

Keeping on the level: Living well *with* (long-term) health conditions

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Aims for today:

- Biopsychosocial Model
- Impact of health conditions on our emotional health and wellbeing
- Acute versus chronic conditions
- Process of Acceptance/Adjustment
- Primary and Secondary Suffering
- Identity and Roles
- Values approach to living well with health conditions
- Looking after your mental health and quality of life
- Role of Medical Psychology

- *Reminder to look after yourselves today (talking about grief)*

Why Clinical Psychology?

Biopsychosocial model (Engel, 1977)

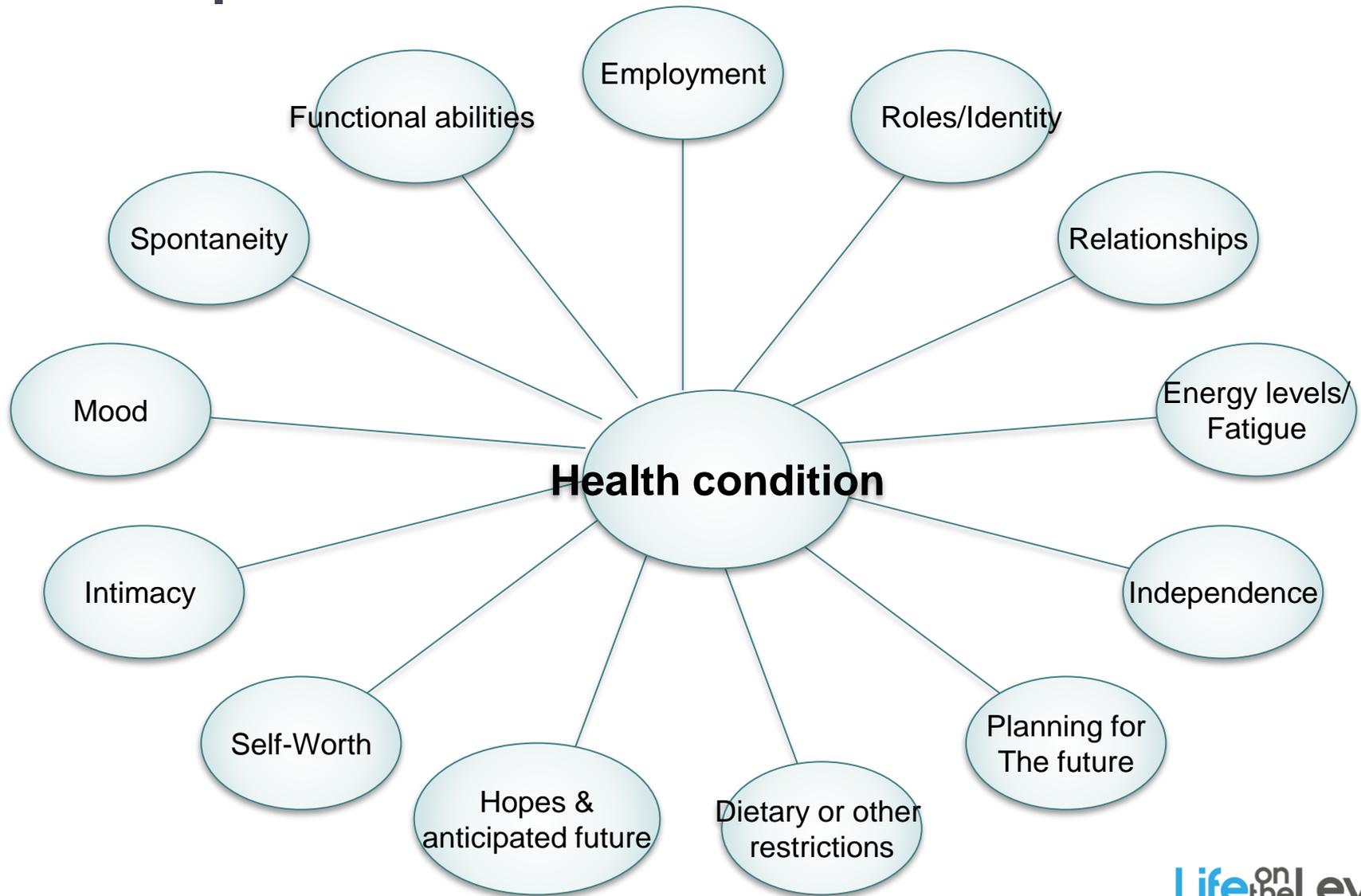
- Understanding the impact of health conditions is not just about understanding the physiological or medical aspects of the condition in isolation, but also understanding the thoughts, feelings, and behaviours the person may have in relation to their health condition, including ways of coping- the “psycho”
- As well as understanding the context of the person’s life (family, community, culture, economic situation) which may impact how they cope/manage – the “social”

Why Clinical Psychology?

