



PoTS UK

Managing the Psychological Impact of Living with Chronic Illness

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Psychological impact of chronic illness



- Difficult journey to diagnosis
 - Medical trauma
- Significant strain on individuals and their family
 - Financial, social, role-related
- Adjustment to change
- Uncertainty around condition
- Symptom fluctuations
- Anxiety & depression
- Grief

Risk factors



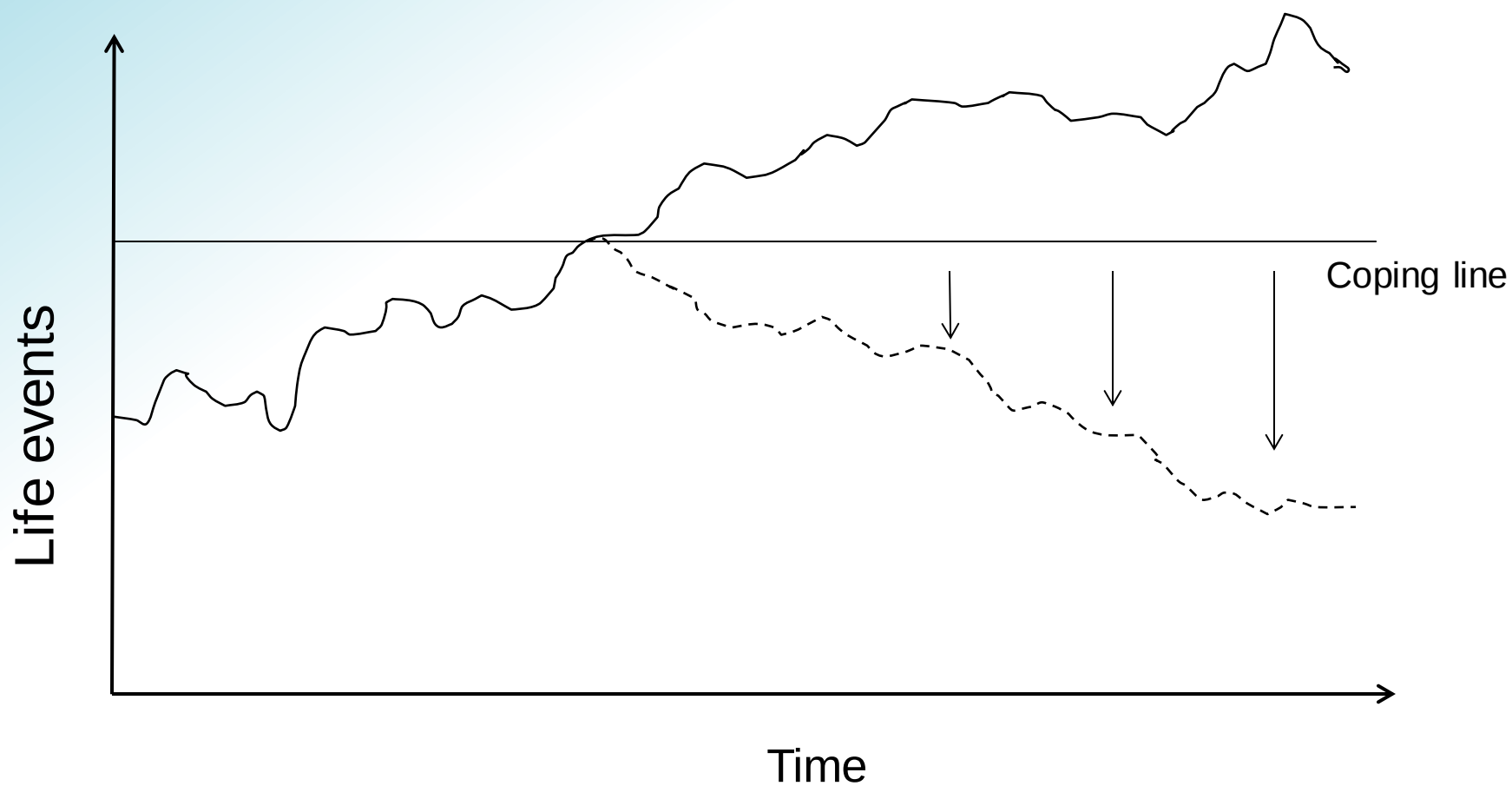
- Lack of social support
- Personal beliefs about health
- Family interaction patterns
- Poor doctor-patient communication



