AN EXPERIENTIAL INTRODUCTION TO ACCEPTANCE AND COMMITMENT THERAPY FOR PEOPLE LIVING WITH MND

Professor Rebecca Gould
Division of Psychiatry, UCL

OVERVIEW

Background

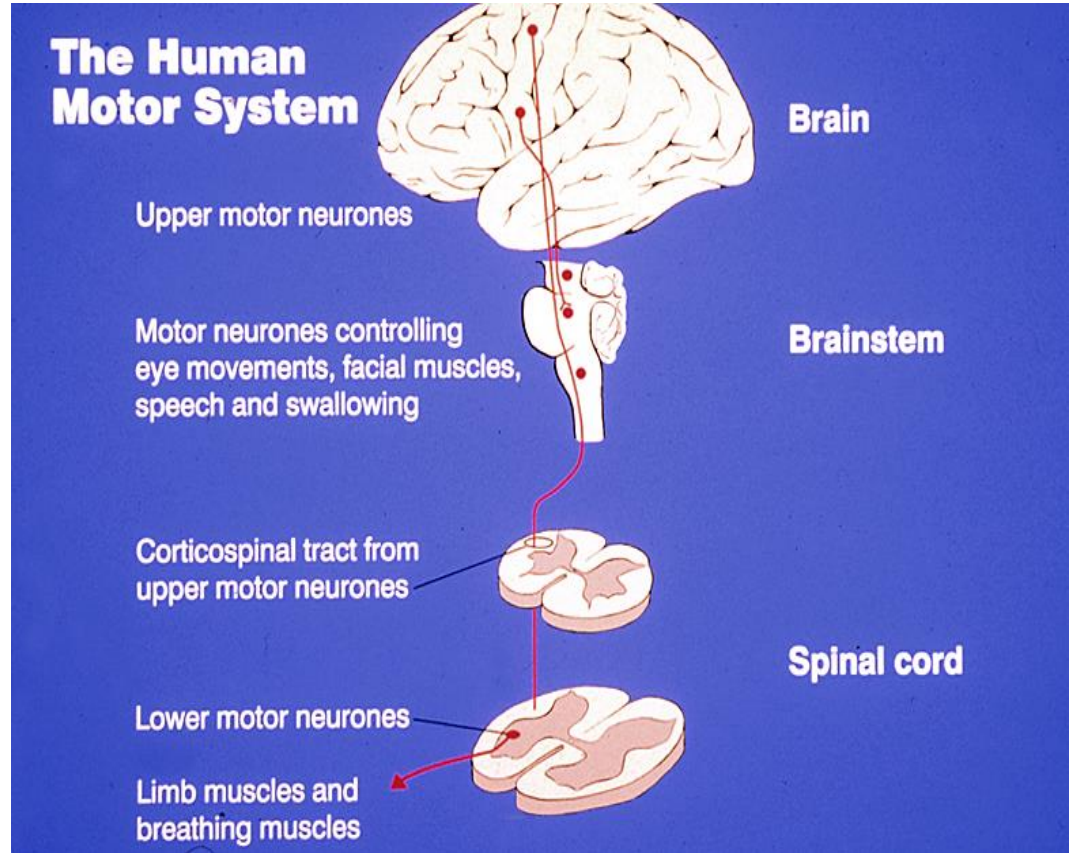Acceptance and Commitment Therapy
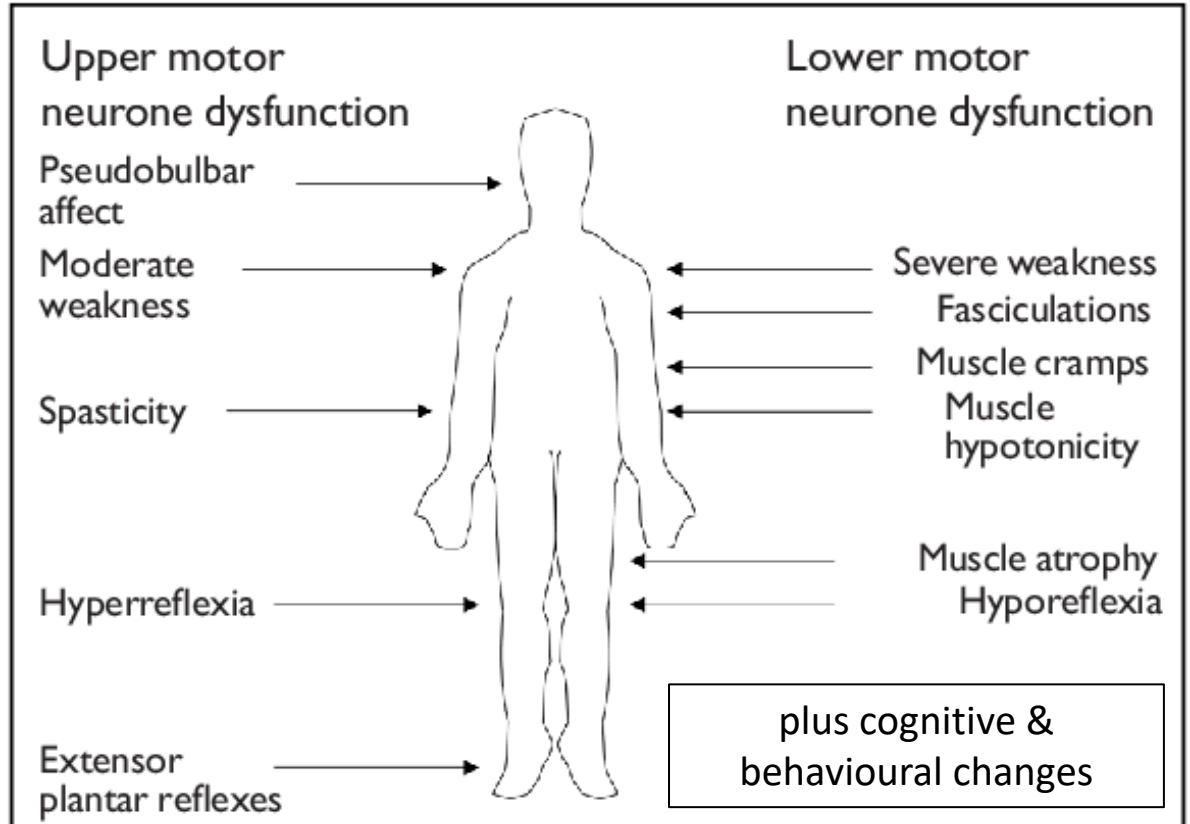
COMMEND development work
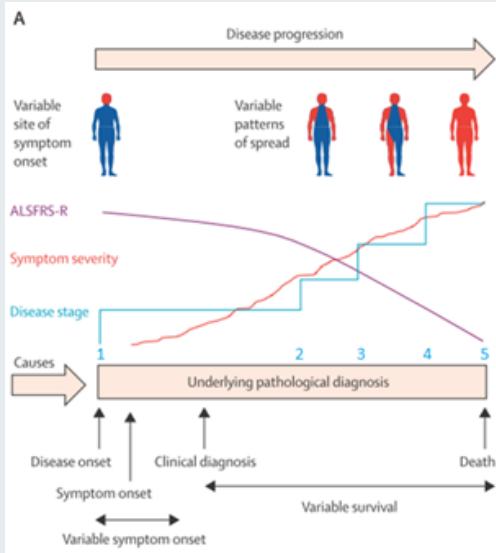
COMMEND RCT