Biopsychosocial model (Engel, 1977)

- Clinical Psychologists working in health settings aim to help people with health conditions understand their reaction to their illness, recognise and make sense of their feelings, and help them to add to/increase their ways of coping with their feelings to enable them to make positive changes to their lives and reduce the distress associated with their health condition
- About helping people to make changes to the “psycho” part in the context of the “social” to improve quality of life

Impact of a health condition



Common Emotional Reactions

- Loss and grief- functional ability (physical and/or cognitive), independence, occupation and roles, relationships and intimacy, dignity, respect
- Regret
- Stress
- Worry, uncertainty
- Anxiety & Panic
- Low Mood/ Irritability/ Depression
- Loss of pleasure and fun
- Anger/ Resentment
- Poor motivation, helplessness
- Relationship difficulties, isolation
- Guilt (dependency)
- Self-esteem or confidence, loss of control

Common thoughts

- Why me?
- What will happen to me?
- What does this mean for me?
- How will I cope?
- I have let people down!
- What did that doctor say again?
- How do I get better?
- How long will this last?

Acute versus Chronic

- Our previous experiences and belief in medicine becomes questioned when we have a long-term (chronic) health condition
- We are used to a straight (linear) journey from illness to recovery (acute model)
- However, when this does not happen (or takes time to get better) it can have a significant impact on our lives and we can feel stuck because we have not recovered and may struggle emotionally to cope with on-going ill health
- About our struggle with being out of control of our lives and our destiny – something we understandably take for granted when well.

Acute versus Chronic

- Balance conditions have good treatments and interventions and there is a lot of hope for recovery
- For some, this may take time to get to that recovery stage, and relapses may also happen
- Different people will be at different stages of that recovery process and as such will be at different stages emotionally in their process of acceptance/adjustment
- There are places we may get stuck and things that may help us to move forward psychologically
- We may have done well with physical recovery but take longer to 'catch up' emotionally and move forwards emotionally in line with our physical recovery

Factors affecting Acceptance

- How the health condition started- Was it traumatic?; Out of the blue?; Were there a lot of changes or losses at the time?
- Symptom severity and frequency and the magnitude of the losses or things on hold while you recover
- Social and emotional support from others; having an invisible illness; having inconsistency in presentation
- Mental health
- Other stressful life events
- Past response to stress or loss

