Sense-making through stories:

How collaborative curiosity helps patient and practitioner to learn together

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Opening Remarks

I am going to speak, today and tomorrow, about the way we meet, support and work with people facing the ends of their lives, in our work as palliative care professionals.

I will tell some stories of my own. I will invite you to remember some of yours.

I will not be showing any pictures of people who are no longer alive, and I will not be using their real names.

I will be using the words ‘dying, death, dead’ for clarity, and I intend no offense to those among us who prefer not to use such direct language. Please bear with me.

Learning Outcomes

This talk won't make you a Cognitive Therapist. I hope it will enable you to:

- describe the components of a CBT formulation and the way those components are inter-related; recognise the therapeutic value of creating a summary CBT formulation

- recognise the importance, and be ready to explore and develop, some components and skills underpinning guided discovery

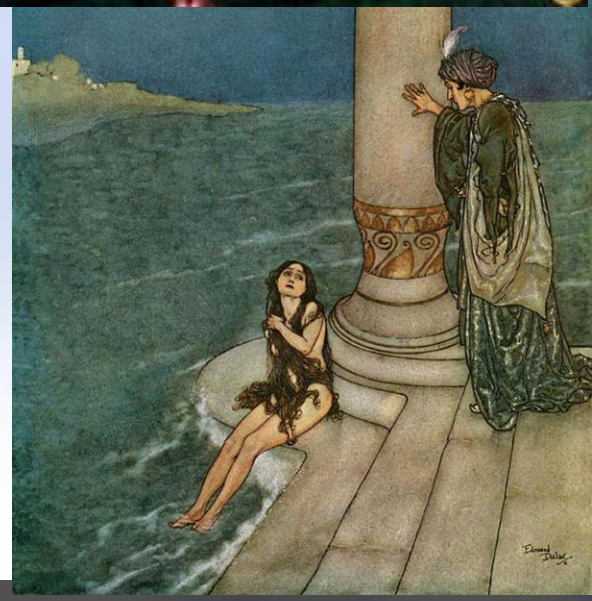
- understand the roles of cognitive and behavioural techniques in exploring their patients' distress, and be ready to devise simple behavioural experiments with a patient

- appreciate the specialist skills of your local Cognitive Therapists, and to make better-informed referrals to them

Q: How do we share Wisdom?

A: Through stories

Once upon a time….



Storytelling in Palliative Care

Take a moment to think about a patient who has stayed with you long after you worked with them

What do you remember about that person, and about that episode of care?

How much detail could you describe that episode in now?

What helps you to remember all that information?

Storytelling in Palliative Care

The people we remember touch us in a particular way.

They remind us of someone who is emotionally significant to us, or their situation echoes a tender spot of our own: we discover that this person's situation matters to us. Our stories resonate.

Examples: before and after close personal bereavement; before and after parenthood.

These 'special' patients remind us of our own stories.

This is a special story of mine, and it will help us to look at how using a CBT approach can empower our patients to understand their own stories better, and even to re-shape them.

CBT basics

A ‘talking therapy’ with a large evidence base

Adaptable for use in a palliative care setting

Collaborative, Curious, Exploratory

Individualised formulation guides interventions

Assessment → formulation is illuminating and helpful in itself

Formulation

Describes the relationship between thoughts and the resulting emotions and behaviours; in physical health settings, also incorporates interplay with bodily sensations.

Makes sense to the patient by being jointly derived with/discovered by him/her.

Describes the patient's experience and is developed/embellished as further discovery is made, further links become apparent or new insights are revealed.

Case story and examples of core skills to take away

Vronny, 32, disseminated Ca cervix → renal failure, neuropathic leg pain, oedema

Pain consultation

Discussion of her elegant but tight trousers → enormous distress

'If I can't look like this, I won't be me…'

Guided discovery Question: '…and what would that mean?'
A: 'I'll be dying'
Q: '…and what is the hardest thing about that, for you?'

A: 'I am abandoning my children'

Skill one:
Guided discovery by curious questioning

All questions are simply curious

No assumptions by helper about meaning, importance, accuracy of responses

We are listening to understand, not to persuade or 'change someone's mind.'

To begin with, we are not seeking solutions, we are seeking clarity.

'What happens when…? How do you feel about that? Is it ever any different? What do you put the difference down to?'
'What do you notice about your body when that difficult thing is happening? Does it affect you in other ways? Is it always the same?'

