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ACT Neurological: Living well with neurological conditions

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NHS
South Tees Hospitals
NHS Foundation Trust

Disclosure

- Relevant Financial Relationships:
  - Employed by NHS South Tees Hospitals FT, England, UK.
  - Independently employed in Private Practice (Clarity Psychology)
  - Consultant in Feasibility RCT funded by Stroke Association charity with Manchester University.
- Relevant Nonfinancial Relationships
  - Guest Lecturer Teesside University

Why Neurological conditions?

- Neuropsychological adjustment (e.g., Stroke, Traumatic Brain Injury, TBI, Brain Tumour, Multiple Sclerosis, MS) **can be extremely challenging and emotionally painful** (Intercollegiate Stroke Working Party, 2012; Neurological Alliance, 2017).

- These neuro-pathologies can cause diverse forms of suffering (e.g., cognitive problems, fatigue, health anxiety, hopeless thoughts, see Kangas & McDonald, 2011).

Why Neurological conditions?

- ACT conceptualizes that psychological health naturally emerges when we are able to freely contact the present moment in committed valued action (i.e., psychological flexibility).

- If we find ourselves fused and avoiding without presence or committed action, **we may become inflexible and stuck,** and experience great difficulty.

Executive functioning

Not my metaphor!

Postal & Armstrong, 2013

Irish Times https://www.irishtimes.com/culture/music/classical/who-comes-first-the-conductor-the-composer-or-the-orchestra-1.3092226

- The executive functions are suggested to be the broad mechanism that facilitates psychological flexibility (e.g., Kashdan & Rottenberg, 2010).

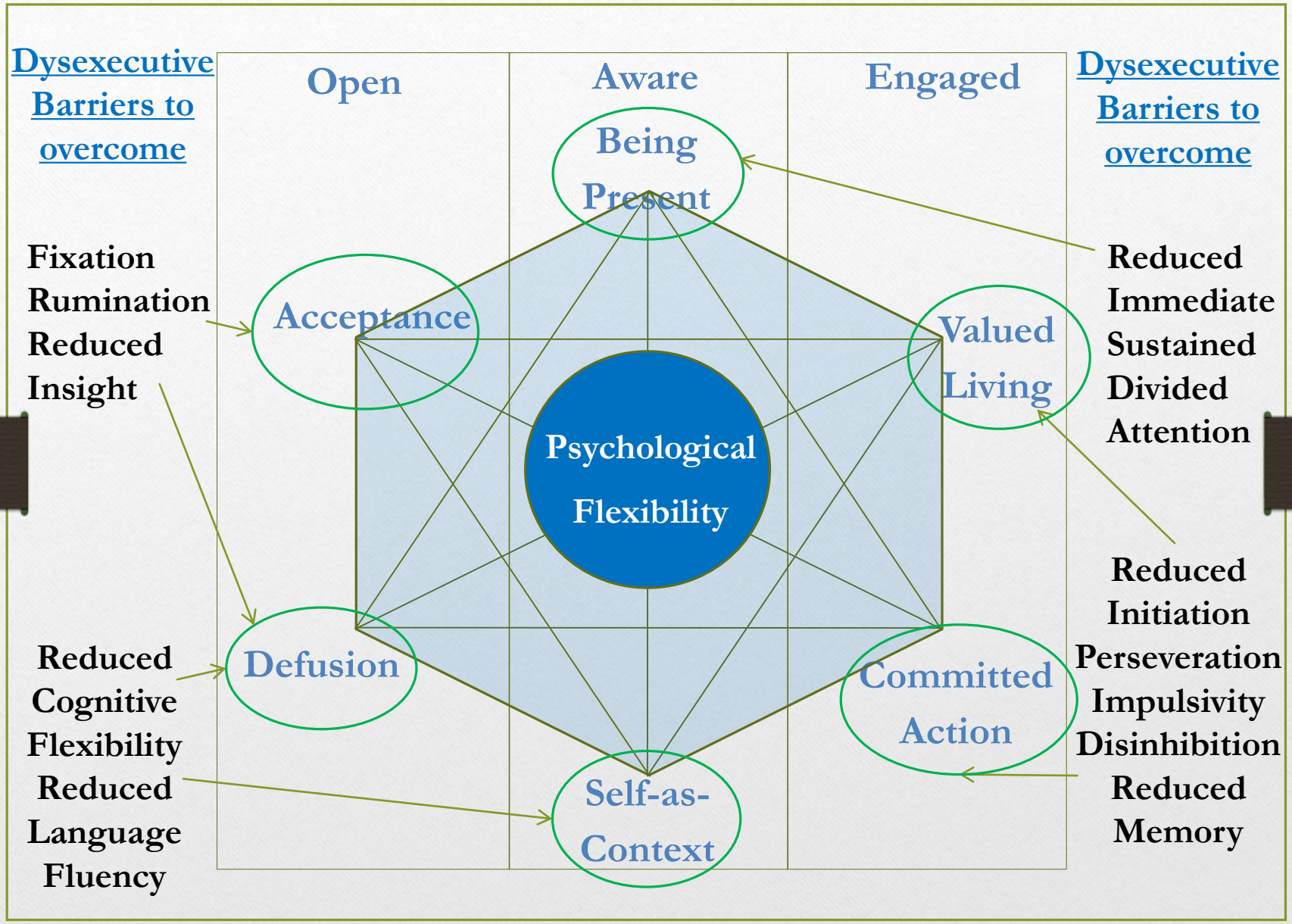
Why Neurological conditions?

