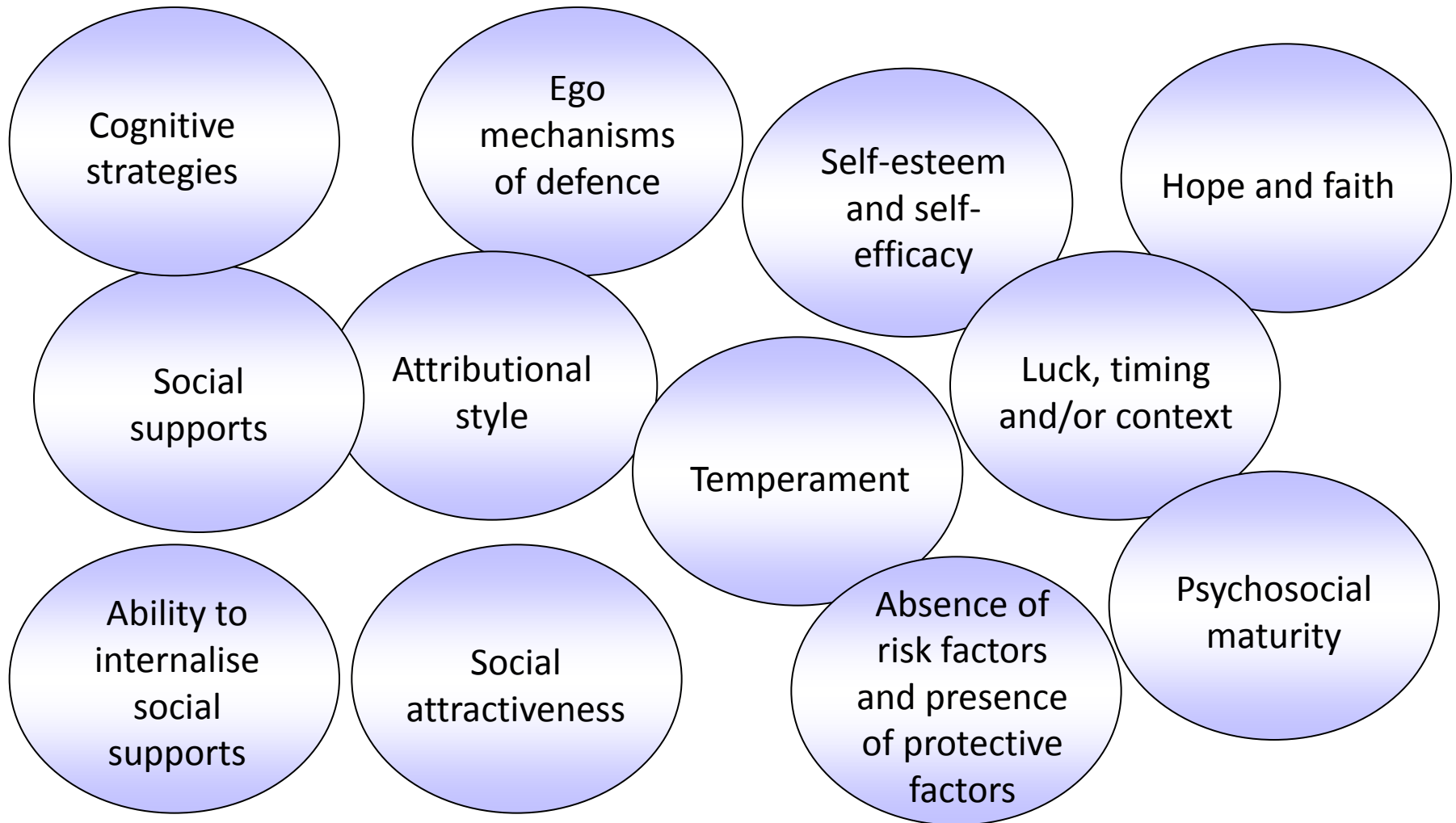
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