Geraldine et al. (2014)

- People with MND:
    - Equated living with MND as a ‘death sentence’.
    - Felt MND had ‘robbed’ them of their identity.
    - Growing awareness of limitations and recognition of future losses.
    - Felt forced to accept and adapt to diagnosis due to ‘having no choice’.
    - Focusing on the present and attempting to engage in normal activities was seen as a way to exert control.
    - Perceptions of losing control prompted people to exert control in interactions with service providers.

Aoun et al. (2012)

- Bereaved family caregivers:
    - A diagnosis of MND has a profound effect on family caregivers.
    - Duties are often taken on by caregivers without thinking about their own personal needs.
    - Changing from a spouse to a caregiver has a negative impact on the level of intimacy in one’s relationship.
    - Feelings of hopelessness.
    - Absence of empathy from health care professionals at the time of their loved one’s diagnosis and throughout the course of the disease.

Facilitators of engagement

- Qualities of the therapist
    - Being able to build rapport
    - Having knowledge about MND

- Qualities of the therapeutic environment
    - Safe space in which to offload and given permission to talk
    - Responding to variability with flexibility

Barriers to engagement

- Location
  - Remote areas
  - Accessibility
  - Difficulties in getting out of the house with equipment
- Sex differences
  - Perception that men prefer not to talk about issues
- Impact of symptoms and equipment on therapy
  - Dysarthria and fatigue

The ‘ideal’ psychological Tx?

- Will need to:
    - Address facilitators and barriers to engagement
    - Make adaptations for communication difficulties
    - Make adaptations for physical mobility difficulties
    - Make adaptations for cognitive and behavioural changes
    - Tap into what we know about predictors of psychological wellbeing in people with MND

The COMMEND study

- A feasibility study and randomised controlled trial of Acceptance and Commitment Therapy for people with motor neuron disease
- 4.5 year study funded by NIHR HTA and MND Association
- Co-applicants: Chris McDermott (co-leading RCT), Laura Goldstein, Chris Graham, Lance McCracken, Marc Serfaty, Ammar Al-Chalabi, Pamela Shaw, Robert Howard, David White, Mike Bradburn, Tracey Young, Vanessa Lawrence, Cindy Cooper

The University Of Sheffield.

SITraN
Sheffield Institute for Translational Neuroscience

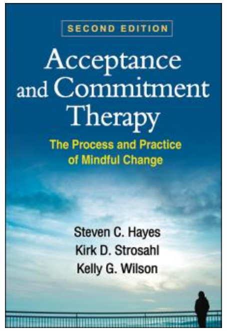
Funded by
NHS
National Institute for Health Research

mnda
motor neurone disease association

Research question

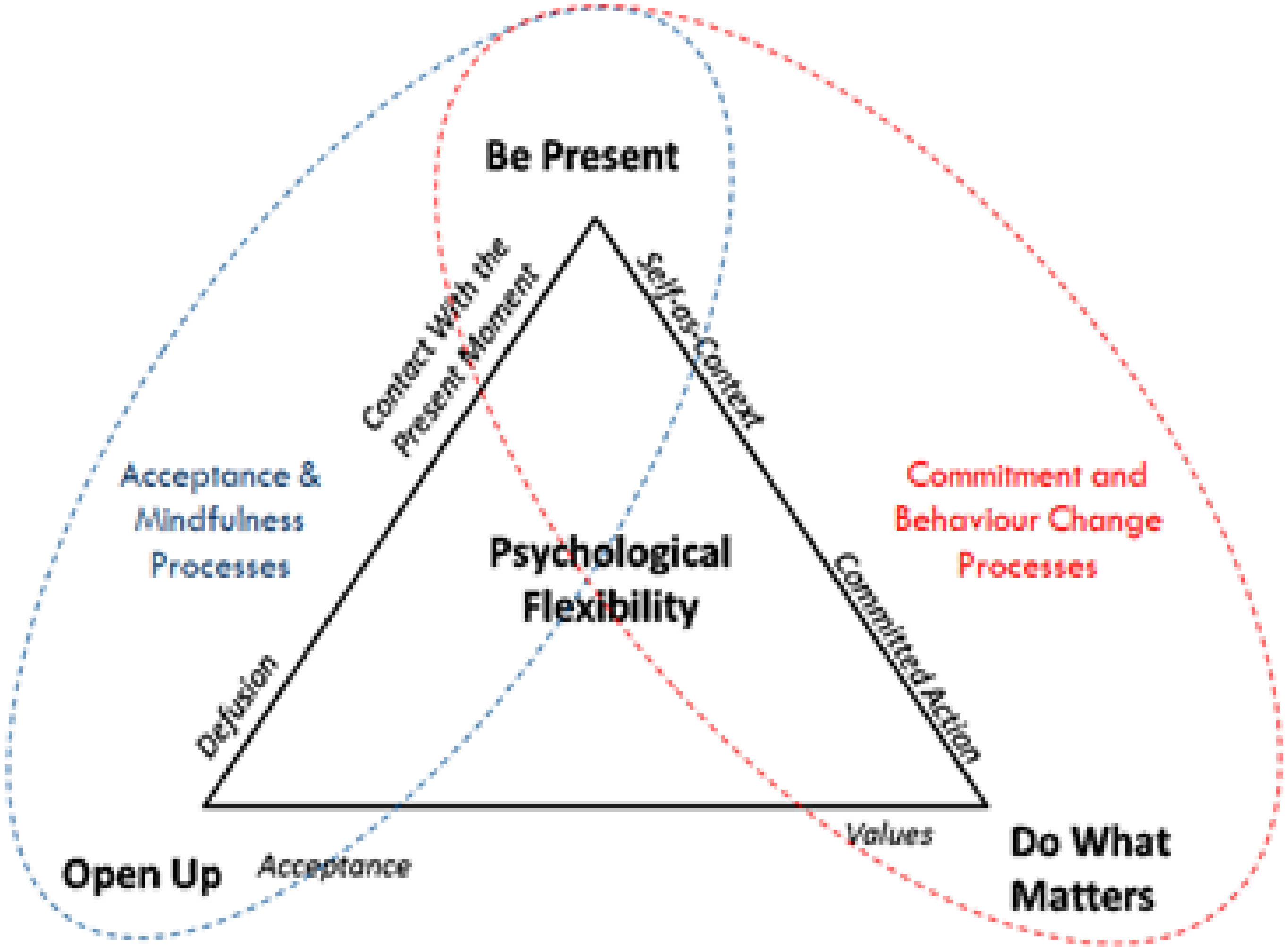
- What is the clinical and cost effectiveness of modified Acceptance and Commitment Therapy plus usual multidisciplinary care in comparison to usual multidisciplinary care alone for improving psychological health in people with MND?

