



Mental Health for the Rare Disease Community

# **Living with PSP and CBD: Looking after your emotional wellbeing**

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**Rareminds' vision** is that the psychological and emotional aspects of living with a rare condition are recognised as an integral part of rare condition care, with access to specialist quality services for all.



# There is no health without mental health

The relationship between physical and mental health is well established



**Poor mental health** can impact on physical health, the capacity to selfcare, resilience etc

**Poor physical health** can cause higher rates of depression, anxiety etc



# The challenges of living with a rare condition

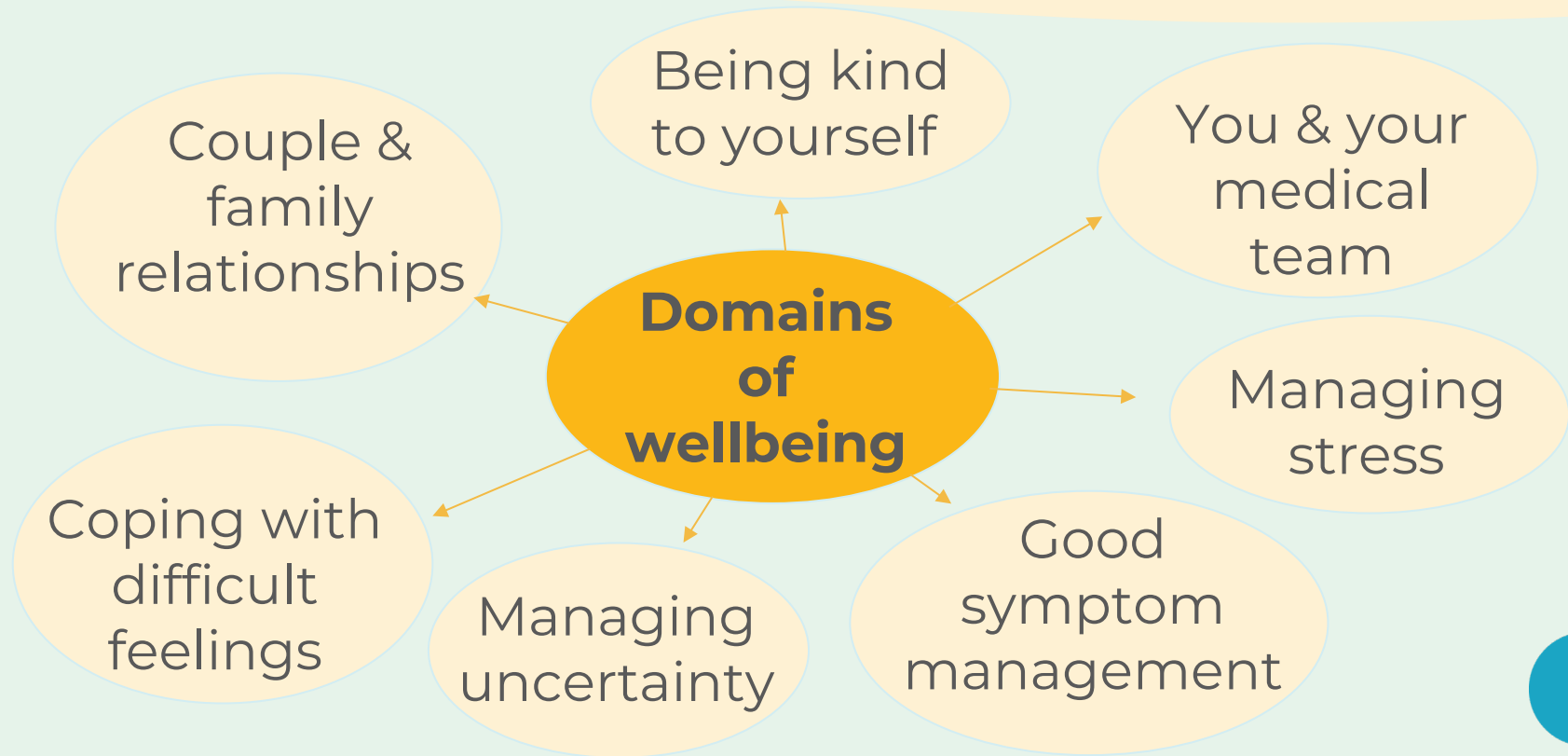
- Diagnosis
- Low disease awareness
- Logistics of care
- Impact on work & social life
- Emotional impact