ACT in other palliative care settings

MOTOR NEURON DISEASE (MND)

The Human Motor System

Upper motor neurones

Motor neurones controlling eye movements, facial muscles, speech and swallowing

Corticospinal tract from upper motor neurones

Lower motor neurones

Limb muscles and breathing muscles

Brain

Brainstem

Spinal cord

SYMPTOMS

Upper motor neurone dysfunction

Lower motor neurone dysfunction

Pseudobulbar affect

Moderate weakness

Spasticity

Hyperreflexia

Extensor plantar reflexes

Severe weakness

Fasciculations

Muscle cramps

Muscle hypotonicity

Muscle atrophy

Hyporeflexia

plus cognitive & behavioural changes

PROGNOSIS

Life expectancy is 2-4 years following diagnosis

There is no cure

Riluzole prolongs median survival by approx. 30%

PSYCHOLOGICAL WELLBEING

Prevalence rates: up to 44% for depression and 30% for anxiety

Poor QoL and psychological distress are associated with numerous negative outcomes

PSYCHOLOGICAL SUPPORT II

Prematurely stopped RCT of CBT vs. treatment as usual (N = 15; van Groenestijn et al., 2015)

Case controlled study of hypnosis-based psychodynamic Tx (N = 15; Kleinbub et al., 2015)

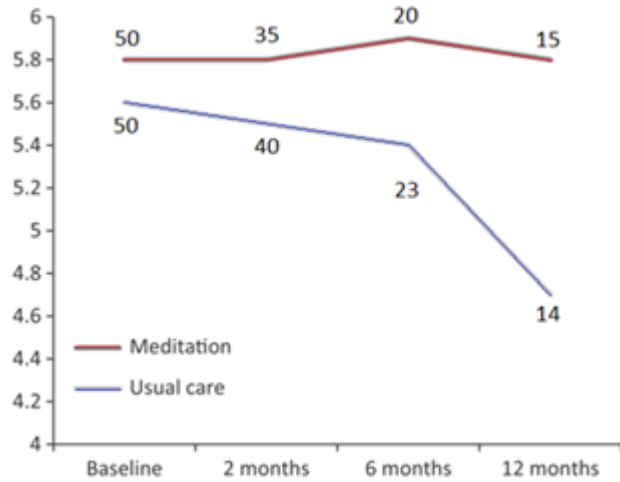RCT of 8-week meditation training vs. usual care (N = 100; Pagnini et al., 2017)

(Zarotti et al., 2021)
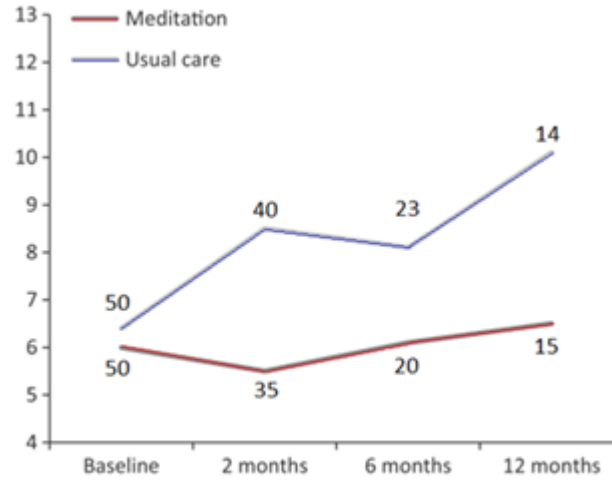
Figure 2 Quality of life (ALSSQOL-R) scores.

Figure 3 Depression (HADS-D) scores.
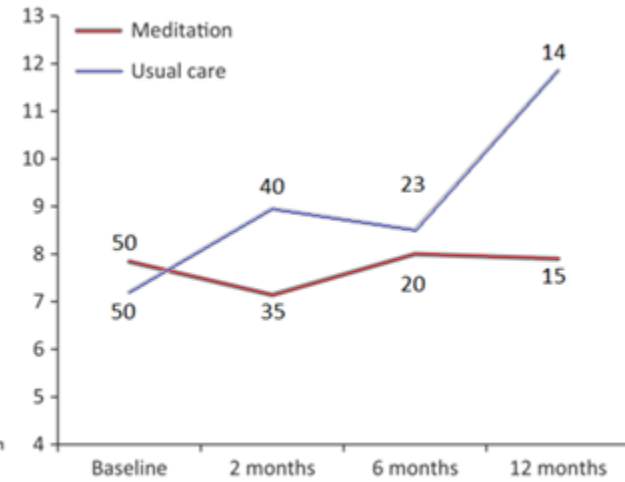
Figure 4 Anxiety (HADS-A) scores.

PAGNINI ET AL. (2017)

NICE CLINICAL GUIDELINES (2016)

NICE National Institute for
Health and Care Excellence

NICE
guideline

Motor neurone disease:
assessment and management

NICE guideline
Published: 24 February 2016
www.nice.org.uk/guidance/ng42

© NICE 2020. All rights reserved. Subject to Notice of rights (https://www.nice.org.uk/terms-and-conditions#notice-of-rights). Last updated 23 July 2019.
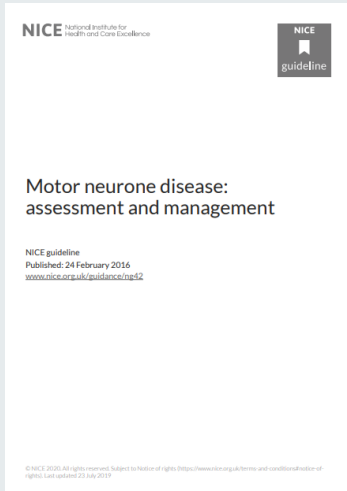
Discuss the psychological and emotional impact of MND and enquire about needs

Signpost to sources of emotional and psychological support

Refer for specialist assessment and support, if necessary

Provide different ways of getting in touch with services due to communication issues

BEHAVIOURAL & COGNITIVE THERAPIES
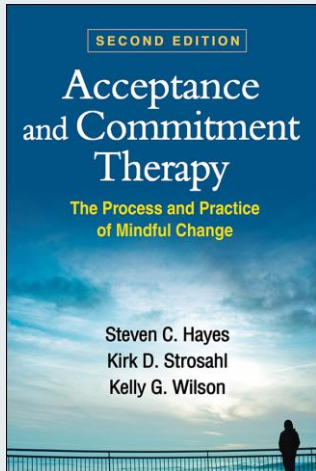
First wave (e.g. Behavioural Therapy)