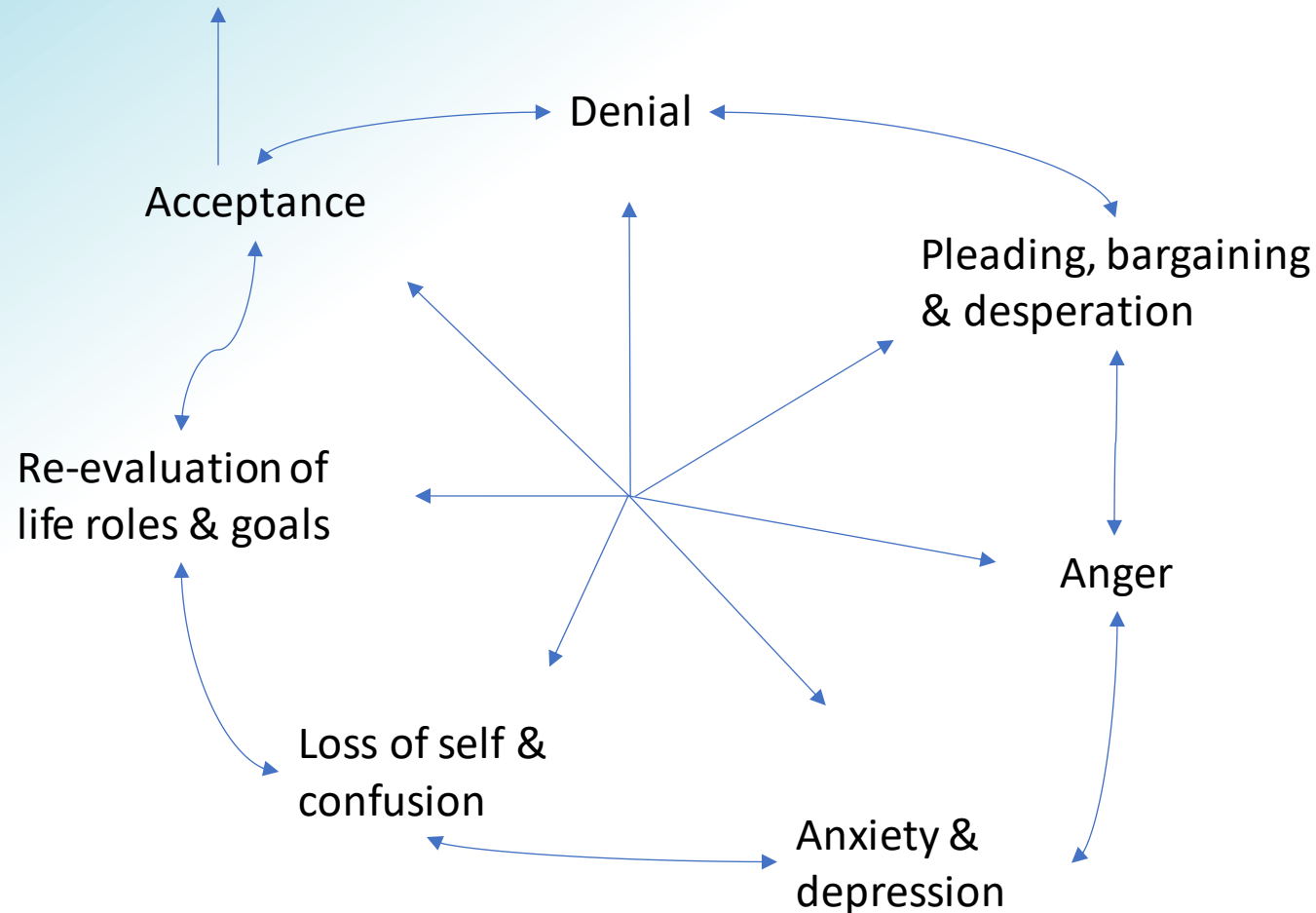
Protective factors

- Optimism
- Self-esteem
- Locus of control
- Social support
- Quick diagnosis
- Good understanding of the illness