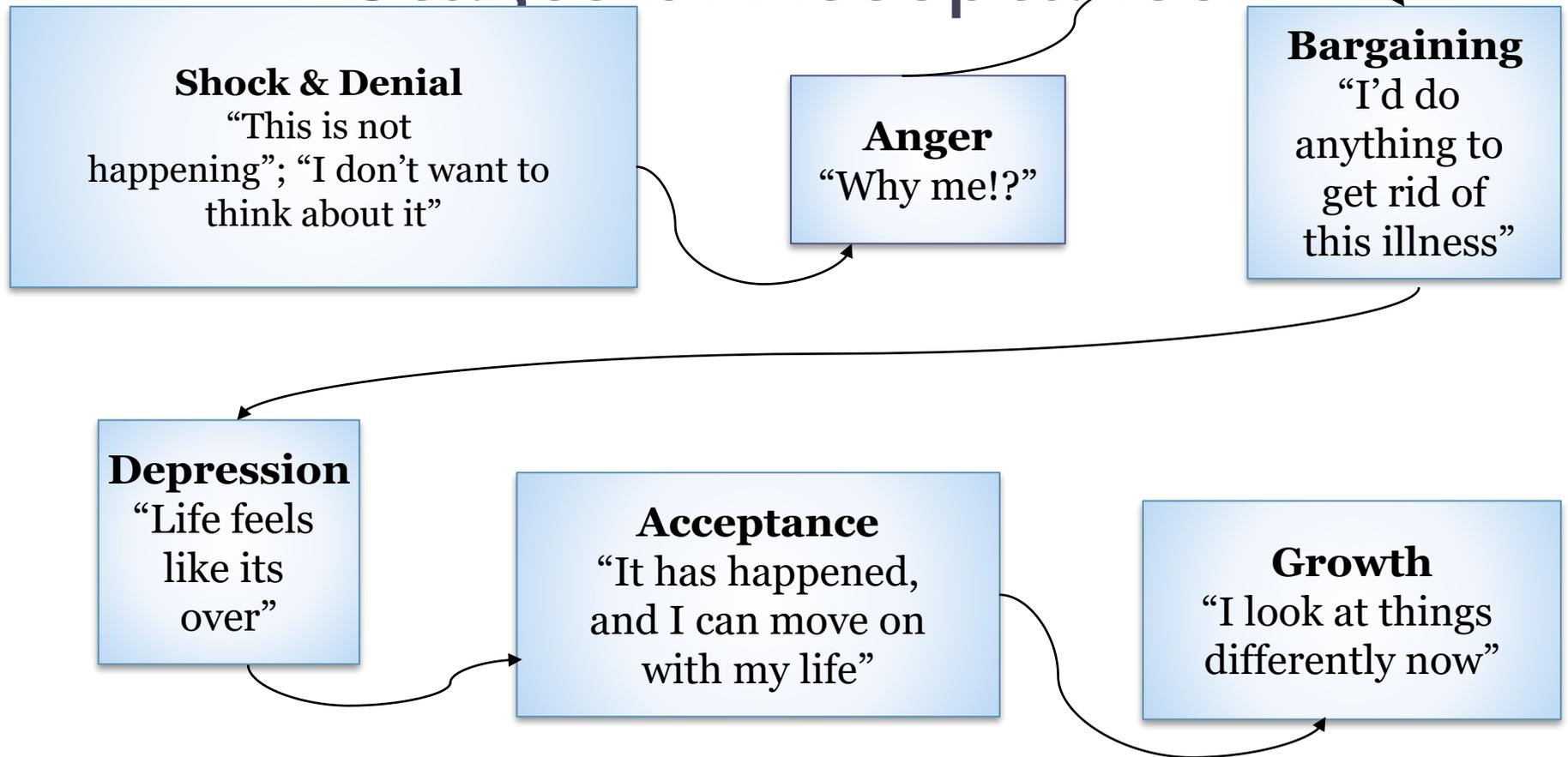
Grief Process

- Health conditions can have such a psychological impact because the person is grappling with a loss of sense of self (what makes you, you) and identity (the person I like to be, the person before the illness) and the difficulty we can have with change/adapting
- What stages do we go through emotionally when we experience *any* change/loss/grief?

Acceptance & Loss (see Kübler-Ross' stages of grief, 2014)

- Shock/Denial – Struggling to accept what has happened
- Anger – About situation/ Towards self and/or others
- Bargaining – Trying to negotiate (I will do anything to...)
- Depression – A realisation of change (comfortable rut?)
- *Acceptance* – Recognising loss(es) whilst realising there is hope to move forward