Second wave (e.g. Cognitive Therapy & Cognitive Behavioural Therapy)

Third wave (e.g. Mindfulness-Based Cognitive Therapy, Mindfulness-Based Stress Reduction, Compassion Focused Therapy, Dialectical Behaviour Therapy)

ACCEPTANCE & COMMITMENT THERAPY (ACT)

Acceptance-based behavioural therapy

Not aimed at reducing distress or symptoms

AIMS OF ACT

Acceptance & Commitment Therapy

Be more open to and accepting of their experiences

Become more aware of their experiences

Commit to doing things guided by what they value and care about

ACT MODEL

EXPERIENTIAL EXERCISES & METAPHORS

Psychologically flexible process	Examples
Acceptance/willingness	Passengers on the bus; Physicalising exercise; Willingness exercise
Cognitive defusion	"I notice I'm having the thought..."; Leaves on a Stream; Imagine a thought on a computer screen
Contact with the present moment	Notice 5 things; Tracking your thoughts in time; Daily mindfulness; Centering exercise
Self-as-context	Labels exercise; House/furniture metaphor; Very brief self-as-observer
Values	Lifetime achievement award; Values list; Life compass; Pieces of the pie
Committed action	Willingness and action plan incorporating SOC principles; Small steps exercise

McCracken et al. (2022)

I spend most of my time paying attention to what is happening in the present moment

ATTENTION TO PRESENT SCALE

I spend most of my time lost in thoughts about the past or future
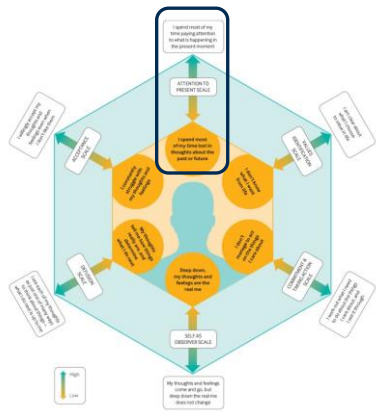
Examples:
Excessively worrying about the prognosis or excessively ruminating about what they used to be able to do

High PF

Low PF

AN EXAMPLE

Lack of contact with the present moment
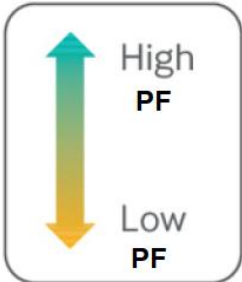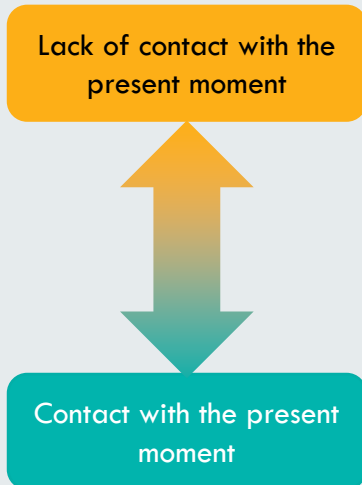
Contact with the present moment

Centering exercise

High
PF

Low
PF
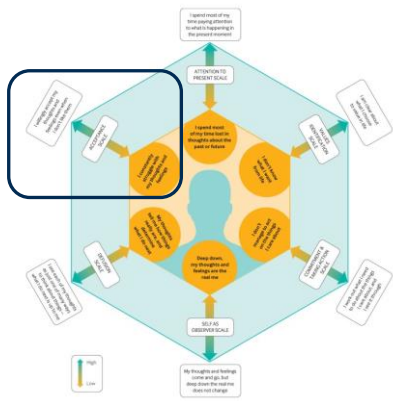
I willingly accept my thoughts and feelings even when I don't like them

ACCEPTANCE SCALE

I constantly struggle with my thoughts and feelings

Examples:
Avoiding going to an MND support group, avoiding using a wheelchair, or avoiding thinking about end-of-life issues

AN EXAMPLE
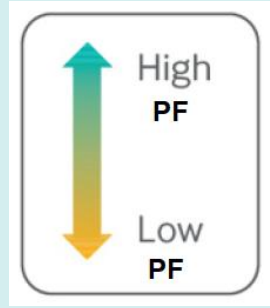
Experiential avoidance

Acceptance/willingness
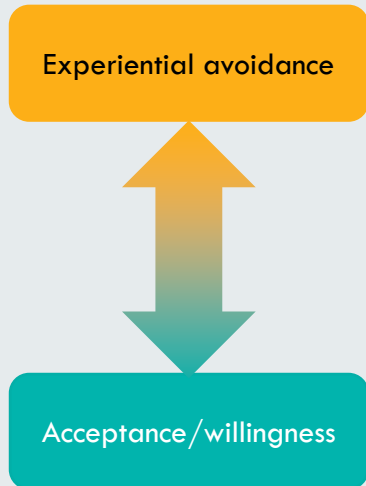
Passengers on the bus metaphor

AN EXAMPLE

DEFUSION SCALE

My thoughts tell me how things really are, and determine what I do next
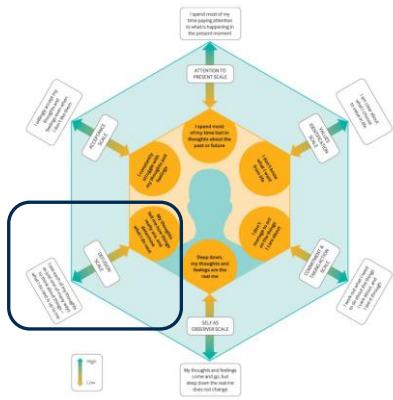
I see each of my thoughts as just one of many ways to think about things – what I do next is up to me

Examples:
Fusion with thoughts such as "It's not the same" or "It's not fair"