- Many people with neurological conditions have frontal or cerebellar injuries that cause reduced executive functioning.
- These **dysexecutive difficulties** (e.g., Stuss & Alexander, 2007; Stuss, 2011) are associated with reduced mindfulness, and poorer emotional regulation (Mclaughlin, Bowman & Hill., in preparation).

Why Neurological conditions?

- Taken together this suggests that people with dysexecutive difficulties are potentially more prone to becoming 'stuck' in their suffering.

- This is due to the likely difficulty with the executive **mechanisms that naturally support the person to become unstuck and more psychologically flexible.**

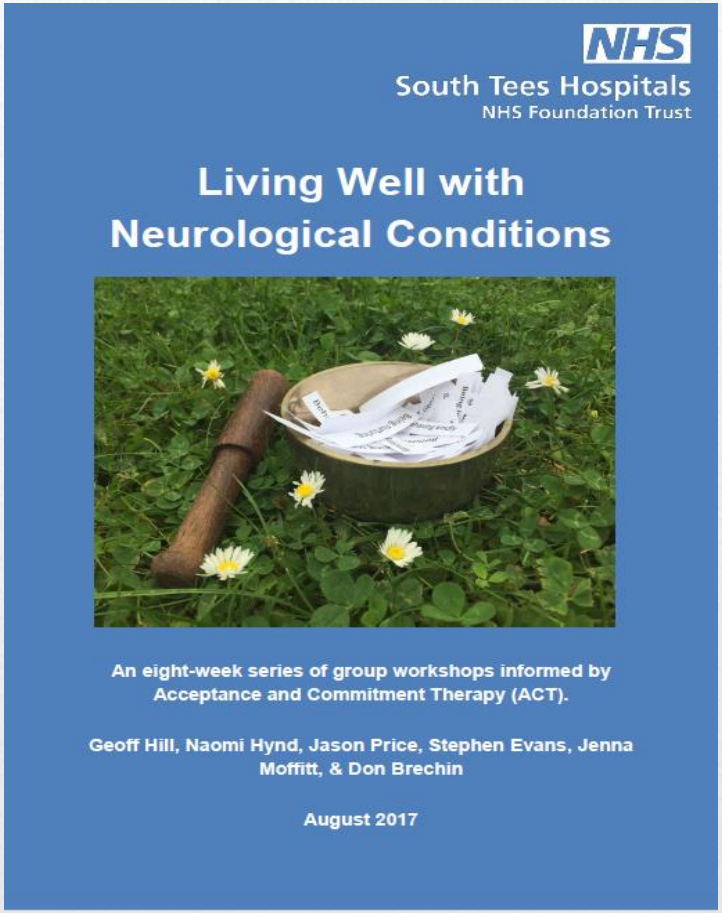

Dysexecutive Barriers to overcome
Open
Aware
Engaged
Dysexecutive Barriers to overcome
Being Present
Fixation
Rumination
Reduced Insight
Acceptance
Valued Living
Reduced Immediate
Sustained Divided Attention
Psychological Flexibility
Reduced Initiation
Perseveration
Impulsivity
Disinhibition
Reduced Memory
Reduced Cognitive Flexibility
Reduced Language Fluency
Defusion
Committed Action
Self-as-Context

So can ACT be effective even in this context?