Skill one:
Guided discovery by curious questioning

'Downward arrow' technique – is an especially powerful questioning technique (so use with care) to discover the root of someone's distress

Q1 'What is troubling you the most about that?'

Q2 'And what is the hardest/most troubling thing about that/what would that mean?'

Q3 Continue to ask what this means/would mean; what is the worst thing about that, etc

At the bottom of the arrow is an idea or thought that is existentially challenging/unbearable.

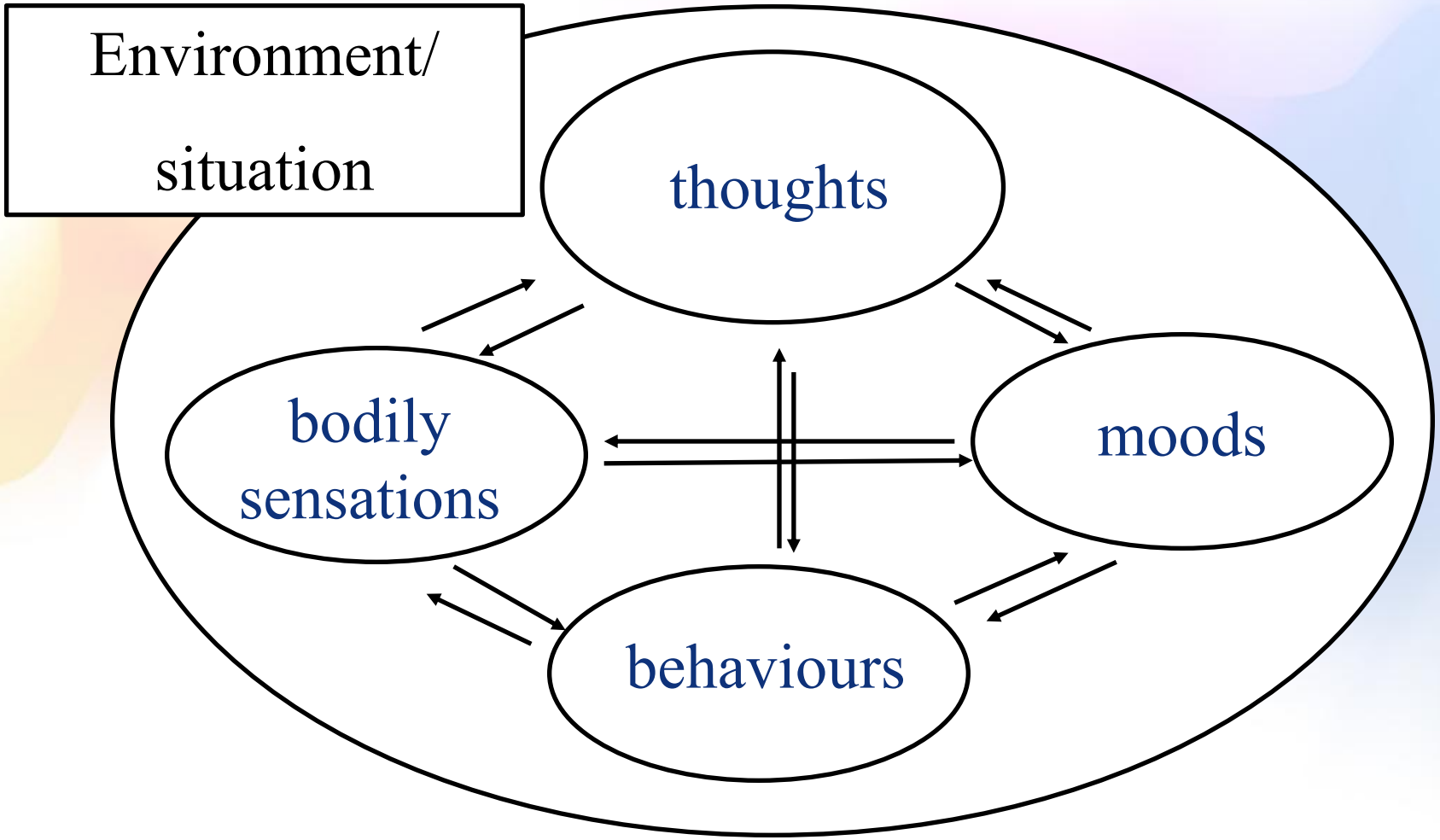
Skill two:
Formulation

Co-production of a diagram that summarises the patient's experience

Formulation includes their ideas, mental images and thoughts; their emotions; the behaviours that arise in response to their thoughts and emotions; and how these domains interact with bodily sensations.