High PF

Low PF

AN EXAMPLE

Cognitive fusion

Defusion
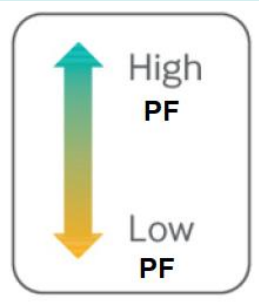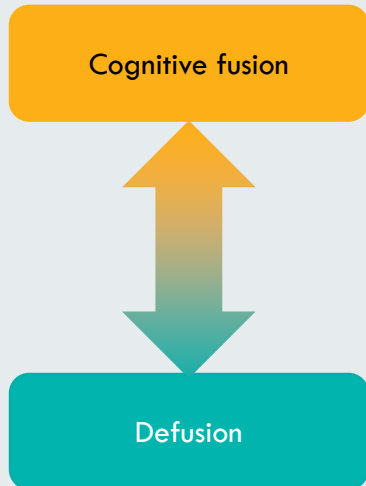
Imagine a thought on a computer screen
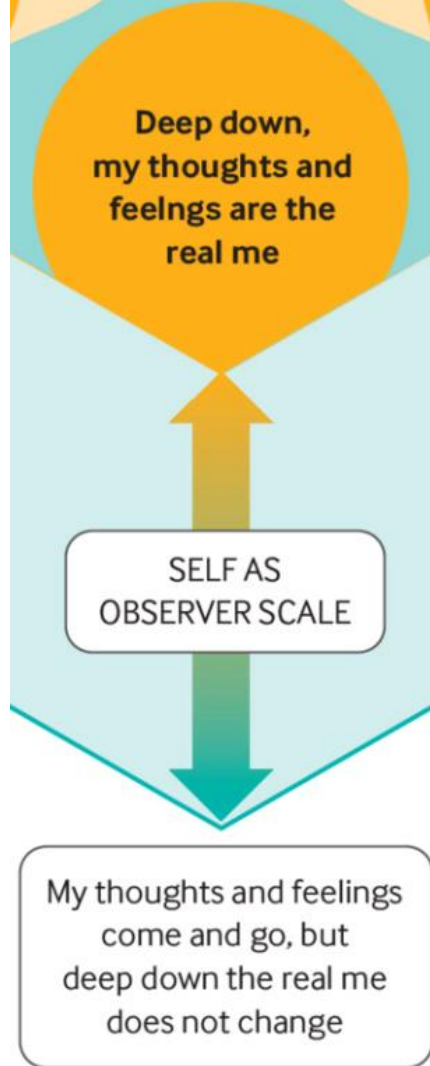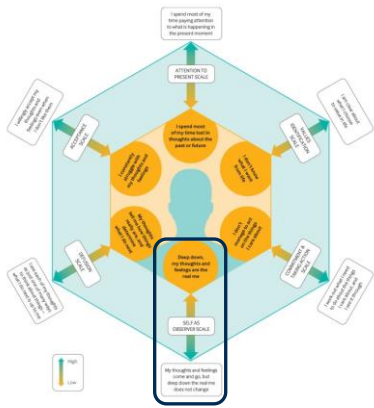
Examples:

Seeing themselves as defined by the label "I'm a patient" or "I'm not the person I used to be"

Deep down, my thoughts and feelngs are the real me

SELF AS OBSERVER SCALE

My thoughts and feelings come and go, but deep down the real me does not change

High
PF

Low
PF

AN EXAMPLE

Self-as-content

Self-as-context
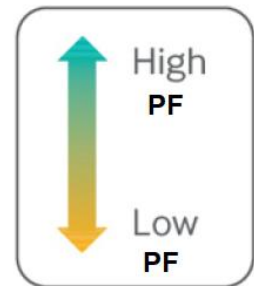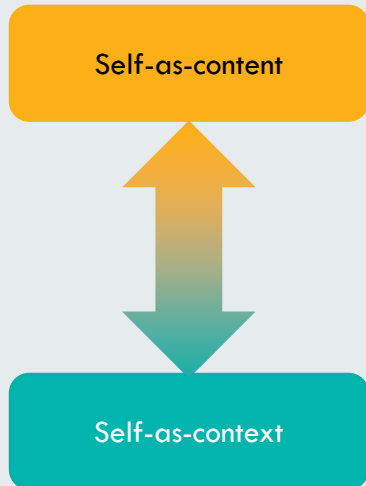
Sky & the weather metaphor

VALUES IDENTIFICATION SCALE

I am clear about what I choose to value in life

I don't know what I want from life
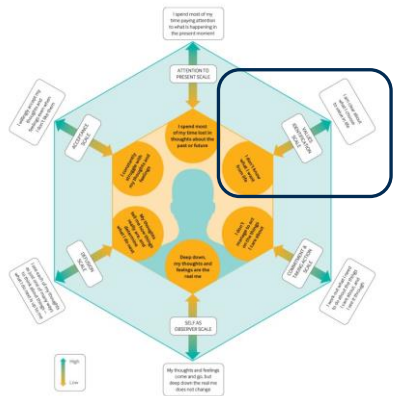
Examples:
Unable to identify what matters (e.g. "I don't know anymore")

High PF

Low PF

AN EXAMPLE

Lack of clarity or loss of contact with values
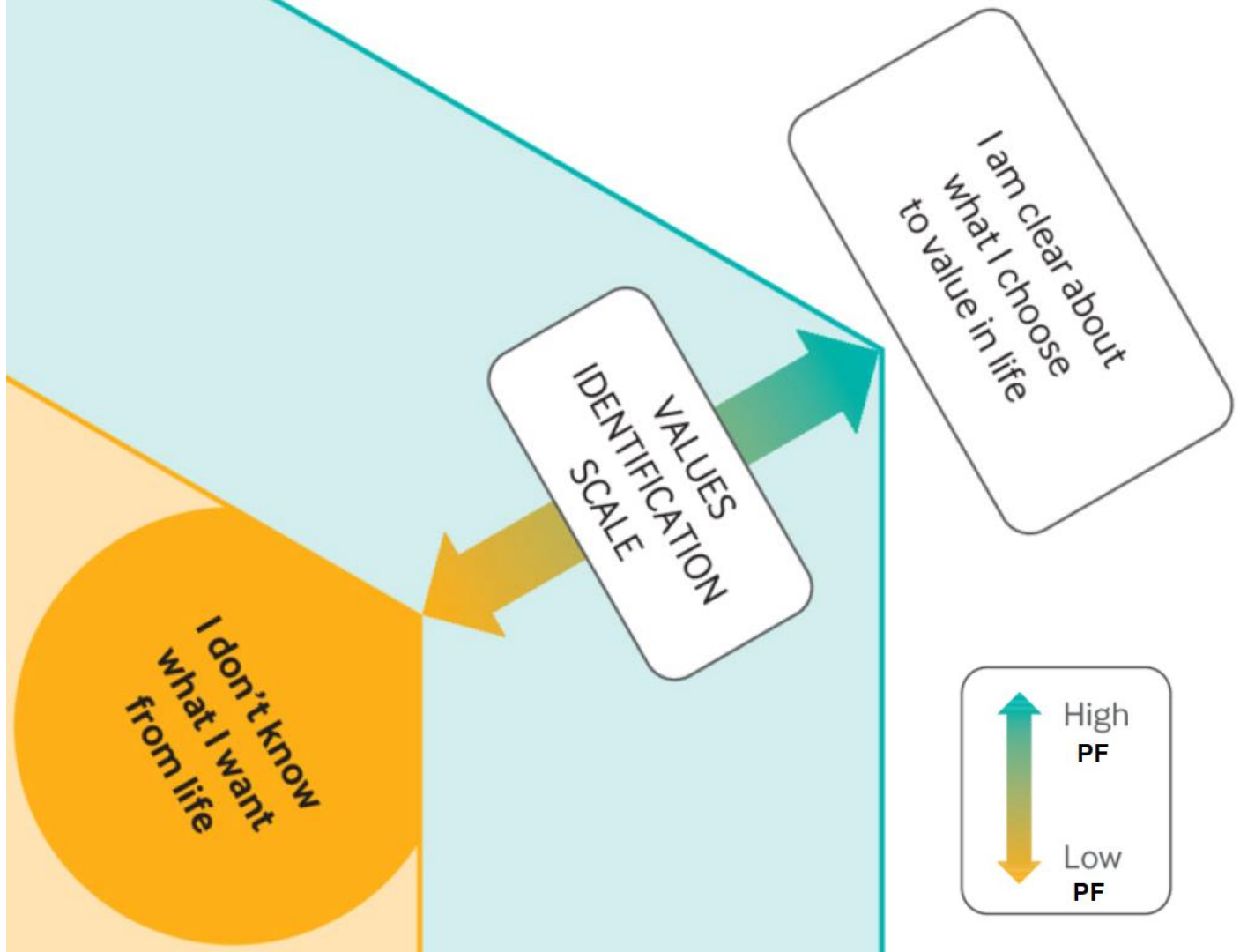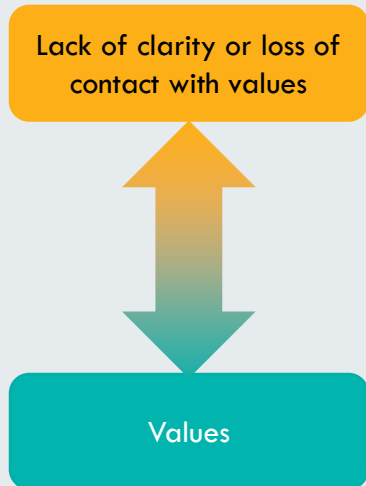
Values