- Small, growing number of promising peer reviewed studies (22 studies) in **TBI** (Whiting et al., 2019), **stroke** (Graham et al., 2015; Large et al., 2019), **epilepsy** (Lundgren et al., 2008), **MS** (Pakenham et al., 2018; Sheppard et al., 2010), **functional** (Graham et al., 2018), and more…
- Yet still sparse with conditions unrepresented (e.g., brain tumours), and insufficient volume for larger-scale investigations of efficacy (see Graham et al., 2016 for review; Kangas, 2011).

The Living Well Workshops (LWNCs)

- Initially inspired by Better Living with Illness (Brassington et al., 2016).
- Adapted and developed in 2015, low-intensity ACT group intervention for those having difficulties in adjustment to neurological conditions.
- Eight, weekly (3 hrs) mixed group sessions (any neurological diagnosis).
- Accessible for those with mild to moderate emotional, cognitive or fatigue difficulties.



Downloadable from Hill et al., 2017b and ACBS website

Session	Title	Content
1	**Beginning Again**	Forming a group, group rules, introduction to ACT, overcoming forgetting, goal development (pre-intervention measures)
2	**Bringing Yourself Back to the Moment**	What is mindfulness, guided mindfulness of drinking, guided body meditation
3	**Understanding Your Thoughts and Feelings**	Guided body meditation, cognitive defusion exercises: understanding sadness, fear and anger when they come along in your life.
4	**Living Well With Suffering**	Guided body meditation, personal exploration of suffering, ACT in nutshell metaphor, identifying emotional control/avoidance strategies
5	**Identifying Your Values**	Guided mindfulness of the breath (brief), famous people's values, clarifying and constructing values (wealth metaphor), passengers on the bus
6	**Living For Me, Not My Condition**	Guided mindfulness of the breath (brief), constructing personal values and goals, SMART (ACT definition) goals, mindful valued living plan
7	**More Living For Me, Not My Condition**	Guided mindfulness of the breath (brief), constructing personal values and goals, SMART (ACT definition) goals, mindful valued living plan.
8	**Planning Mindful Valued Living**	Choice of guided mindfulness practice, review of workshop content, mindful valued living plan, acknowledgement of endings/new beginnings, (post-intervention measures)

Hill et al., 2017a

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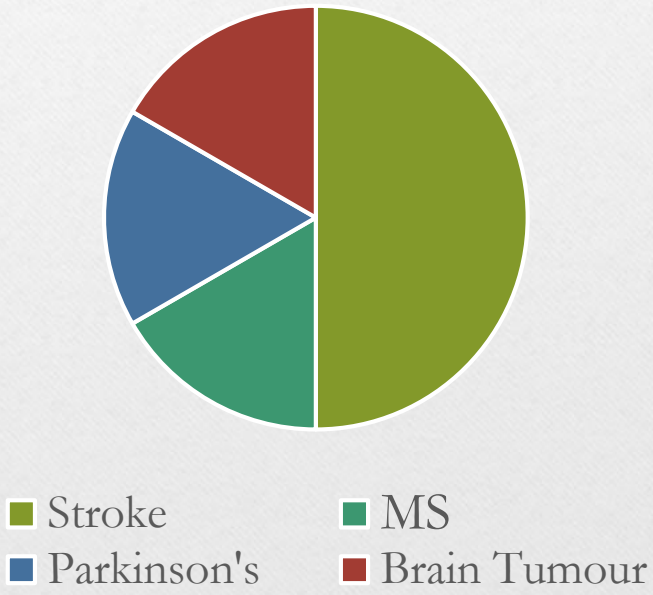
Promising early findings

- Sig. increased **psychological flexibility** (AAQ-II) with reduced self-reported **depression** (HADS-D), & **general distress** (CORE-OM-10, N = 6, Hill et al., 2017c).