Coping line



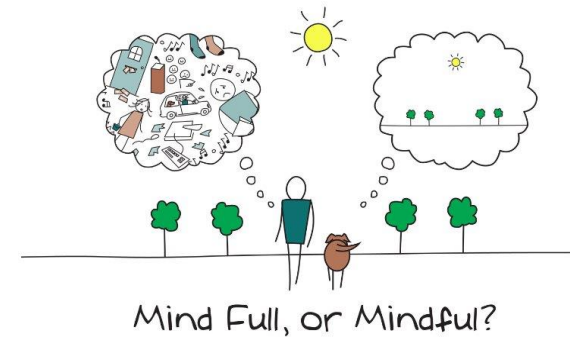
Stages of grief for chronic illness



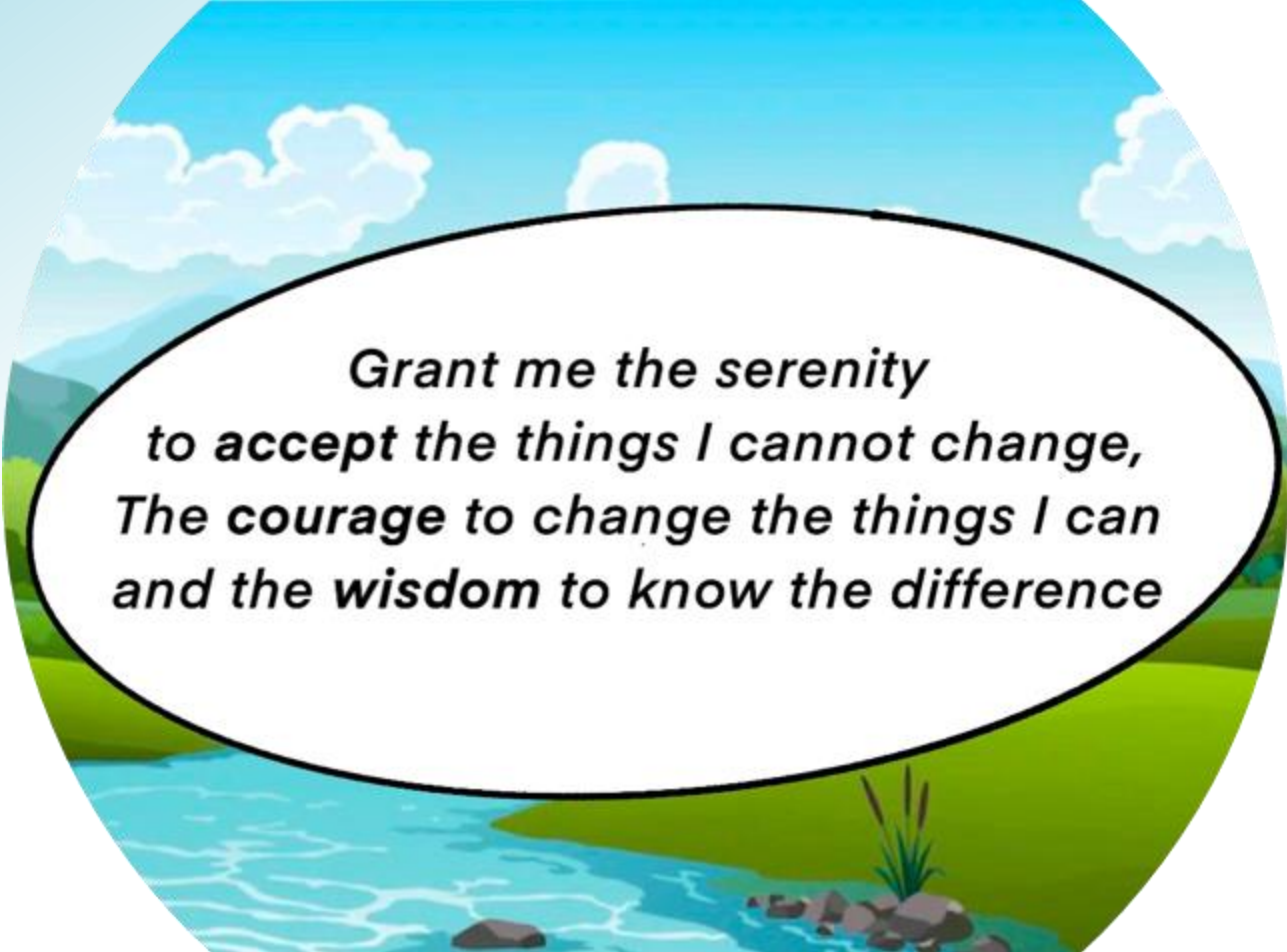
Strategies to support emotional wellbeing