Lifetime achievement award
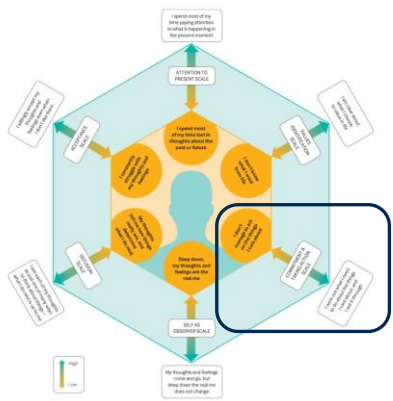
Examples:
Failing to take action to be the loving & caring father they want to be

I don't manage to act on the things I care about

COMMITMENT & TAKING ACTION SCALE

I work out what I need to do about the things I care about, and I see it through

High
PF

Low
PF

A SIMPLE EXAMPLE

Inaction, impulsivity or avoidant persistence

Committed action
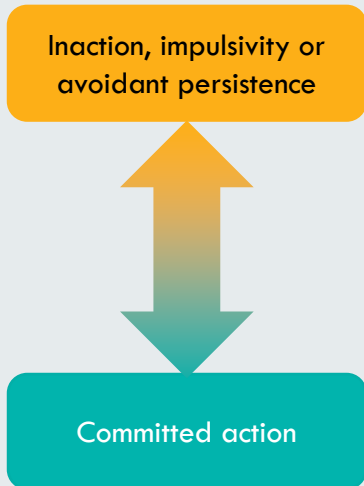
What's the smallest step you could take in the next 24 hours that would move you towards the things you value and care about?

AN EXTENDED EXAMPLE

Inaction, impulsivity or avoidant persistence

Committed action
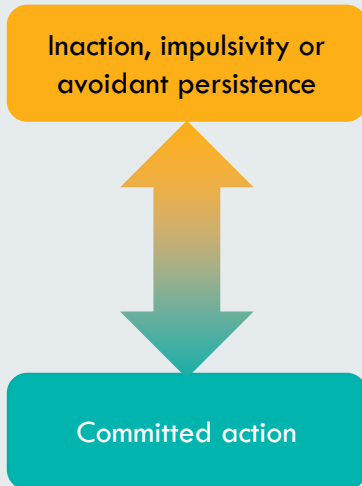
Doing what matters plan

AN EXTENDED EXAMPLE

Inaction, impulsivity or avoidant persistence

Committed action
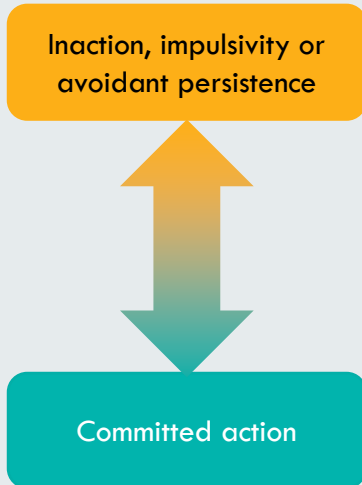
What do I want to do? What is my goal?

Why is this goal important to me?

What potential barriers might get in the way of this goal?

What is the smallest step I could take to achieve this goal?

How can I handle these potential barriers?

^UCL

AN EXTENDED EXAMPLE

Inaction, impulsivity or avoidant persistence

Committed action
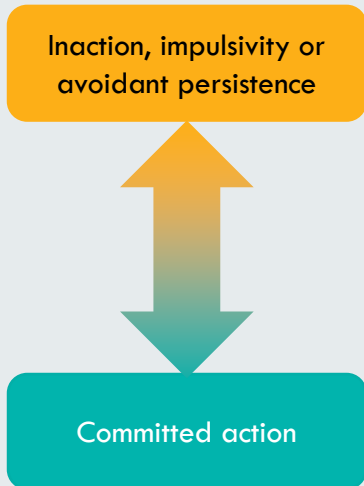
What do I want to do? What is my goal?
Send future birthday messages to my kids

Why is this goal important to me?
Helps me to be the loving and caring Dad I want to be to them

What potential barriers might get in the way of this goal?
No longer able to speak, fatigue, sadness, thoughts such as "It's too painful"

What is the smallest step I could take to achieve this goal?
Decide what I want to say in the first birthday message

How can I handle these potential barriers?
Record messages using Eye Gaze, pace myself, allow passengers along for the ride

EMBODYING ACT PRINCIPLES: ROB BURROW

Opened up to difficult thoughts & feelings that came with recording messages

Lived his life in the present moment

Valued being a loving Dad & an inspiration to others

"That's the most difficult part for me… I've always been a hands-on Dad."

