

Ataxia: Handling Diagnosis & Managing Our Mental Health

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Rareminds: Our Story



- 2013 – began providing workshops, Online/Telephone Counselling Services, talks, training to on psychological impact for one small charity www.amend.org
- 2017 to date: began to be invited to work with other rare disease organisations , speak on psychological impact. Increasingly aware that despite many patient organisations and groups documenting psychological distress across a wide range of rare diseases and conditions, it remained an ‘unmet need.’
- 2018 Rare Disease and Mental Health Report (Rare Disease UK)* 95% felt worried/anxious; 93% stressed; 90% low
- In Oct 2020, raremindsCIC was born as a not-for-profit organisation as a resource for the rare disease and genetic conditions patient communities with respect to mental health and emotional wellbeing, to support patient organisations, and medical/mental healthcare professionals, and to shape good practice in this area

* Living with a Rare Condition: the effect on Mental Health (2018) www.raredisease.org.uk



Living With A Rare Condition

(May remove)

- Journey to diagnosis is often not straightforward
- Low disease awareness; having to be the 'expert'
- Uncertain prognoses , or timings and impact of treatments
- Logistical and financial burdens of hospital attendance and disease management
- Emotional and practical impact of treatments
- Inter-acting emotional, cognitive and physical symptoms
- Loneliness, and 'being different'
- Impact on family life , life choices and relationship dynamics
- Visibility/invisibility
- Impact on sense of self and identity



Let's Talk About Diagnosis

Diagnosis is an event and a process ...

'[Trying to get a diagnosis] was really difficult. I remember in the night sort of going to bed and just crying myself to sleep, not so much because I was sad but more because I was frustrated, because you feel like you're constantly saying the same thing and no-one's listening to you, you know?'

*(Carer)**

' You get to the point where sometimes you don't even want to see a doctor anymore because it's the fear of being ridiculed and being labelled, you know, as somebody that 'it's all in your head' basically, when you know it's not, and you can actually see the symptoms and feel the symptoms happening.'

*(Patient)**

... with an ongoing fluctuation in intensity throughout life



12 Common Feelings About Diagnosis

Envy

Despair

Anger

Resentment

Fear

Numb/Nothing

Anxiety

Disbelief

Relief

Low Mood/Depression

Guilt

Grief and
Loss



The Stress Bucket: Ordinary Life

Ongoing demands

Big Life Events

Day to day / Week to week issues

Global world events

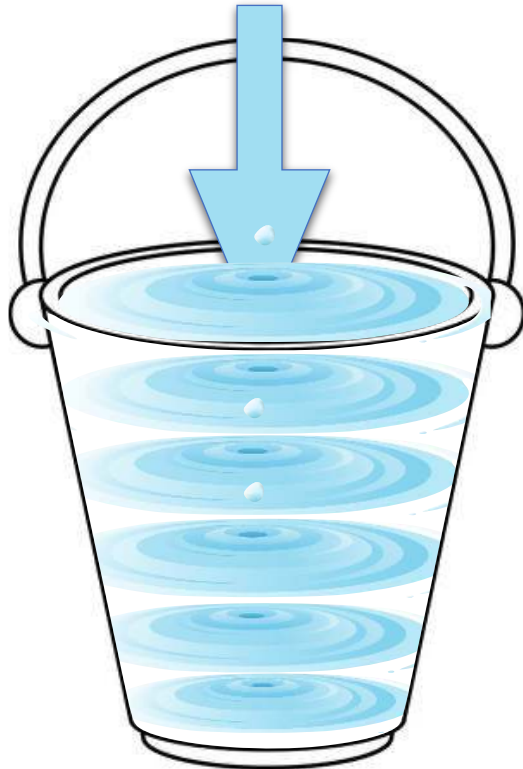
'Ordinary life'



The Stress Bucket: With A Rare Condition

Uncertainty (Macro and Micro)
Managing Symptoms & Side Effects
Difficult Thoughts & Feelings
Family/Friends
Healthcare Team
Fears about the future

Managing the impact
of a rare
disease/condition
takes 'emotional
work'