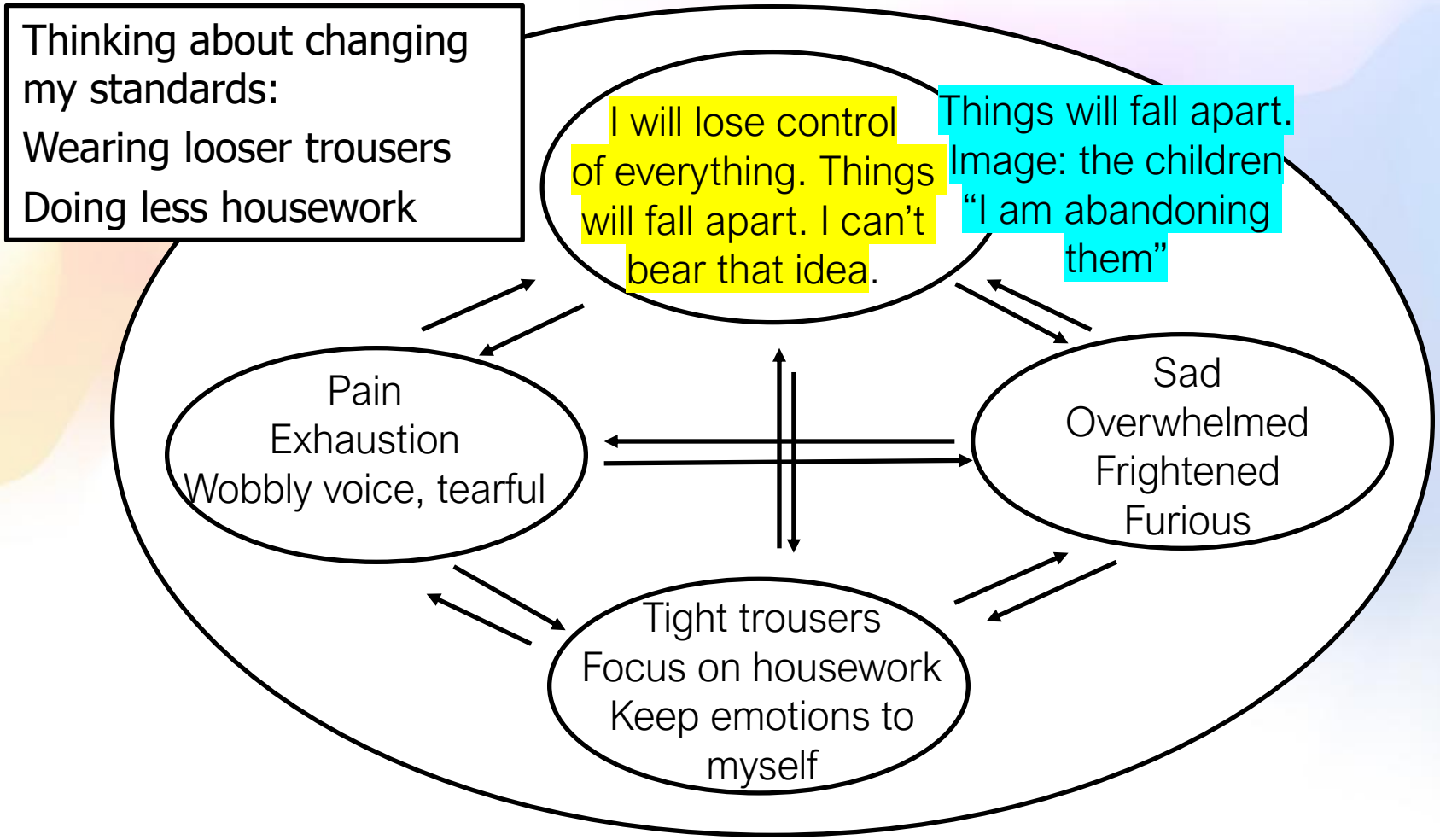
A formulation diagram summarises 'current understanding' and it allows us to look at examples of difficulties in a more objective way, with curiosity about the detail and about other possible behaviours, or alternative thoughts/ideas/interpretations. It's a way of 'holding the story so far.'