Unhooked from the "You shouldn't dare to dream" thoughts

Took action to be the loving Dad he wanted to be & to inspire others

Stepped back from the "I've always been a hands-on Dad" self-story

DARE TO DREAM ROAD

https://www.bbc.co.uk/news/articles/crgg4m707x1o

UCL

A FEW KEY POINTS

I try to keep a positive mindset

I try to live in the moment

Thoughts and feelings are not inherently problematic or dysfunctional

Truth is defined on the basis of workability

Not all forms of experiential avoidance are problematic

Almost any behaviour can be workable or unworkable

RATIONALE

Beneficial outcomes seen in previous systematic reviews of ACT

CBT techniques may be unhelpful or perceived as invalidating

Preliminary evidence that meditation training may be beneficial for plwMND

COMMEND PROJECT

COMMEND PROJECT

Phase 1: Intervention development

| Qualitative interviews | Adapted ACT for specific needs of plwMND |

HOW ACT WAS ADAPTED FOR PEOPLE LIVING WITH MND

- ACT processes
- Therapeutic delivery
- Issues specific to MND
- ACT for plwMND
- Adaptations for physical difficulties
- Adaptations for cognitive & behavioural difficulties
- Adaptations for communication difficulties

COMMEND PROJECT

Phase 1: Intervention development

Qualitative interviews	Adapted ACT for specific needs of plwMND

Phase 2: Uncontrolled feasibility study

Acceptability	Feasibility

UCL

COMMEND PROJECT

Phase 1: Intervention development

Qualitative interviews	Adapted ACT for specific needs of plwMND

Phase 2: Uncontrolled feasibility study

Acceptability	Feasibility

Phase 3: Randomised controlled trial*

Clinical effectiveness	Cost-effectiveness

*Co-led by Rebecca Gould & Chris McDermott

UCL

191 people living with ALS, PMA or PLS aged 18+, with or without Sx of depression or anxiety

Recruited from 16 MND CCs & clinics across UK and via self-referral

Secondary outcomes

i) Anxiety, depression, function, etc

ii) Costs & resource use

iii) QoL & burden in caregivers

Satisfaction questionnaires

i) PlwMND

ii) Therapists

PHASE 3: RANDOM TRIAL

RESULTS: STUDY FLOW

Randomised (n=191)

Allocated to Intervention (n=97)

Allocated to Control (n=94)

Primary outcome measure at baseline (n=96)
• Missing due to item non-response (n=1)

Primary outcome measure at baseline (n=91)
• Missing due to item non-response (n=3)

Received at least one session (n=87)

Discontinued (n=15)
Withdrew consent (n=7); participant died (n=7); unknown (n=1)

Discontinued (n=13)
Withdrew consent (n=3); participant died (n=6); clinician withdrew participant (n=1); unknown (n=3)

Retained at 6 months (n=82)

Retained at 6 months (n=81)

Included in primary outcome analysis (n=80)
• Missing due to item non-response (n=1)
• Primary available but baseline missing (n=1)

Included in primary outcome analysis (n=75)
• Missing due to survey non-response (n=2)
• Missing due to item non-response (n=2)
• Primary available but baseline missing (n=2)

Discontinued (n=11)
Withdrew consent (n=3); participant died (n=3); lost to follow-up (n=4); unknown (n=1)

Discontinued (n=13)
Withdrew consent (n=2); participant died (n=7); lost to follow-up (n=4)

Completed study (n=71)

Completed study (n=68)

RESULTS: BASELINE CHARACTERISTICS

Characteristic	ACT plus UC (n=97)	UC alone (n=94)	Total (n=191)
Male	57 (59%)	54 (57%)	111 (58%)
Median age (range)	63 (28-85)	64 (33-92)	63 (28-92)
White/White British	96 (99%)	89 (95%)	185 (97%)
Married, civil partnership, co-habiting	77 (79%)	73 (78%)	150 (79%)
Retired	53 (55%)	61 (65%)	114 (60%)
Degree or higher	40 (41%)	40 (43%)	80 (42%)
Diagnosis of ALS	78 (80%)	79 (84%)	157 (82%)
Median months since diagnosis (range)	9 (1-221)	7 (1-141)	8 (1-221)
Case level of depression (m-HADS)	10 (10%)	8 (9%)	18 (9%)
Case level of anxiety (m-HADS)	23 (24%)	18 (19%)	41 (21%)