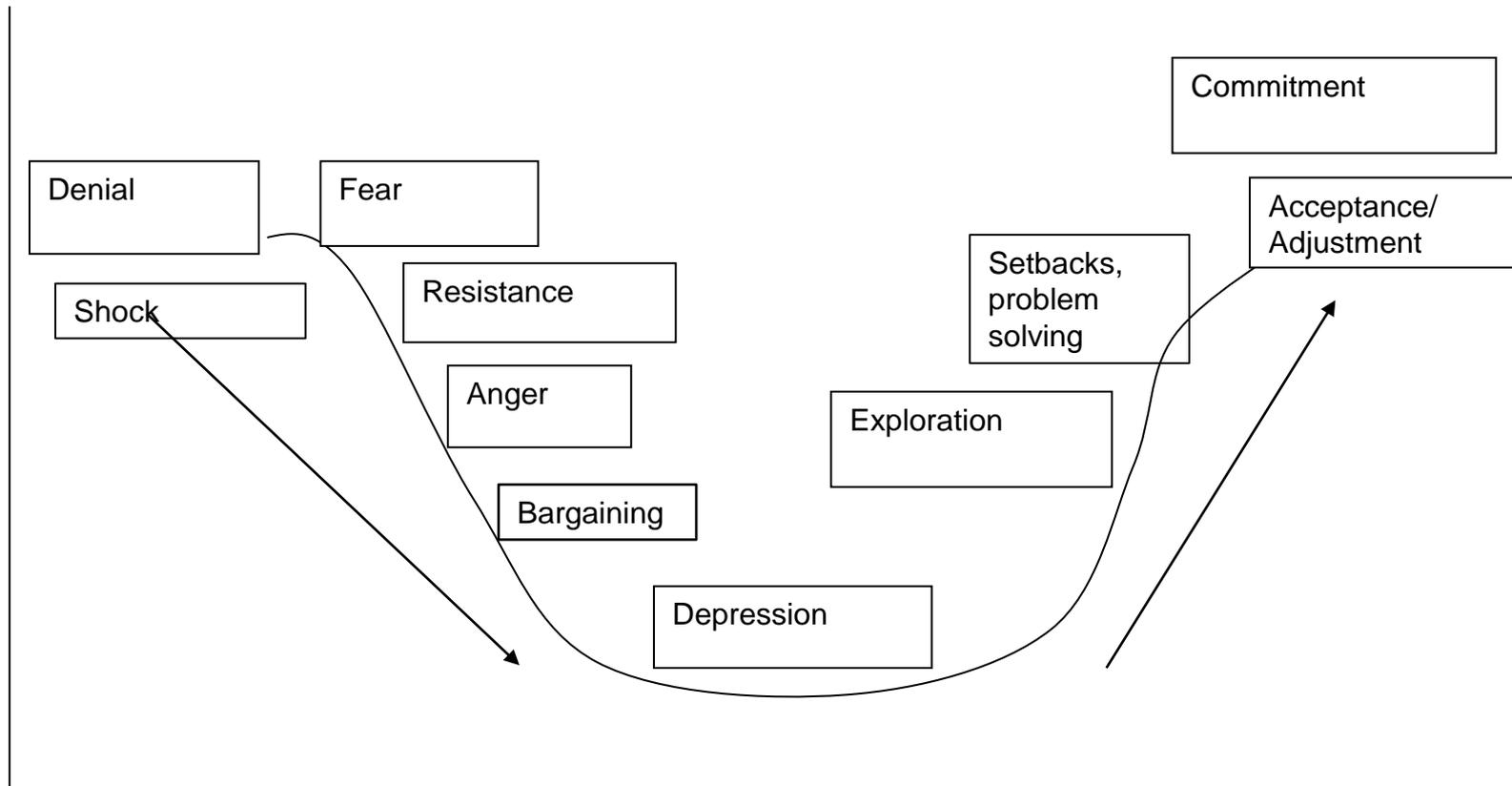
Stages of Acceptance



What changes have you noticed since having a balance condition?

What losses have you experienced as a result of changes to your health?

The change curve (based on Kübler-Ross, 2014)



Time to reflect

**Where do you think you are
at today on this journey?**

Acceptance process

- All totally normal feelings when faced with a big change to your health
- Fear, anxiety, anger, depression are all emotions and are not “bad” in themselves, they are part of our full range of emotions which we have evolved with (our primitive/reptilian brain) and we need to be compassionate towards ourselves for these feelings- it is not our fault to have them, they were there for a reason (to help us to make choices to act for example to escape threat). It is about learning to understand ourselves and what may help us to manage those feelings when they arise
- Remember it is more of a curve than a linear process, we can move about the curve at different times for different reasons (even within one day!)

Acceptance process

- It is about a general move towards acceptance, set backs are part of this and are normal – set backs could be with your health (relapses) or other life events or stresses that may not be within your control (think of the pandemic!)
- Allow time to process these feelings- it is OK that it takes time, do not beat yourself up for this. Be kind to yourself and what you are going through
- You may not experience all of the stages, or you may spend longer at one stage than others

Acceptance process

- There is no magic wand for moving swiftly through this. You cannot wake up one day and decide today is the day you are going to accept things.
- However, different things could help at different parts on the cycle:
 - **DENIAL/SHOCK:** Information on your condition/a diagnosis/understanding of condition/ruling out other conditions can all help move people on emotionally
 - **DEPRESSION:** Being listened to/heard/family and friends or professionals (e.g. clinical psychologist)
 - **MOVING TOWARDS ACCEPTANCE:** Strategies and tools, practical (e.g. physio/being active/treating other health conditions/exercise/dietary changes) and psychological
 - **ACCEPTANCE:** Setback/flare-ups/relapse planning and self-compassion

Acceptance or Adjustment?

- Language around “acceptance” may not always be helpful. Acceptance can imply “giving in” or “giving up”. People may want to “fight” what is happening to them and not “resign” themselves to being ill.
- And who wants to resign themselves to being ill? We may lose motivation to carry on if we do!
- If this is true for you, it may be more helpful to think about things in terms of adjustment to having ill health/a health condition.