The cognitive model

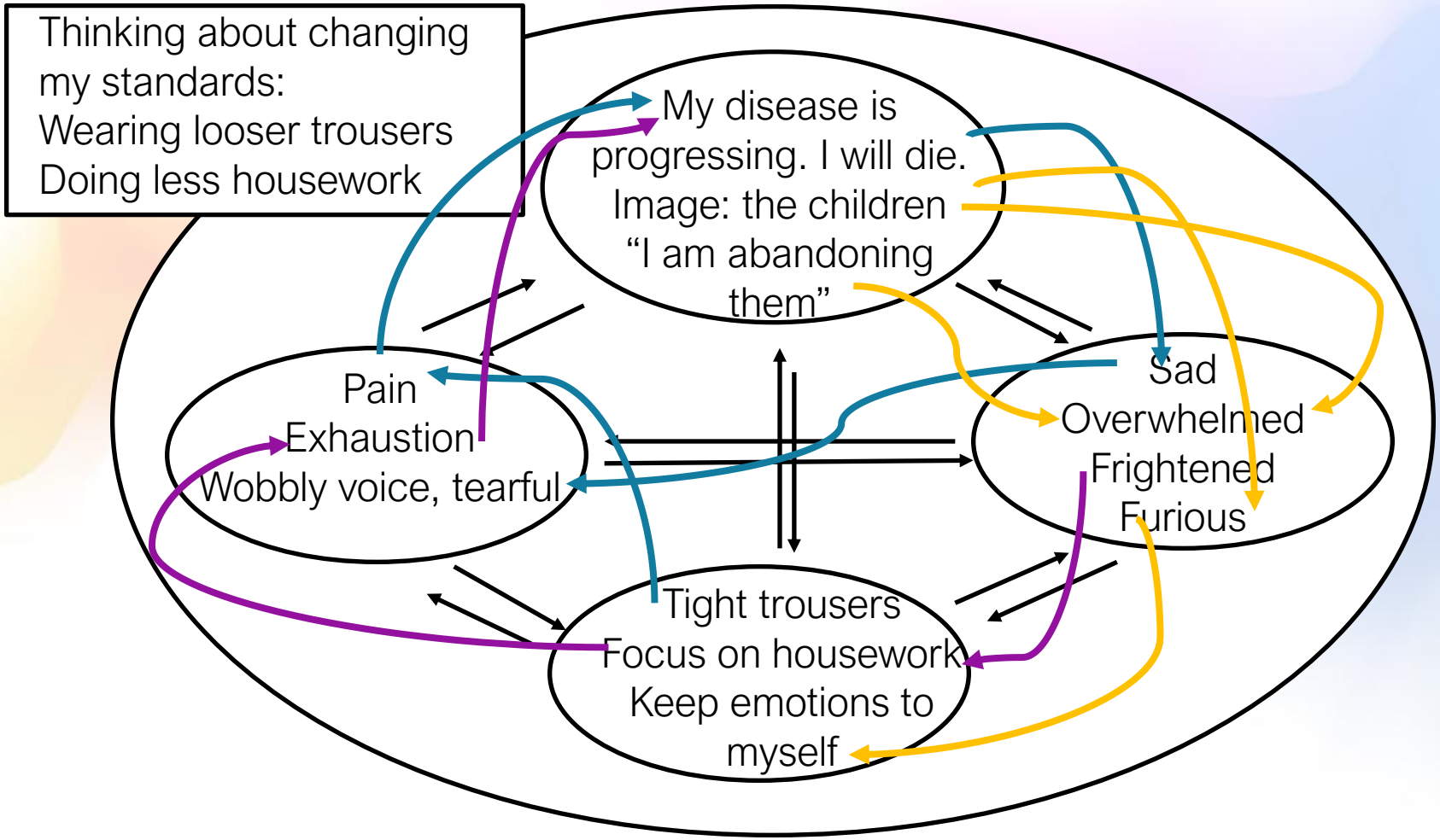


The cognitive model

Thoughts Vronny can bear to say aloud
Thoughts only revealed by further questions



Discovering the links in a formulation



Skill three:
Evaluating a thought/belief

"If I let my standards slip, everything will fall apart."