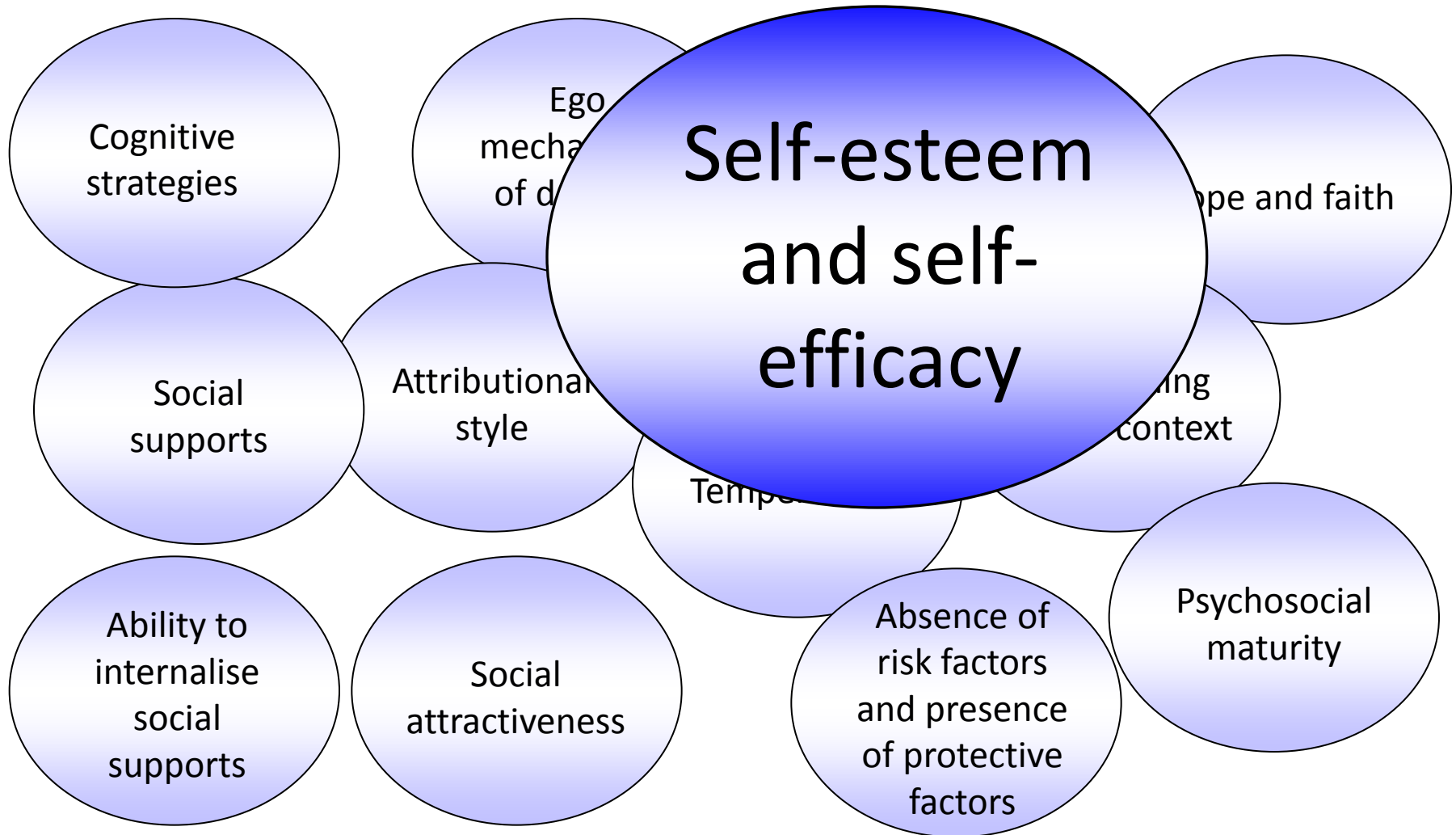
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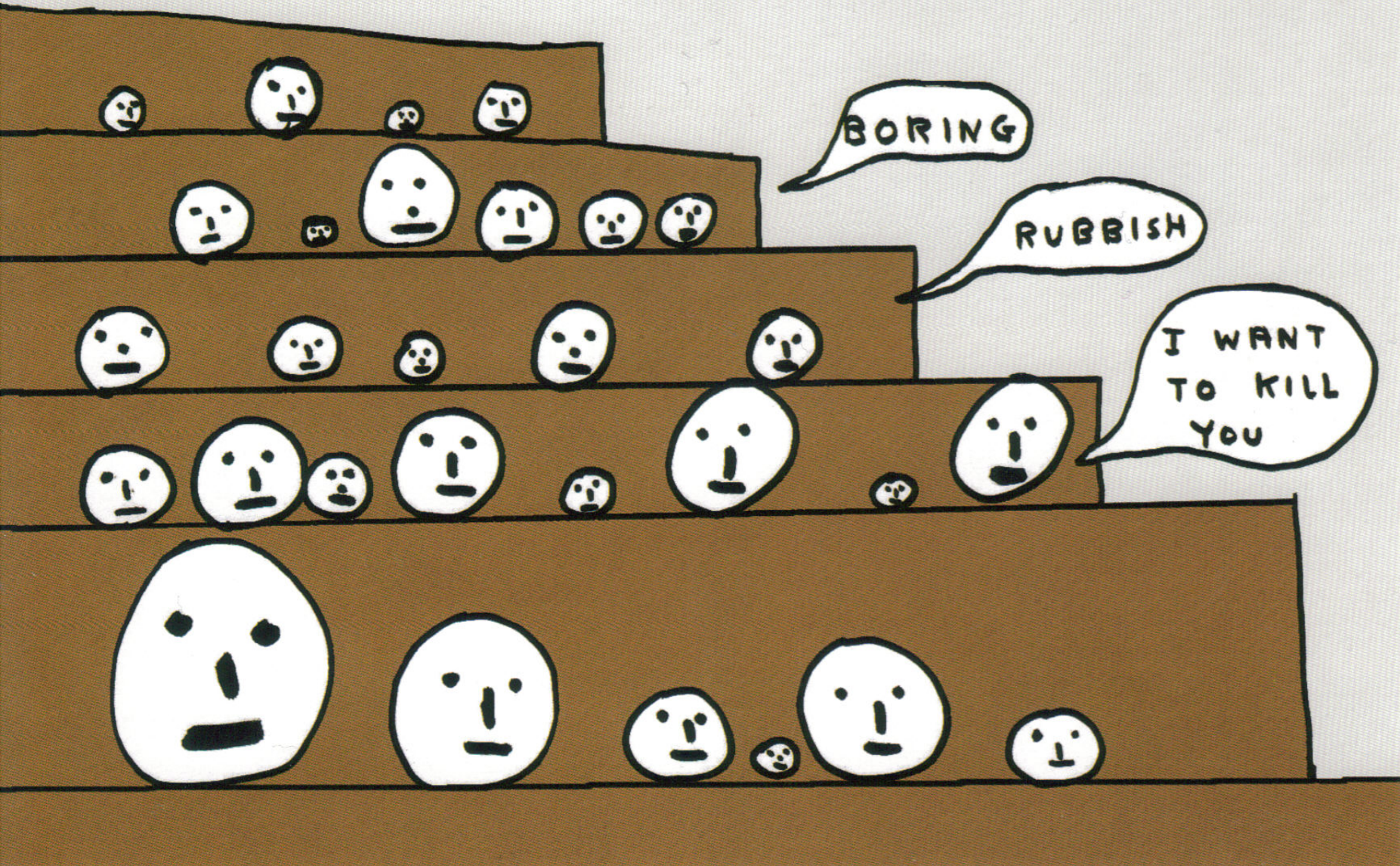
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# What helps us to live well?