- Psychological therapy: ACT & CBT
- Mindfulness – being present in the moment not drawn to the past or what the future holds
- Connecting with values that give our lives meaning e.g. connecting with nature, creativity, love and friendship, honesty
- ACE – plan your week with activities that give you a blend of these three components – evidence shows this supports emotional well-being



Serenity poem

A graphic featuring the Serenity prayer. The text is centered within a large white oval with a black border. The background of the oval is a scenic landscape with a blue sky, white clouds, green hills, and a blue river with rocks and reeds in the foreground.

*Grant me the serenity
to **accept** the things I cannot change,
The **courage** to change the things I can
and the **wisdom** to know the difference*

Recent research

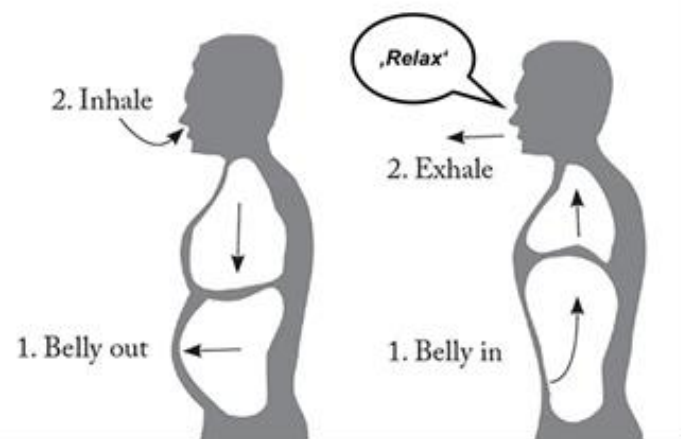
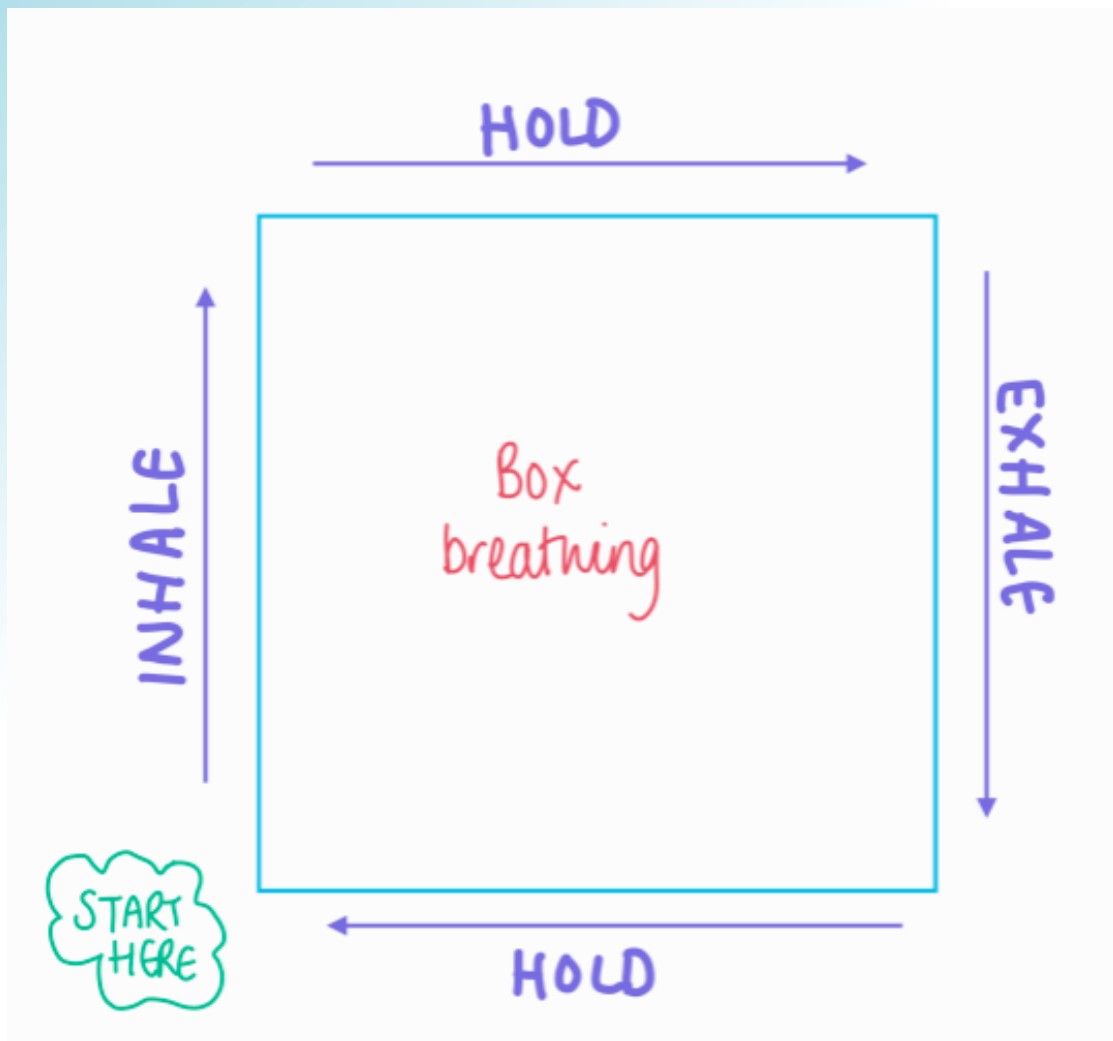