RESULTS: PRIMARY OUTCOME
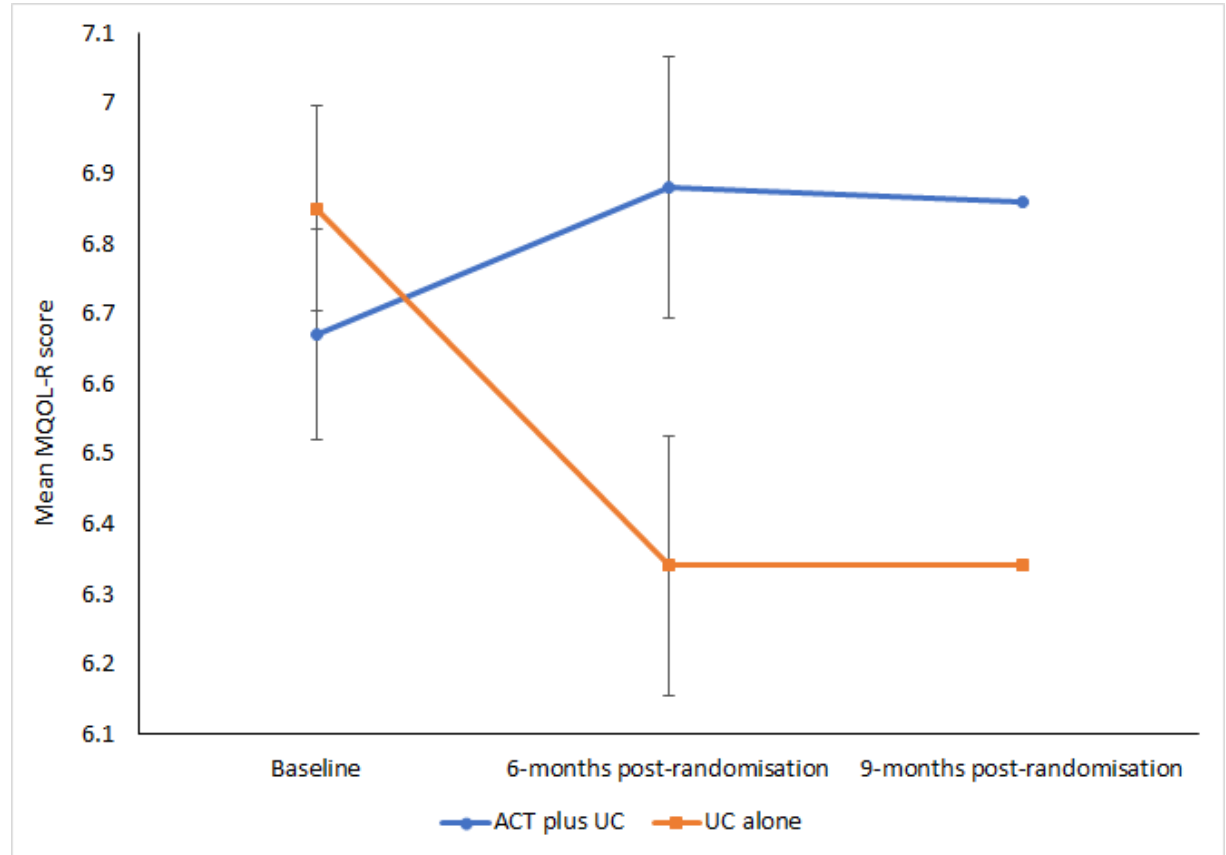
RESULTS: SECONDARY OUTCOMES
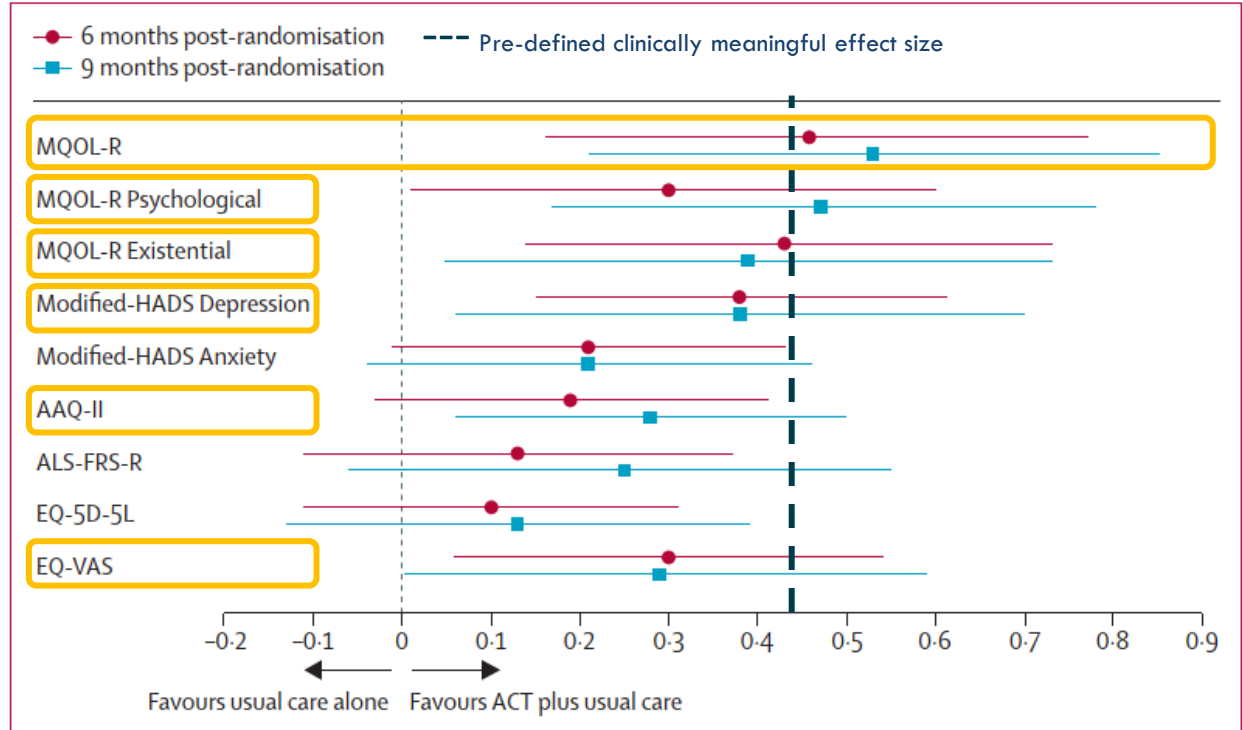
RESULTS: OTHER OUTCOMES

70% of Ps attended all 8 sessions

79% of Ps who had attended at least one session rated ACT plus UC as "satisfactory"

86% probability of being cost effective in those showing a medium rate of deterioration

"Very helpful to come to terms with things... [it] can help you understand and have inner peace."

"I can now be the person I want to be whilst living with MND… I intend to spend the rest of my life concentrating on what matters to me and this disease."

"The therapy was useful as it gave me some coping strategies and the ability to address problems from a different perspective... many of the examples have relevance to my day-to-day activities and thoughts."

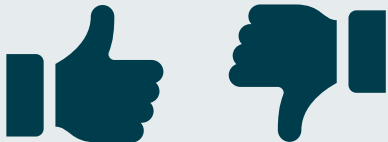"I'm new to MND and early stages... [it's] good to learn now and prepare."

"It has encouraged me to prioritise my values."

STRENGTHS & LIMITATIONS
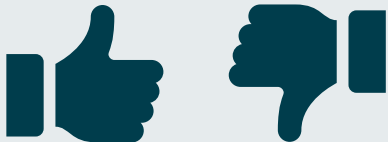
Strengths
First adequately powered RCT of a psychological intervention
First RCT to report the clinical and cost effectiveness of ACT
Geographically diverse regions across UK
Development of an intervention, training & supervision model that could be delivered remotely

STRENGTHS & LIMITATIONS

Strengths	Limitations
First adequately powered RCT of a psychological intervention	Lack of an active control condition
First RCT to report the clinical and cost effectiveness of ACT	Participants from ethnic minorities were under-represented
Geographically diverse regions across UK	Sample may not be representative of those who attend MND clinics
Development of an intervention, training & supervision model that could be delivered remotely	Lack of follow-up assessment beyond 9 months

SUMMARY

ACT is effective at maintaining or improving quality of life and psychological wellbeing in plwMND

"COMMEND provides compelling evidence for the importance of psychological support and specifically the addition of ACT in guidelines for MND." The Lancet Editorial (2024)

ACT IN OTHER PALLIATIVE CARE SETTINGS

Review Article

Acceptance and Commitment Therapy (ACT) for people with advanced progressive illness, their caregivers and staff involved in their care: A scoping review

Tilly Gibson Watt[1] iD, David Gillanders[2],
Juliet A Spiller[1,3] and Anne M Finucane[2,3]

GROUP DISCUSSION

How could you use some of these ideas to support the people you work with?

How could you use some of these ideas to take care of yourself in your work?

EMBODYING ACT PRINCIPLES AS HSCPs

A simple example

Notice thoughts & feelings that you had to make space for in order to be here

Notice the past or future thoughts that you had to unhook from

Notice what mattered enough for you to attend this webinar

Notice the thoughts that you had to unhook from in order to be here

ACT

Notice that by attending this webinar you took action to do something that matters to you

Notice the labels or self-stories that you had to step back from in order to be here

UCL

EMBODYING ACT PRINCIPLES AS HSCPs

Having difficult conversations

- Consider what's important and matters to you
- Notice what thoughts and feelings are showing up
- Practice willingness to have thoughts and feelings
- Slow down and practice mindful listening
- Take care of yourself

IF YOU'RE INTERESTED IN FINDING OUT MORE…

Phase 1: Intervention development

Weeks et al. (2019):
https://doi.org/10.1080/21678421.2019.1621344

Phase 2: Uncontrolled feasibility study

| Gould et al. (2023): https://doi.org/10.1186/s40814-023-01354-7 | Gould et al. (2024): tbc |

Phase 3: Randomised controlled trial

| Gould et al. (2022): https://doi.org/10.1186/s12883-022-02950-5 | Gould et al. (2024): https://doi.org/10.1016/S0140-6736(24)00533-6 | Keetharuth et al. (2024): https://doi.org/10.1111/ene.16317 |

COMMEND

IF YOU'RE INTERESTED IN FINDING OUT MORE...