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THE LECTURE YOU GAVE WAS  
NOT WELL RECEIVED



# Positive illusions



Taylor SE *et al.* (2000) Psychological resources, positive illusions and health. *American Psychologist* 55(1): 99-109.

Taylor SE, Brown JD (1988) Illusion and well-being: a social psychological perspective on mental health. *Psychological Bulletin* 103(2): 193 – 210.

Taylor SE (1983) Adjustment to threatening events. A theory of cognitive adaptation. *American Psychologist* November: 1161-1173.

# Listening generously

- What does this represent to this person?
- What is being communicated about what is significant and important?
- What is the person saying about their sense of themselves?
- What does this say about their hopes and expectations for the future?

Irene and I have always been great caravanners. I don't want the bother of a caravan any more, so I've just recently bought myself a camper van, which means that Irene and I can still go away for weekends.





I'm organising some modifications for it: I'm going to sort out power steering, and I'll have one of those knobs on the steering wheel, like the old truck drivers used to have, that should sort it out. I believe I'll have enough movement in my feet to operate the clutch. I think that should work, don't you?

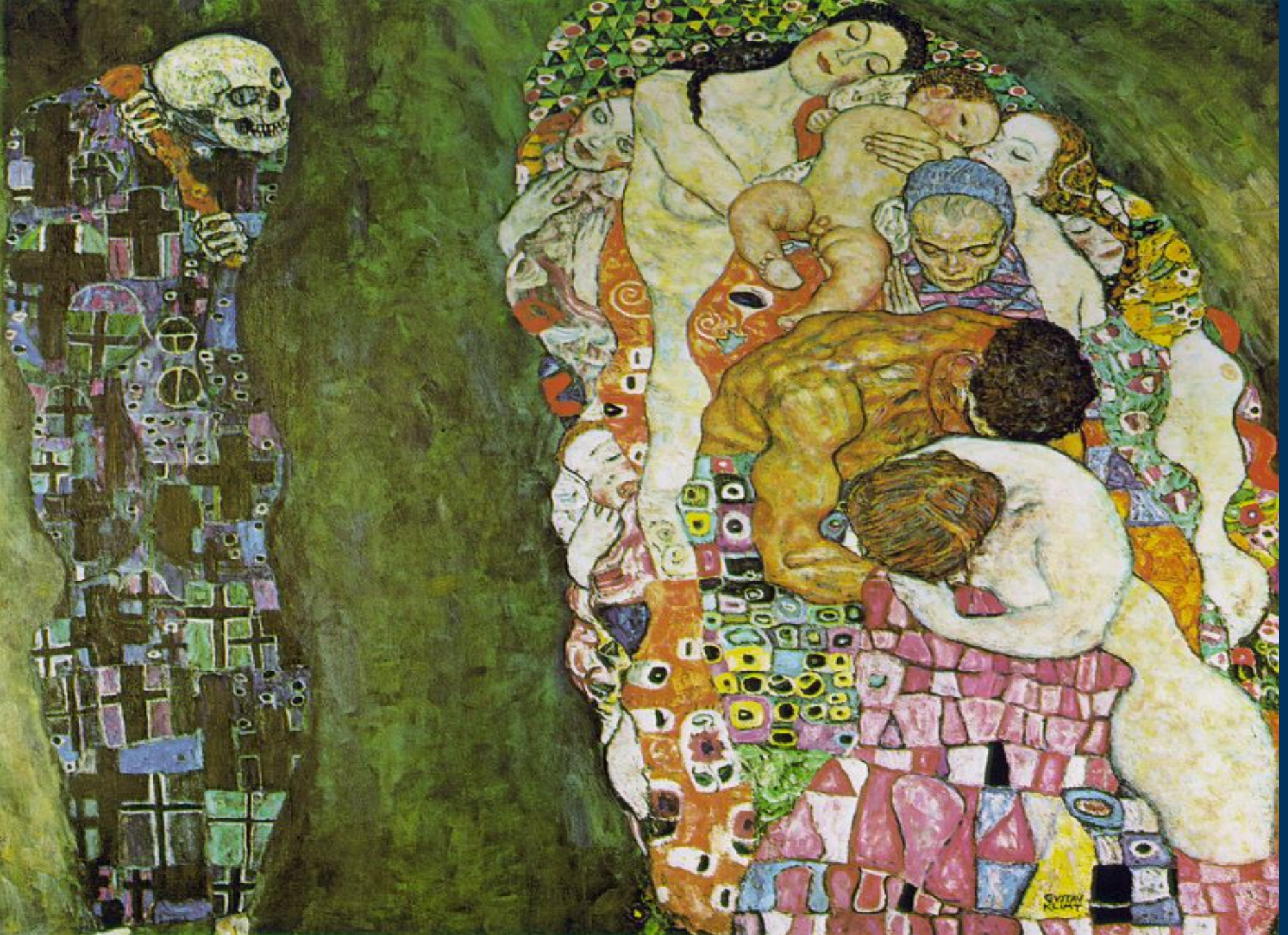


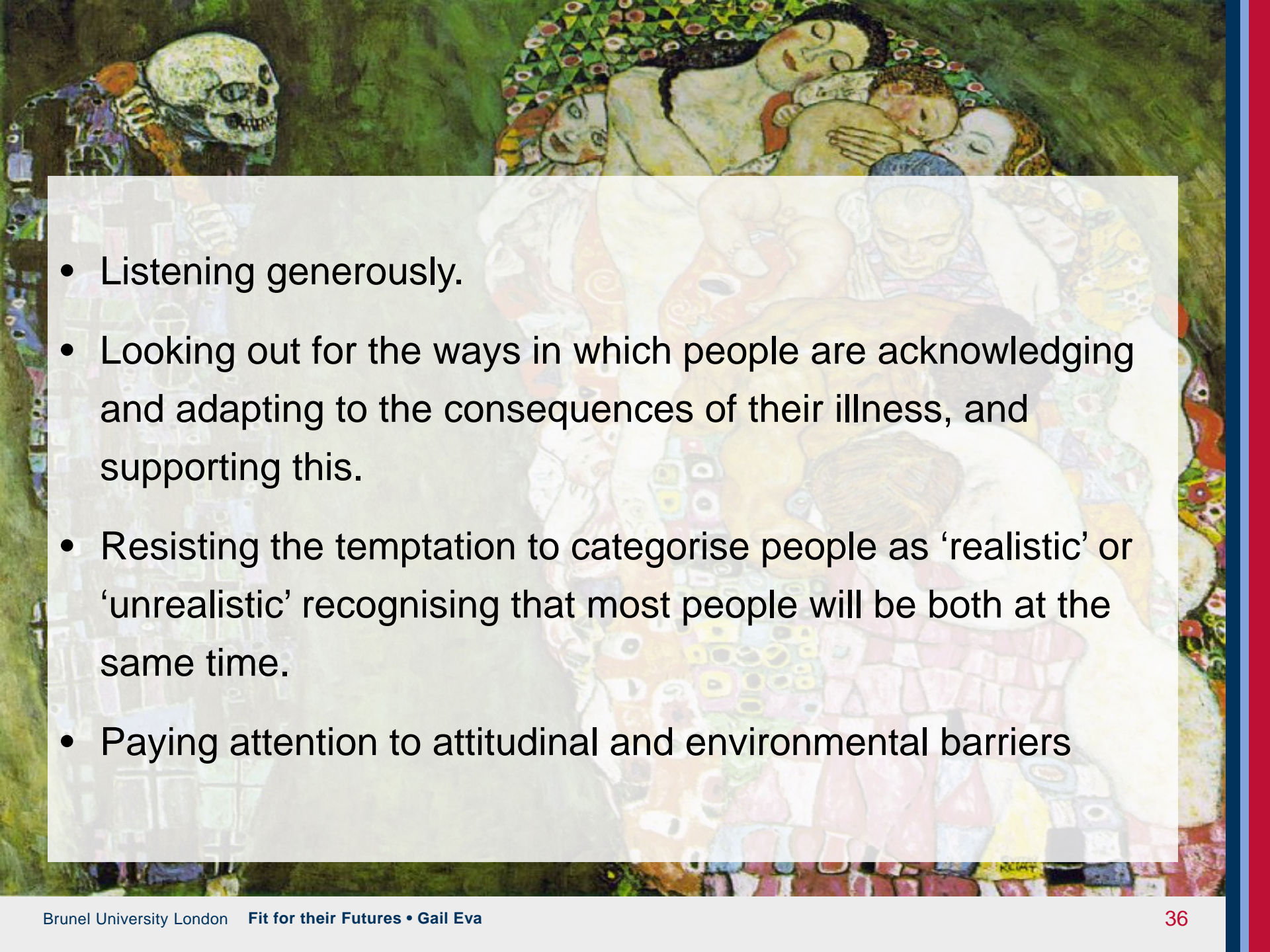
“The most valuable outcomes of rehabilitation [might be] possibilities or ‘feasibilities’ rather than specific achievements.”

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Cardol M, de Jong BA, Ward CD (2002) On autonomy and participation in rehabilitation.

Disability and Rehabilitation 24(18): 970-974.



- 
- Listening generously.
  - Looking out for the ways in which people are acknowledging and adapting to the consequences of their illness, and supporting this.
  - Resisting the temptation to categorise people as ‘realistic’ or ‘unrealistic’ recognising that most people will be both at the same time.
  - Paying attention to attitudinal and environmental barriers

Not

“What’s the matter with you?”

but

“What matters to you?”

# Contact details



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[www.facebook.com/gail.eva](http://www.facebook.com/gail.eva)

[www.twitter.com/gaileva](http://www.twitter.com/gaileva)

*Palliative Rehabilitation Group on Facebook:*

<https://www.facebook.com/groups/110818868948811/> (or go to Facebook and search for palliative rehabilitation)