- Hutt et al., 2020 – Functional capacity & quality of life in PoTS
- Knoop & Dunwoody, 2022 – “You’re always fighting”: the lived experience of people with PoTS
- Hogg et al., 2023 – ‘I never realised that I don’t breath correctly’: Understanding experiences of PoTS and the challenges of altered breathing for intervention development
- Firth et al., 2023 – Psychological stress in PoTS: results of an online survey
- Mizutani et al., 2024 – Association of adolescent PoTS classifications with anxiety: a cross sectional study

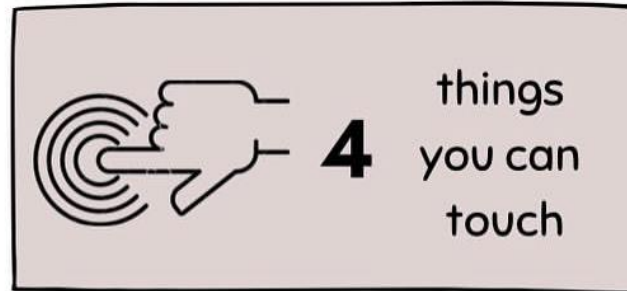


If there is time...

Box breathing



5-4-3-2-1 grounding



[Video example](#)

Sources of support



NHS

- Visit GP - Can advise on an NHS therapist or local IAPT service – often have long term conditions groups
- Self-refer to local NHS Talking Therapies service (formally known as IAPT)

Seeking therapy privately

- Practitioner psychologists should be registered with the Health Care Professionals Council (can search on their register)
- Psychology Today, Counselling Directory, BABCP (cognitive therapy specifically)

Samaritans

- Call 116 123 from any phone, for free
- Email: jo@samaritans.org (24-hour response time)

SHOUT

- Text SHOUT to 85258, available 24/7

In an emergency:

- Call 999 or 111
- Attend your nearest A&E