



# Living with rare endocrine diseases

## Resilience and managing uncertainty

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# What do we do?

- ⇒ **Individual and couples counselling**      6 -12 session integrative model using techniques from evidence -based models e.g., psychodynamic, CBT
- ⇒ **Online Group Programmes**      i.e., *Living With [your condition]: looking after your emotional wellbeing*
- ⇒ **Online Workshops**      e.g., Dealing with Diagnosis; Managing Transition: a survival guide for parents; The Stress Bucket and Six Helpful Habits for Rare Self-Care
- ⇒ **Support for Supporters**      e.g., HCPS's and Patient Leaders (Talks, Training, Therapeutic Consultancy/supervision etc.)

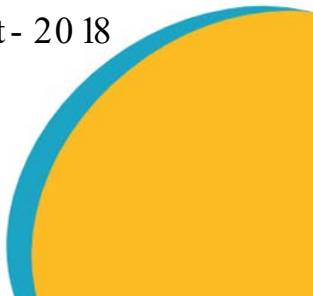
# Why?

“There is no health without mental health”

Brock Chisholm WHO President 1954

“Living with or caring for someone with a rare condition can have a hugely negative impact on emotional wellbeing and mental health”

Rare disease UK: Living with a rare disease report- 2018



# Life can be busy enough.....

Living with MEN adds another dimension, and it's own challenges:

- ⇒ Physically
- ⇒ Practically
- ⇒ Emotionally
- ⇒ Relationships



The good news is - it is possible to cope well 😊

# Common themes across RD's that impact mental health and emotional well-being

Lengthy diagnostic odysseys

Complex interacting emotional and physical symptoms

Impact on relationships, and identity

Logistics of disease management, treatment and care  
(Including medical PTSD)

Anxiety/low mood in the face of degenerative aspects

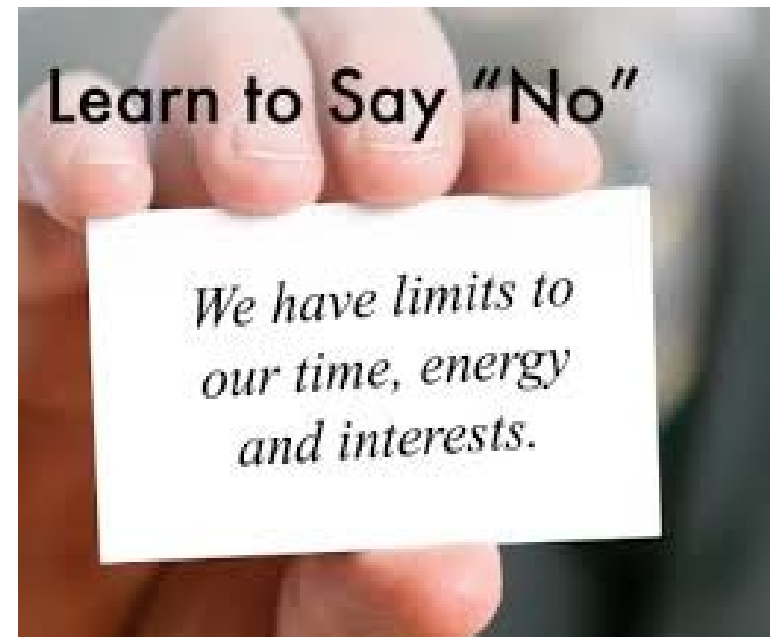
Low trust in HCP's; burden of being 'patient experts'

Isolation, lack of social understanding

The impact of genetic inheritance on family/life choices

# How you can look after yourself practically and Build Resilience

- ⇒ Accept your limitations
- ⇒ Eat as well as possible
- ⇒ Exercise when you can
- ⇒ Make time for fun
- ⇒ Congratulate yourself
- ⇒ Learn to say no



# Self awareness

With any hormone condition, it can really help to become aware of whether your mood might be emotionally – or physically driven

Why might I be feeling like this?

- ⇒ Emotionally driven
- ⇒ Physiologically driven
- ⇒ Combination of the two



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# Looking after yourself emotionally

- ⇒ Emotional work takes physical energy
- ⇒ Learning to live with uncertainty
- ⇒ Try to accept your feelings, not fight them
- ⇒ Find ways of expressing different feelings
- ⇒ Learn to recognise your own 'stress signs'
- ⇒ Learn a technique like Mindfulness
- ⇒ Allow yourself to seek comfort





# Know your (dis)stress signs



# Feelings you might recognise

Envy

Despair

Anger

Resentment

Fear

Numb/Nothing

Anxiety

Relief

Disbelief

Low  
Mood/Depression

Guilt

Grief and  
Loss



# Why does uncertainty make us so anxious?

⇒ We tend to always be on the look out for what might happen next

⇒ Life involves ongoing preoccupation with:

a) Where's the threat?

b) Am I safe?

**Anxiety** is our mind and body working together to try and 'keep us safe'.

**Uncertainty** means we don't have enough clear information to know how best to respond, so the anxiety builds.

# Notice and challenge unhelpful thoughts

- ⇒ Notice and challenge when you are 'what if -in g'
- ⇒ Allow the worry train to pass on by
- ⇒ Try worrying later
- ⇒ Rem ind yourself the future is never entirely certain

**Make room for not knowing**



# Denial

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'It's no big deal'  
'Don't make a fuss'  
'I'm fine'  
'Just ignore it'

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- Not wanting to talk about it
- Avoiding situations or information/news
- Getting annoyed if people want to talk about it
- Being dismissive
- Eating/drinking/sleeping a lot

# Pre-Occupation

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'I can't stop thinking about it'  
'I'll be safe if I keep focused'  
'I have to know something right now'

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- Talking about it a lot
- Researching all the time
- Compulsive fact-finding
- Difficulty sleeping or relaxing
- Finding it hard to be sociable or playful



# Accept anxiety in uncertainty is normal

- ⇒ Consider where you are on the continuum
- ⇒ Don't try and push away feelings, or be critical of yourself
- ⇒ Notice 'what you are like'
- ⇒ Selfknowledge can inform and enable choices



# Learning to live with uncertainty

*Since uncertainty is an inevitable part of the human experience, the quality of our lives improves dramatically if we can learn to make peace with it.*

*When I wake up each morning, I try to reflect that I cannot know for sure what each day has in store - especially with regards to my health.*

*Then I decide to greet the day nonetheless with as much caring attention, self-compassion, and open-heartedness as I can muster.*

*I hope you'll do the same. '*

**Toni Bernhard** (author of *How To live Well with Chronic Pain and Illness*)

# 7 Habits of Highly Effective (MEN) People

1. Self awareness
2. Practical self-care
3. Acknowledging and allowing difficult feelings
4. Learning about your condition
5. Working with your team
6. Finding your community!
7. Helping others help you





# Looking after yourself and your family

- ⇒ Living with MEN takes physical and emotional energy in its own right
- ⇒ Accept your feelings
- ⇒ Recognise and know your 'stress signs'
- ⇒ Looking after yourself emotionally is *integral* to your journey
- ⇒ **Don't struggle alone!**



Specialist rare disease self-help resources for  
patients and carers coming soon!

Find them at:  
[www.rareminds.org](http://www.rareminds.org)

Please follow us on:



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rareminds  
Mental Health for the Rare Disease Community