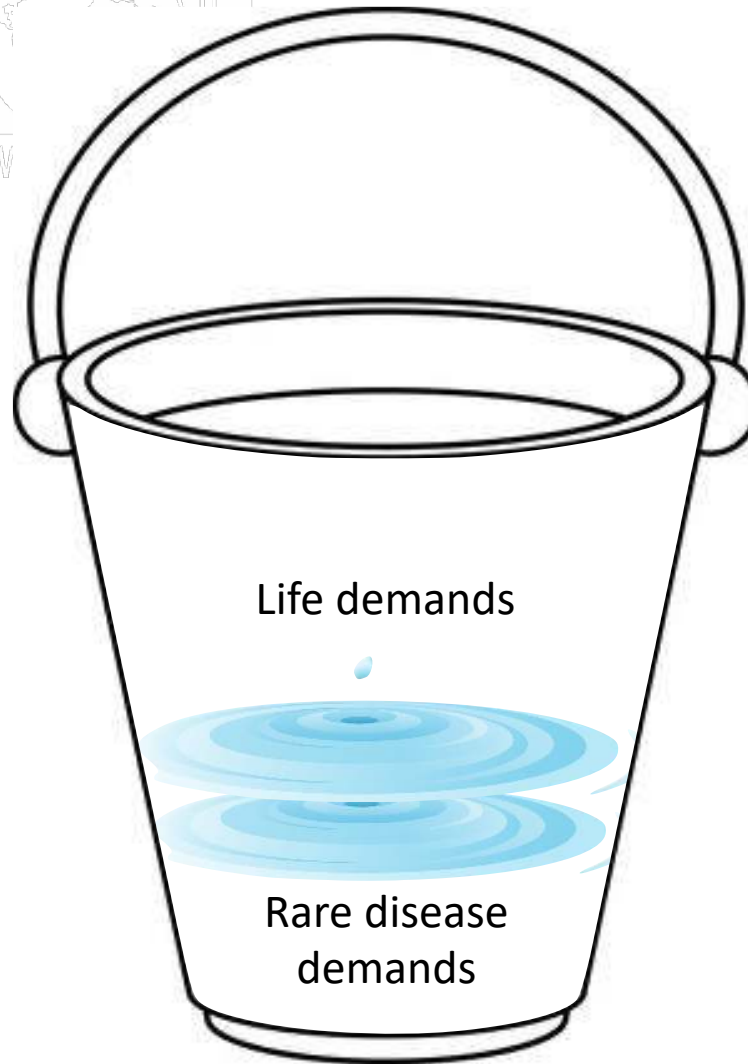


General Bucket Self-Care



How much room your rare disease is taking up affects how much emotional 'space' you have for other stresses/demands without being overwhelmed

Dynamic relationship



How Do We Know Our Bucket Is Filling Up?



How we behave



How we think/feel



Our body shows us



General Bucket Self-Care



Step 1: Recognise

Step 2: Think : how can I deal with this, and what do I need....

a) Long term?

b) Right now?

- Consider talking to someone you trust
- Be kind to yourself

**Remember general self-care... rest, eat well, monitor drug/ alcohol use,
take medication reliably, exercise as best you can**



1. Managing Uncertainty

Macro – uncertainties (disease progressions etc)

Micro – uncertainties (day-to –day impacts)

- Accept the ‘not – knowing’
- Remind yourself that you can deal with uncertainty – we do so everyday
- Make predictable what you can
- Bring yourself back to the present (grounding exercise)



What can I address? What can I not?



2. Managing Symptoms & Side Effects

Facing and embracing - not fighting

Re-befriending your body

- Pain
- Fatigue
- 'Smells and tells' : managing difficult/unpredictable events
- Anxiety



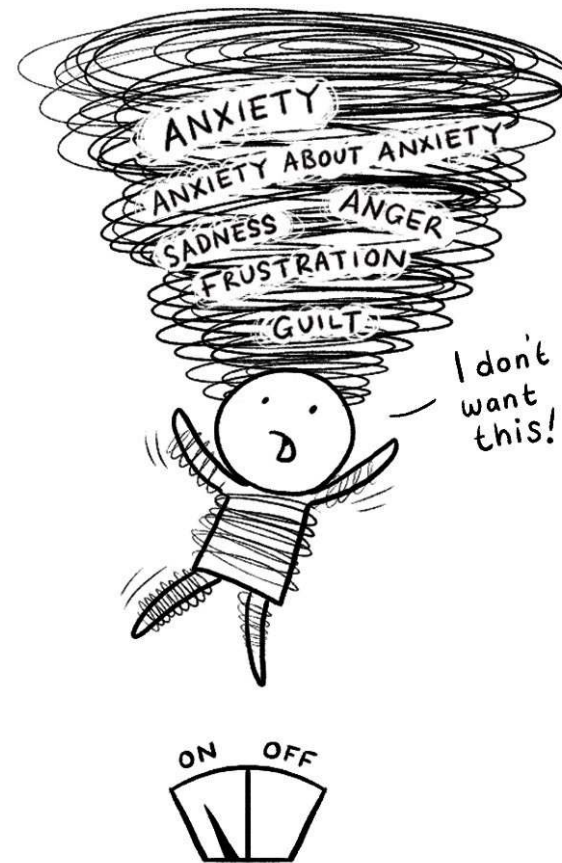
**Finding your sense of agency is key ...
... Working with your body**



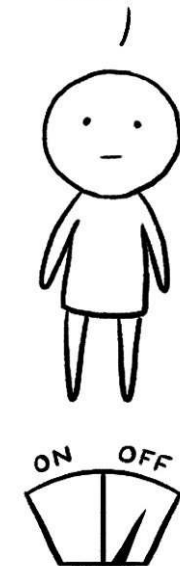
3. Accepting Difficult Stuff



- Notice, and try to name the feeling/s
- Don't judge the feeling - or yourself
- Decide what helps ie talk to a friend/partner? walk/exercise? draw/paint/write? music? distractions?
- Learn how to let the feeling pass , or reduce
- Notice what – and who - helps when a feeling is 'visiting'