Tug of war metaphor

How about you *let go of the rope?*

For an example see: Text © Third Wave Psychotherapy/Seaghan Coleman, LCSW 2015 Images © Jerry Kong
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Primary and Secondary Suffering (See Burch & Penman, 2013)

With health conditions we can talk about 2 forms of suffering:

- Primary suffering:
 - Unpleasant physical sensations (e.g. symptoms of health problem)
- Secondary suffering:
 - The mind's reaction to the primary suffering (e.g. distressing thoughts, unwanted emotions about the health problem)
 - It is about the “serenity creed” - working out what is in your control to change, and what is not, and work on those things you can do something about which includes your emotional response

Experiences of the Family

- They too may have fears and feel uncertain
- They also have to process their reactions to their loved one's diagnosis, prognosis, treatment and changes to their relative
- They are going through their own adjustment curve and you may not match each other at different times which may cause conflict!
- Denial may lead to expectations being placed on you as they cling onto the person you were before and expect the same things of you
- Ways of coping could include becoming over protective, which may be preferable for them to feeling helpless

Core Beliefs

- Ideas we have about the world, ourselves and others
- Guide how we live our lives – “Our rules”
- Tied to our sense of identity - how we believe we “*should*” be
- We may not be aware of them until they are challenged

Can you think of examples of when you have said to yourself.....

.....I 'should', 'ought to', 'have to', or 'must'?

What other thoughts can this lead to?

How did this make you feel? What did you do? What were the consequences?

Impact of health conditions upon Core Beliefs

- Developing ill health/health problems can often test or conflict with long-held beliefs we have about ourselves
- When you make changes to your life as you learn to manage your condition and try new routines to take account of a health difficulty, this may challenge old ways of thinking and can give rise to conflicting feelings and could make it difficult to commit to the way you need to live your life now
- For example, slowing down or looking after yourself more may feel “lazy” and “selfish” if you pride yourself on being busy and helping others – “I should be doing more” and “I need to help others”

Reality Vs Expectation (See Owen, 2014)

• Ideal-self  Hated-self

• Expectation vs Reality

We all have expectations that we place upon ourselves –these can be **unrealistic** at times

Managing the reality

- We know that striving towards your “old self” with all the changes brought about by a health condition often creates a lot of *suffering*
- Equally, we are not saying to scrap these beliefs/views of yourself- that would be unrealistic and hard to do
- It’s about making adjustment – “*Softening*”- This may also be a temporary softening as your health/symptoms improve and you recover

When reflecting on this you could ask yourself:

- ✓ How accurate is my view of any changes? Am I ignoring positives? Am I catastrophising how bad things are?
- ✓ What is my “internal critic” saying? How can I develop a more compassionate self-view? See the Poisoned Parrot example
- ✓ Allow yourself to “mourn” for the things/aspects of yourself you feel you have lost (for now)
- ✓ For any unwanted changes, are these permanent? If not, how can you overcome these (e.g. quality of life, social life, relationships, activity levels)?

Moving Forward

- We are changing all the time (e.g. like a mobile phone company updating the model of the original phone)
- The reality is that we never stay the same for long
- Getting stuck in the past can mean we lose track of what's happening now
- Try to avoid unhelpful comparisons with the past
- Explore and experiment with new ways to achieve what is important to you (i.e. your values)

Values

- “Values” come from Acceptance and Commitment Therapy (ACT) – (see Dahl and Lundgren, 2006) and are a mainstay in the therapy about how to move forwards, the notion of living a valued life.
- We can become so focussed on our problems that we lose sight of what really matters to us
- Values guide us through life, they keep us on the ‘right’ path
- Values are not goals
- What are yours?
- What is one thing about yourself that isn’t related to your health condition?

Values - Hitting the Bulls-eye

(See Dahl &

Lundgren- Living Beyond Your Pain, 2006)

Health

Religion/spirituality

Community

Wider Family

Parenting role

Intimate
Relationship

Grandparent role

Personal growth

Leisure

Friends

Work/Education/
Volunteering/Training

?????? Any other
value not covered?