Cognitive technique: looking for evidence

Taking the thought to Court

Taking a thought to Court

Thought: If I reduce the amount of time I spend on housework, I'll be a bad Mum

Evidence For	Evidence Against
There are 4 of us and nobody else bothers to tidy.	I missed a day last week and things still looked OK.
The cat sheds fur on the carpet.	I'm the only one who notices the cat fur.
I hate to see dirty dishes.	Do the children care? I don't know!
I want the children to come home to a tidy house. Other mums manage it, so I should, too.	Vacuuming takes up energy I need for listening to the children when they come home.
	My friend Gill has an untidy house but happy children

Alternative Thought: If I reduce the amount of time I spend on housework, I might have more energy to spend on my children.

Evaluating a thought/belief

"If I reduce the amount of time I spend on housework, I'll be a bad Mum." Original thought.

"If I reduce the amount of time I spend on housework, I might have more energy to spend on my children." Hypothesis after taking the thought to court.

Behavioural technique: testing the hypothesis

A Behavioural Experiment – what would happen if…? (Can I change this story for myself?')

Skill Four:
Behavioural Experiment

Thought/belief: If I reduce the amount of time I spend on housework, I'll be a bad Mum
Question: What happens to my 'Mum energy' if I do less housework?

Experiment: to find out what happens to the time I spend with the children if I spend less time on housework

Plan – devised by Vronny, with support.

I'll choose days when I feel OK.

On at least 2 days I'll spend only 20 mins/hour on housework, then 40 mins resting, between 9am and 2pm. I won't skip lunch.

On other days I'll do my housework as usual.

I'll compare what happens.

Day	Housework & time spent	Energy levels at 3pm	How I spent time 3 – 5pm	Satisfaction & Pleasure score today
Monday	Dust, vacuuming, laundry, ironing 5h	4/10 😟	Cross, tired Sent the children to play in their rooms	S = 7/10 P = 2/10
Tuesday	Dishes, vacuum stairs Rests	7/10	Chat with both children with juice and biscuits, watch TV with them	S = 6/10 P = 9/10
Wednesday	Forgot about the experiment!			
Thursday	Get ready for visitors but took rests.	6/10	Chatted with Katy about her art project. Ben at friend's house	S = 6/10 P = 8/10
Friday	Visitors arrive tomorrow! Dusted, prepped meals for weekend. No rests.	4/10	Too tired, but all food is ready. Ben was sad, too tired to ask why.	S = 8/10 P = 3/10 I feel like a bad mum.
Saturday	Asked Danny to change beds, Katy wanted to help. I had a snooze then a chat with Ben.	8/10	Lovely day. Bedrooms ready for visitors, Katy loved helping. Ben told me about his school worries.	S = 9/10 P = 10/10

Behavioural Experiment: outcome

Thought/belief: If I reduce the amount of time I spend on housework, I'll be a bad Mum

What I learned:

Doing lots of housework eats up my energy.

Taking lots of rest slows down the housework, but it ends up 'good enough'

Taking rests saves my energy.

Having more energy for the children makes me a better mum.

Bonus discovery – my family will help, and we all feel good by being a good team.