- Trends in self-reported **valued living** (VQ), **wellbeing** (WES), **mindfulness** (FFMS), **anxiety** (HADS-A), and **quality of life** (EQ-5D) non-sig, but in expected direction…



Demographic variables of each participant
Note. Participant age range (45 – 63 years), 50% Female, White British.

Recent whole dataset

	N	Mean Pre-	Mean Post-	t	Sig.	Cohen's *d*
Clinical Outcomes in Routine Evaluation CORE-OM-10	30	16.86	13.33	3.33	.002*	0.60
Five Facet Mindfulness Q-Total	25	104.16	116.40	3.175	.004*	0.63
Acceptance and Action Q (AAQ-II)	30	31.53	29.23	1.755	.090	0.32
Valuing Q (VQ)	28	56.75	60.17	0.873	.391	0.164

- Sig. improved self-reported distress and mindfulness (Medium to Large effects).
- AAQ-II and VQ suggestive and approaching sig.

Outcomes

- Starting swimming again.
- Eating salad
- Learning to play the guitar.
- Meditating and noticing more daily
- Feeling my left-side again
- Realising that I do have feeling in my feet
- Not fighting with the MS
- Knowing I'm not a fraud
- Feeling less isolated
- Not being in as much pain.
- Understanding fatigue more
- Not being as bullied by fear passenger
- Spending more time with grandchildren

Feedback & Reflections

- Accessible: 100% would recommend to friends and family so far..
- Mixed opinions on meditation.
- Techno-problems.
- Not long enough: Requests for follow-up, maintenance sessions.
- Parallel similar groups for carers, partners and family?

Challenges and Developments

- Outcome measures not fit for purpose – need more Neuro-ACT (N-ACT) developments!
- ACT and Moderate to severe neuropsychological presentations?
- Next generation Living Well W – audio-visual to support cognition! Including mindfulness practice app.
- Beyond service evaluation to more robust Living Well W research and controlled investigations.
- **Can we meaningfully and practically separate group effects from ACT effects? What is the active component in the protocol?**

Development and early testing of group-based psychological support for life after stroke

https://www.stroke.org.uk/research/development-and-early-testing-group-based-psychological-support-life-after-stroke

Principal Investigator: Dr Emma Patchwood (Postdoctoral Fellow, University of Manchester). Year Awarded: 2018 Region: North West.

Some lessons learned and helpful ACT adaptations

- **Effective screening**: Some people with more severe difficulties (e.g., aphasia, disinhibition) can find it extremely difficult to access the group context.
- **Match quantity of experiential exercises and pace of delivery to the person's cognitive function** (e.g., information-processing speed), with adequate breaks.
- **Provide metaphors in as plain language as possible**, avoiding abstract concepts (reducing cognitive load), scaffolding with pictures, writing, video, sound as appropriate (**more senses, more memorable!**). **Consider a therapeutic workbook**

- **Promote learning and memory:** It's fine for it to take multiple sessions to support the person to meaningfully experience an exercise.
- **Grow through the barriers & 'Make room' for discouragement -** If the person is having insurmountable cognitive difficulty with an exercise, support them to turn towards this adversity.
- **Make mindfulness audio-aphasia friendly** - short, brief.
- **Match expectations to the person**: e.g., people with neurological fatigue can find it extremely hard to regularly practice meditations (**What's the person's route back to the present?**).

Summary

- A neurological condition can bring great unwanted suffering into a person's life.
- ACT is increasingly being adapted for those individuals who are tangled-up in language and struggling with their condition (e.g., Living Well Workshops).
- Cognitive symptoms such as dysexecutive difficulties can undermine the person's ability to become more psychologically flexible, yet with the right adaptations, with kindness and the flexibility of ACT, promising results are emerging ever more frequently…
- There is currently good proof of concept! But much, much more needs to be done.

Thank you!

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