Writing your values

Consider:

- What are my values/roles?
- How important is each value to me (you may want to rate this out of 10)
- How close to the bulls-eye am I to meeting that value right now? (again you could rate this, with 1 being the centre of the bulls-eye)
- Decide where to focus your energy- which value could I work on? What goal could I then set?
- Make the goal realistic and achievable –see SMART goals
- Think about all the mini steps that you need to take to achieve the goal

Example of Values

- **Parenting:** I value my children being able to have fun and enjoyment out of life, I would like them to be able to come to me with their problems, I want to have quality time together. Importance= 10/10; Meeting it=5/10
- **Goal:**
 - To spend two hours on a Sunday afternoon, technology free, playing a board game

Other ways to think about improving your quality of life

- Balanced lifestyles – See “BACE”
- “Nourishing and depleting” tasks
- Relaxation and mindfulness
- Looking after your emotional wellbeing- see websites

Role of a Clinical Psychologist- Medical Psychology

- Offer a safe space to explore emotions in relation to health condition
- Support the adjustment process
- Mood management
- Managing anxieties and health anxiety
- Behavioural strategies – values/ activities/pacing/goal setting
- Managing health related trauma
- Introduction to relaxation
- Support with managing health care and treatments
- Identify and promote coping strategies

Referrals for Medical Psychology

- Referrals to Medical Psychology come via your University Hospitals of Leicester (UHL) Consultant or Specialist Nurse - ask them to refer you. This could be in the balance clinic for example.
- You must live in Leicester, Leicestershire or Rutland or have a GP in that catchment area. Referrals **cannot** come via the GP (we are funded by UHL).
- You must be experiencing psychological difficulties that arise from or are contributing to your physical health condition.

Referrals for Medical Psychology

- A referral is **not** appropriate if:
 - You are receiving/waiting for on-going therapy/support/counselling from adult mental health services within LPT (e.g. CMHT, CBT) or other services for example vita health (previously Lets Talk Wellbeing services) or Turning Point (substance misuse service)
 - You have long standing mental health difficulties which are a priority at present (e.g. severe depression, psychosis) or current difficulties with substance misuse which are a priority at present
 - You are actively suicidal and require risk monitoring
 - You have other life events or difficulties that overshadow the physical health issues and would prevent you from focussing on therapy related to your health

Other ways to seek mental health support

- If you are not open to a consultant within UHL you can still seek support for your mental health
- Talk to your GP about your difficulties and possible services to refer to
- You can self- refer for therapy:
 - <https://www.vitahealthgroup.co.uk/nhs-services/nhs-mental-health/leicester-leicestershire-rutland/>

Mental health crisis helpline (Leicester, Leicestershire and Rutland)

Mental Health Central Access Point
0808 800 3302

Helpline for anyone to call 24/7 if you have urgent mental health needs (not a medical emergency please dial 999 or go to A&E). The helpline will then advise/refer you to the most appropriate service for your needs.

Download the “Stay Alive” app – has links to websites and local services to help as well as tools you can use to help keep yourself safe.

Conclusion

- Managing the emotional impact of having a health condition is about being gentle with yourself, being compassionate towards your experiences and what you are going through, what may have been lost for now, and what you are struggling to do for now.
- Remember it is a process, and set backs happen emotionally and physically
- Learning to focus on what is important to you and drives you, and not losing sight of what makes you you may help you keep emotionally well when living with a health condition
- Changes and adjustments that are necessary right now may not be permanent, so learning to live for the now and focus on how to manage your expectations for now may help you. Be kind to yourself. You are doing marvellously!

Resources

- Balanced lifestyles:
<https://www.getselfhelp.co.uk/docs/ACE.pdf>
- Nourishing and depleting activities:
<https://www.getselfhelp.co.uk/docs/NourishingDepleting.pdf>
- Poisoned parrot:
<https://www.getselfhelp.co.uk/docs/TheParrot.pdf>
- Emergency self soothe box:
<https://www.getselfhelp.co.uk/docs/EmergencyBagBox.pdf>

Resources

- Learning to live in the here and now:
<https://www.getselfhelp.co.uk/docs/APPLE.pdf>
- Helpful when goal setting- follow SMART principles:
<https://www.getselfhelp.co.uk/docs/SMARTgoals.pdf>
- www.getselfhelp.co.uk – lots of resources for mental health
- Williams, M. & Penman, D. (2011). Mindfulness: A practical guide to finding peace in a frantic world.

Resources

- Mindfulness- book references and access to free meditations:
www.franticworld.com
- Calm app- some content for free
- Headspace app- some content for free
- www.nhs.co.uk/livewell
- www.mind.org.uk
- <https://web.nth.nhs.uk/selfhelp/> - range of self help leaflets
- www.compassionatemind.co.uk – introduction to compassion focused therapy
- <https://www.psychologytools.com/> - self-help resources for mental health
- www.yourcovidrecovery.nhs.uk

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