Skill Five:
Working with true, unhelpful thoughts

Thought/belief: I am going to die, and my children will be bereft

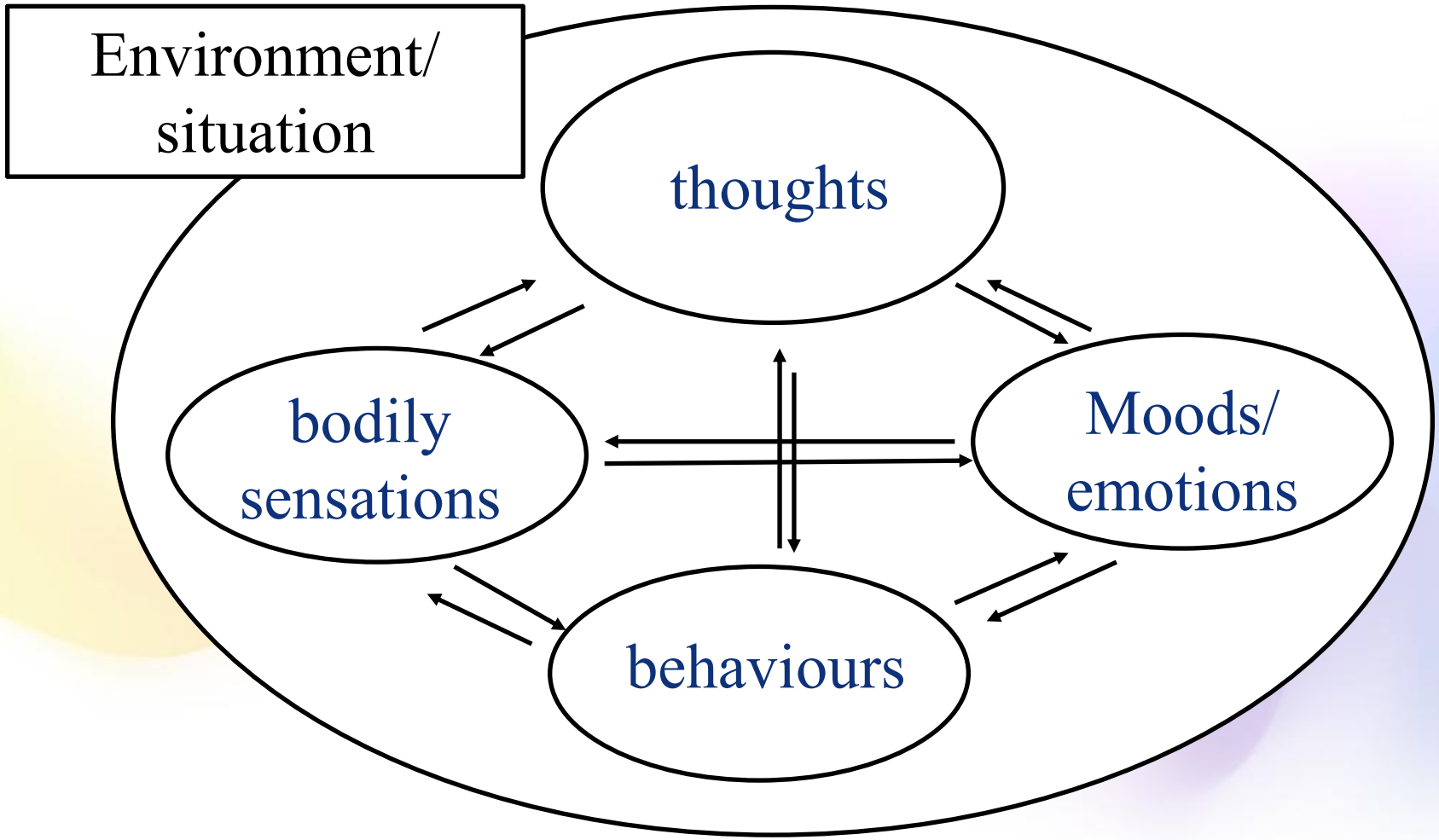
How helpful is this thought to me right now?

What would I advise a friend in this situation?

What previous life experience can I apply here?

Could this thought have a helpful component? What can I do with that?

How can I remove my attention from this thought?



CBT Bingo

People will judge me

I feel stupid

Angry Doing nothing

I feel sad

Worry It's overwhelming

Crying Hopeful

Sleeplessness

Making a worries list

I feel cold Nausea

I feel unable to settle

In summary:

CBT style is collaborative, curious and sees the patient as a fellow storyteller and a peer investigator.

Building a formulation collaboratively during assessment may be an intervention in itself.

We can investigate the helpfulness/unhelpfulness of thoughts and of behaviours using both cognitive and behavioural techniques.

The CBT process seeks first to understand the current situation, before seeking solutions.

CBT seeks to help an individual understand, evaluate and manage their distress by learning to observe themselves and to use the techniques they have learned in therapy to help themselves.

Further Reading:

Christine Padesky

Socratic Questioning: changing minds or guiding discovery?

https://padesky.com/wp-content/uploads/2012/11/socquest.pdf

CBT for Chronic Illness and Palliative Care: A Workbook and Toolkit

Nigel Sage et al https://bit.ly/3U8FFKG

Examples in practice are included in stories in 'With The End In Mind' (panic, respiratory distress) and 'Listen' (overview of CBT, guided discovery)

Thanks, and good luck!

With thanks and appreciation to

the patients, families and colleagues (especially nurses) who have helped me to become a better doctor,
to tell their stories in the interests of public education, and to develop and refine
CBT First Aid Skills training,
to my publishers who were prepared to risk backing a book of stories about dying,
to my family for their patience and support.

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