What is ACT?


SECOND EDITION
Acceptance and Commitment Therapy
The Process and Practice of Mindful Change
Steven C. Hayes
Kirk D. Strosahl
Kelly G. Wilson

- A form of talking therapy that has three aims:
  - (1) Help you to identify the things that are important and meaningful to you, what you want to do in your life, and the sort of person you want to be (i.e. your values);
  - (2) Help you to become more aware of when you are moving away from your values and the short- and long-term costs of this;
  - (3) Help you to learn new ways of handling your difficult thoughts, feelings and sensations so that they have less impact on you in order that you can do the things that are important and meaningful to you.

What is ACT?


Be Present
Contact With the Present Moment
Self-as-Context
Acceptance & Mindfulness Processes
Psychological Flexibility
Commitment and Behaviour Change Processes
Defusion
Committed Action
Open Up
Acceptance
Values
Do What Matters

How does it differ from CBT?

- 1st wave
  - Behavioural Therapy → Focus on direct behaviour change
- 2nd wave
  - Cognitive Therapy → Focus on changing content and frequency of thoughts, feelings and sensations
- 3rd wave
  - ACT, MBCT/MBSR, DBT → Focus on changing one’s relationship to thoughts, feelings and sensations

Why ACT?

- Improvement in outcomes in SRs for a range of chronic diseases, life-limiting illnesses, and long-term conditions (Graham et al., 2016a; Hann et al., 2014)
- ACT processes predict functioning and quality of life in MND (Pagnini et al., 2015) and other progressive, incurable, life-limiting conditions such as muscle disorders and advanced cancer (Graham et al., 2016b; Low et al., 2012)
- ACT is particularly suited to improving outcomes in objectively difficult or immutable situations, such as living with MND and other chronic diseases
- ACT may better meet the needs of people with disabling long-term conditions and life-limiting illnesses than conventional CBT

Aims

- 1) Develop and refine a manualised intervention tailored to people with MND.
- 2) Explore the acceptability and feasibility of the intervention in an open uncontrolled feasibility study.
- 3) Evaluate the acceptability and feasibility of participating in an RCT of ACT through qualitative interviews with people with MND.
- 4) Clarify study design parameters for an RCT.
- 5) Establish the clinical and cost effectiveness of ACT plus UC for people with MND compared to UC alone in an RCT.
- 6) Examine perceived mechanisms of impact with people with MND.

Phase 1 (Dec 17 - Jun 19)

- Develop a manualised intervention tailored to people with MND
    - Interviews and workshops with people with MND, caregivers and MND healthcare professionals
- Open uncontrolled feasibility study (N = 28)
    - Co-primary outcome measures: Uptake and initial engagement
    - Assessments at 0 and 6 months
    - Post-Tx interviews with up to 15 people with MND and all therapists and ACT supervisors

Phase 2 (Jul 19 – May 22)

- RCT (N = 188)
  - Single-blind, parallel 2-arm RCT
  - Internal pilot in first 10 months
  - Primary outcome measure: McGill Quality of Life Questionnaire at 6-months
  - Assessments at 0, 6 and 9 months

Inclusion & exclusion criteria

- Main inclusion criteria
  - 18+
  - Familial or sporadic MND (definite, lab-supported probable or probable ALS)
- Main exclusion criteria
  - Need for gastrostomy feeding or non-invasive ventilation
  - Comorbid diagnosis of dementia

Thank you for listening

- Any questions?