Here's anxiety
I do not want it
or like it but I'm not
going to struggle
with it




TheHappinessTrap
© Russ Harris 2018
Illustrations by Louise Gardner

THE STRUGGLE SWITCH
THE MORE WE STRUGGLE THE WORSE IT GETS

Remember that feelings 'ebb and flow'



4. Relationships With Friends, Family & Colleagues



- Knowing what you want (and from whom)
- Learning to say what you need
- Taking risks (and reviewing accordingly)
- Knowing 'who is good for what'
- Bearing disappointments
- Find your 'people' - personal / rare disease related



Remember that feelings 'ebb and flow'



5. Relationship With Your Healthcare/ Professional Team



- Train them up for you as an individual
- Be clear about what works for you (and doesn't)
- If you don't feel something has been 'heard', say it again
- See it as a partnership over time



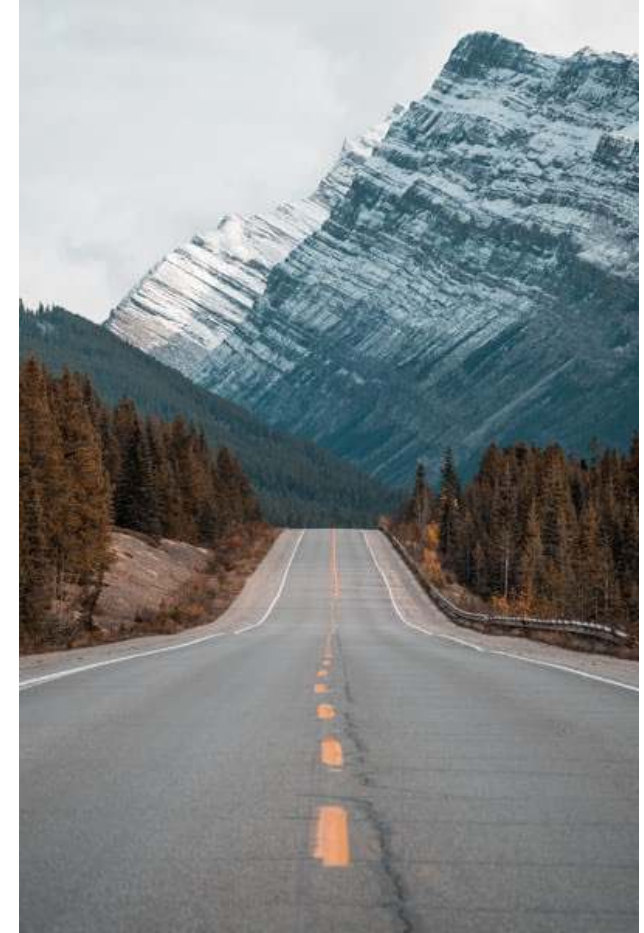
**Remember that your team is there to look after you ...
... not the other way round**



6. Facing Fears About The Future



- Walking up to fears, and walking round them...
- Ask yourself...
 - What can I know (and do something about)?
 - What can I 'not know' ?
- Consider: talking to someone you trust about these...
 - Partner?
 - Friends? Family member?
 - Healthcare professional?



Coming To Terms With Diagnosis

- *'I wouldn't have chosen to have all this, but I do see life differently now. I don't 'sweat the small stuff' as much. I used to be stressed out all the time, but I think I'm probably nicer to be around now'*

(Mike, 48 Dad to Polly age 10)

- *'It's weird, it's part of who I am now. I wouldn't be me without it - I'd be someone else, and I don't mind who I am. Even my scars (which I never thought I'd say.)'*

(Maddie, 18)

- *'I felt really frightened at first and couldn't cope. But I've learned to accept the ups and downs, and take things a bit at a time. My counsellor says 'just do the next thing, that's all.' I feel good about realising I'm stronger than I thought I was.'*

(Aredi , 35 – Mum to India age 4)



Helpful Resources

For General Anxiety & Mood

smartphone/tablet Apps:



Mindfulness Courses

specifically for health conditions, pain & anxiety

Breathworks www.breathworks-mindfulness.org.uk/

For Fatigue

Spoon Theory <https://www.bjchealth.com.au/blog-fitness/the-spoon-theory-managing-fatigue-with-chronic-illness>

From Fatigue to Energy Oxford University NHS Trust
<https://www.ouh.nhs.uk/patient-guide/leaflets/files/45345Pfatigue.pdf>

Urgent Help

Your GP

The Samaritans (116 123) www.samaritans.org

CALM www.calm.com

SHOUT www.giveusashout.org

Books

Bogosian, A. (2020) *Living Well with a long-term health condition* (2020) Routledge. London

Berhard, T *How to Live Well with Chronic Pain and Illness*

Burch , V (2008) *Living Well with Pain and Illness*. Piatkus. UK

Rareinds helpful resources available soon on our website



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Mental Health for the Rare Disease Community