Acceptance:
https://www.youtube.com/watch?v=jrmKtaMqOh4

Defusion:
https://www.youtube.com/watch?v=BXAzdXJGMeE

Contact with the present moment:
https://www.youtube.com/watch?v=kthk-vmQ02A

Self-as-context:
https://www.youtube.com/watch?v=kl5cyCXelZc

Values & committed action:
https://www.youtube.com/watch?v=yoVmoOnjscM

IF YOU'RE INTERESTED IN FINDING OUT MORE…
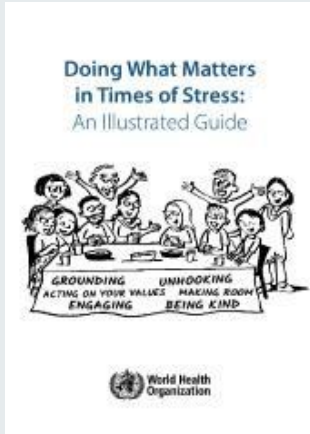
Doing what matters in times of stress: An illustrated guide

https://www.who.int/publications/i/item/9789240003927

ACKNOWLEDGEMENTS

Participants in Phases 1-3

Intervention therapists & supervisors

Site PIs & research staff

COMMEND trial team, co-applicants & collaborators

Members of Trial Management Group & Patient and Caregiver Advisory Group

Members of Trial Steering Committee & Data Monitoring and Ethics Committee

UCL

TRIAL TEAM, CO-APPLICANTS & COLLABORATORS

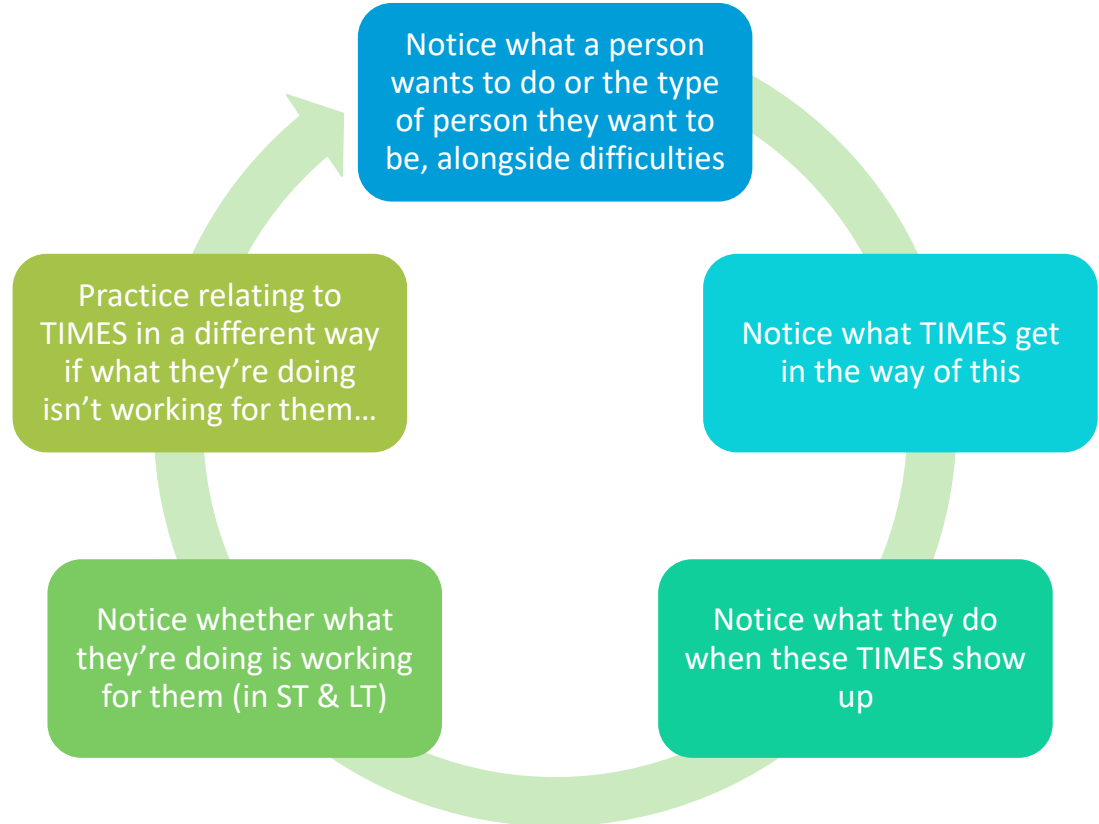| Core trial team		Other co-applicants & collaborators	
Becky Gould	Chief Investigator & co-lead of RCT, UCL	Rob Howard	Co-applicant, UCL
Chris McDermott	Co-lead of RCT, University of Sheffield (UoS)	Marc Serfaty	Co-applicant, UCL
Ben Thompson	Study Manager, UoS	Chris Graham	Co-applicant, University of Strathclyde
Mike Bradburn	Statistician, UoS	Lance McCracken	Co-applicant, Uppsala University
Matt Bursnall	Statistician, UoS	Laura Goldstein	Co-applicant, KCL
Tracey Young	Health Economist, UoS	Ammar Al-Chalabi	Co-applicant, KCL
Anju Keetharuth	Health Economist, UoS	Vanessa Lawrence	Co-applicant, KCL
Charlotte Rawlinson	Research Assistant, UCL	Pamela Shaw	Co-applicant, UoS
Pavithra Kumar	Research Assistant, UoS	Cindy Cooper	Co-applicant, UoS
David White	Deputy CTRU Lead, UoS	Nicola Drewry	Collaborator, PPI Member
Emily Turton	Data Manager, UoS	Brian Dickie	Collaborator, MND Association
Simon Waterhouse	Data Manager, UoS	Francesco Pagnini	Collaborator, Catholic University of Milan
Rowena Seaton Kelly	Trial Support Officer, UoS		

THANK YOU FOR LISTENING

Rebecca Gould
r.gould@ucl.ac.uk

BROAD AIM

TIMES = thoughts, images, memories, emotions, sensations, urges

BROAD
F O C U S

Notice what a person wants to do or the type of person they want to be, alongside difficulties

Notice what TIMES get in the way of this

Notice what they do when these TIMES show up

Notice whether what they're doing is working for them (in ST & LT)

Practice relating to TIMES in a different way if what they're doing isn't working for them…