- Grief, change & loss
- Uncertainties
- Symptoms
- Impact on family/couple
- Inheritance
- Feeling different/alone



# Seven domains to support wellbeing



# 1 - You and your medical team

## **Making the most of your appointments:**

- What do you want from this person or appointment?
- What is the priority for **you**?

**Train your HCP up to support you as an individual**

**Be clear about what works for you (and doesn't)**



## 2 - Coping with difficult feelings: 'Giving them 'air time'

Try to notice **what** and **how** you are feeling?

What might help that feeling 'feel more bearable', or pass?



### Therapist Tip

Notice yourself when describing an emotion as 'I am....', what feels different if instead you say 'I feel.....?'





### 3 - Managing Stress: What are your 'stress signs'?

**Physical body** - 'Aches & pains', headaches, upset stomach, exhaustion, getting more colds & bugs

**Feelings** - Jittery, tearful, anxious, exhausted, 'numb', 'on a short fuse', mood up & down

**Behaviours** - Eating, alcohol, smoking, drugs, compulsive scrolling, irritability

**Thinking** - Negative, pessimistic, self-critical, can't concentrate, foggy

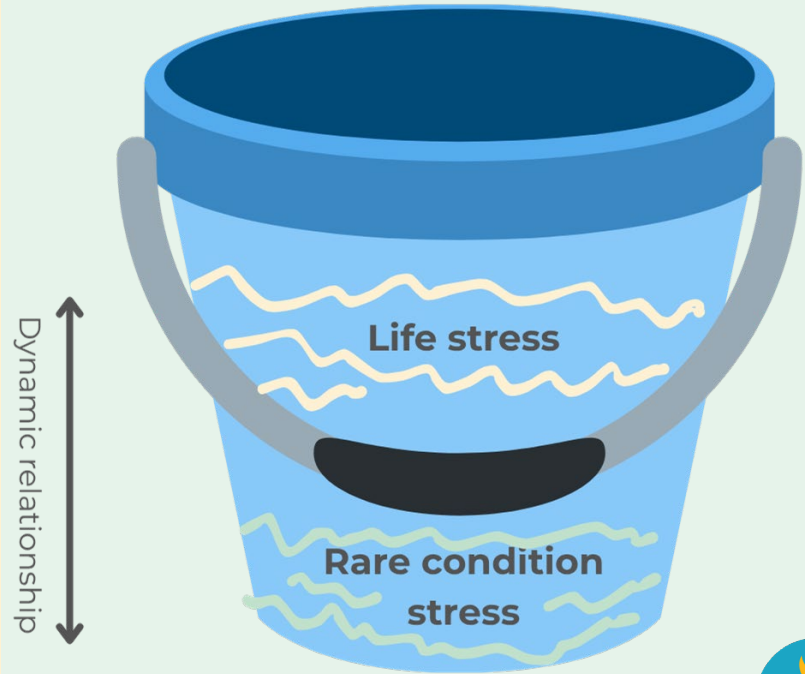


# Looking after your 'stress bucket'

How much room your **PSP/CBD** takes up..

...affects how much **'emotional capacity'** you have available...

for managing **life's 'ordinary' stresses** and demands..  
and vice versa



# How full is your bucket? Keeping an eye on your 'levels'

**Make conscious decisions about priorities or 'what's possible today'**

**Accept limitations (this can be hard)**

**Break big tasks into smaller ones**



## Therapist Tip

If you find it hard to ask for support, try 'reframing' it to yourself as offering someone the opportunity to feel good about themselves by helping you out



## 4 - Personal, couple and family relationships

Illness, stress  
and hardship  
do not always  
bring out the  
best in us

***We are often the ‘most difficult’  
with those we are closest to***

***TIP:*** *In couple relationships,  
the things we find most annoying  
about someone are often the very  
things we first fell in love with!*



# Managing relationships

**What do I need right now?**

**Build a support network of people you feel understood, and supported by**

**Know 'who is good for what'**



## Therapist Tip

Relationships are like plants, they need regular 'food and water' like care, attention, love and nurturing, otherwise they start to show signs of stress. Different relationships have different care needs, but all need at least some time and attention to keep them alive and well.



## 5 - Symptom management supports mental wellbeing

Pain, mood

Sleep, Fatigue

Mobility, flexibility

Diet

Sensory (e.g. vision,  
hearing, voice)

**Don't struggle alone with  
things you are finding  
difficult**

**Talk to some you trust with  
personal or professional  
expertise in that area**



## 6 - Coping with uncertainty

### Short term (micro) uncertainties



*'Will today be a good/bad day?'*

*'Will my GP call back?'*

*'Will these meds help?'*



### Longer term (macro) uncertainties



- *Rate of disease progression*
- *Speed of decline*
- *Death/dying*



# Learning to live with 'not knowing'

## ***PLAN B's***

**Help manage  
the unexpected, and  
help mitigate  
disappointment**

## ***PLAN C's***

**C is for Crises.  
Help you to feel  
prepared, and help  
mitigate anxiety**



# Learning to live with 'not knowing'

We tend to fill the 'void' of not knowing with our fears, and anxieties

Try to recognise when you are doing this

**Ask yourself if your fears and anxieties need (or can) be addressed right now, or are 'not for now'**

**Reassure yourself you will deal with them 'when you know more' or 'when you need to.' Stay in the present**



## 7 - Be kind to yourself

**You did not ask for, or expect  
a rare condition to be part of your life**

We cope as best we can (sometimes not as well as we'd like)

We are often much harder on ourselves than others are

**Rare conditions happen whilst we are making other plans**

(..with apologies to Bob Dylan!)



# Some helpful tools

## Mindfulness can help with:

- Managing pain, difficult thoughts and feelings
- Making the most of simple pleasures

**[breathworks-mindfulness.org.uk](https://breathworks-mindfulness.org.uk)**

**‘Spoon Theory’  
can help with with  
managing fatigue  
and exhaustion**



# The PSPA Counselling Service

To find out more,  
or to arrange an  
initial consultation,  
please email:

**[david@rareminds.org](mailto:david@rareminds.org)**



**David Phipps**  
**Lead Counsellor**



**Poppy Brent**  
**Associate Counsellor**



# You and your mental wellbeing: Rareminds resources

## Wellbeing Hub



## Podcast



# General mental health support organisations

**Every Mind Matters** - [www.nhs.uk/every-mind-matters](http://www.nhs.uk/every-mind-matters)

**Hub of Hope** - [www.hubofhope.co.uk](http://www.hubofhope.co.uk)

**Anxiety UK** - [www.anxietyuk.org.uk](http://www.anxietyuk.org.uk)

**The British Association for Counselling & Psychotherapy**

[www.bacp.co.uk](http://www.bacp.co.uk)

**Carers UK** - [www.carersuk.org](http://www.carersuk.org)

**BAATN UK** - [www.baatn.org.uk](http://www.baatn.org.uk)



# Crisis support

Contact **GP** or **NHS 111**. You can also go straight to **A & E**.

**Samaritans** - 116 123 [www.samaritans.org](http://www.samaritans.org)

**Befrienders Worldwide** - [www.befrienders.org](http://www.befrienders.org)

**SHOUT** - Text SHOUT to 85258

**Papyrus** - 0800 068 4141 - (9am-midnight)

**SilverLine** - 0800 4 70 8090

**CALM** - 0800 585858 [www.thecalmzone.net](http://www.thecalmzone.net)



# Relaxation exercises and techniques

5 4 3 2 1  
GROUNDING  
TECHNIQUE



BOX  
BREATHING



**Thank you :)**

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