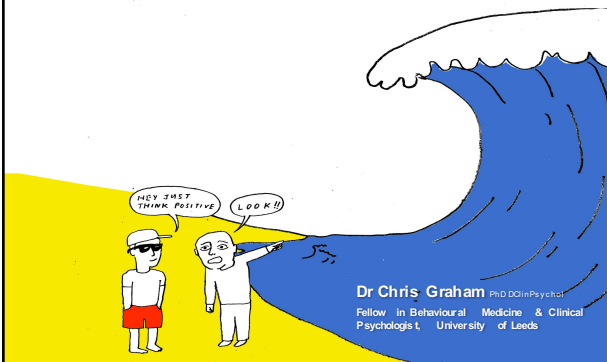


Psychological interventions (mostly ACT) for improving well-being in muscle disorders



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1. How psychological interventions might improve well-being in MD...
2. Acceptance & Commitment Therapy (ACT): what it is and why it might be helpful for some with MD?
3. The ACTMuS Trial
4. Discussion

How might psychological interventions improve well-being in MD?



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The challenges people with MD describe...



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Symptoms

- Progressive Weakness
- Pain
- Fatigue
- Limited disease modifying treatment



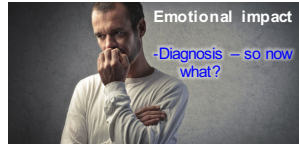
Work/ social Functioning

- Progressive attrition
- Financial impact



Emotional impact

- Diagnosis – so now what?



Identity





## What is Acceptance and Commitment Therapy (ACT) and how is it applied?

1. How do you cope with tricky situations (work, family, those presented by MD etc.)?
2. How do you cope with the emotions that the tricky situation brings?
3. Day to day, how often are you really present, doing things in a way that reflects who you want to be?

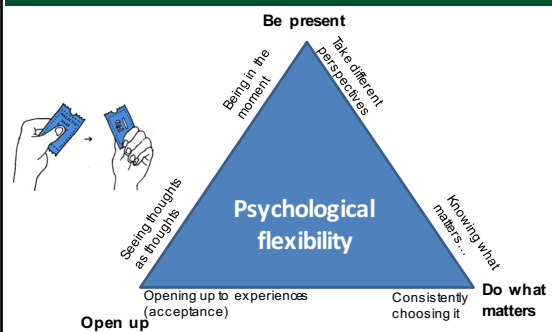
## What is Acceptance & Commitment Therapy?

A newer type of treatment that uses mindfulness and behaviour change methods to improving **psychological flexibility**:

"...the capacity to persist or to change behaviour in a way that:

- 1) includes conscious and open contact with thoughts and feelings (Open-up);
- 2) appreciates what the situation affords (Be aware), and;
- 3) serves one's goals and values (Do what matters)"

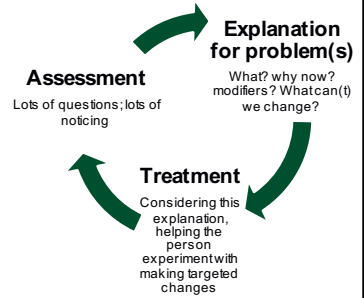
(adapted from McCracken & Morley, 2014, p.225)



## What does Acceptance and Commitment Therapy (ACT) actually involve?

**Treatment Goal**  
Help the person make progress via identifying aspects of psychological flexibility that can be improved

**Ethos**  
Curious, open, kind  
Experiential – explore/reflect, not tell



## ACT Assessment

**Question themes**

*What is important to this person?*

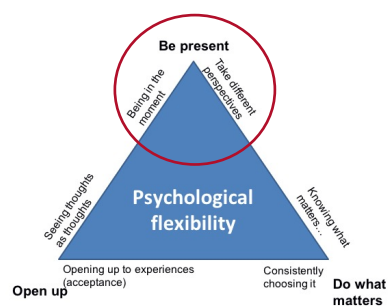
*How consistently are they choosing behaviours that are guided by their values?*

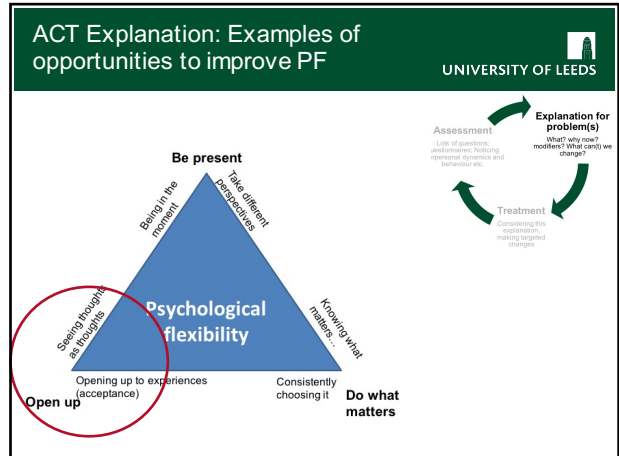
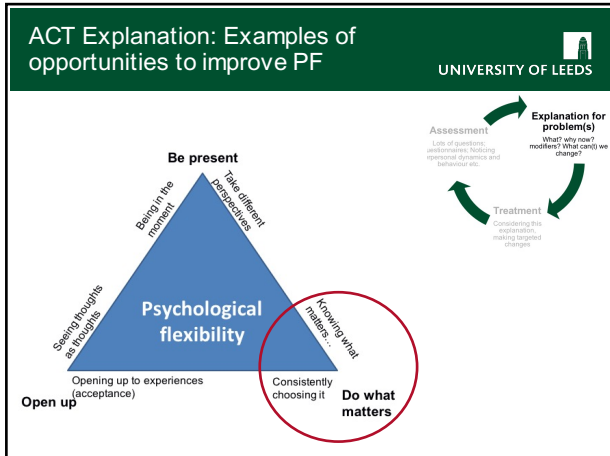
*What do they do when difficult thoughts and feelings – e.g. about illness - are there; does this help them to move forward or get in the way?*

*How do they see/label/relate to themselves and others?*



## ACT Explanation: Examples of opportunities to improve PF





### ACT treatment/training

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**Do what matters**

Conversation

"...you have mentioned your relationship with x a few times you think there is something important here?"

"...how often do you choose to do that or to do it like that..."

"...when you did that was it a step towards or away from your values?"

Exercises

Smallest possible step

The diagram is identical to the top-left one, but a red circle highlights the 'Do what matters' vertex.

### ACT treatment/training

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**Be Present**

Conversation

"And when you get really caught up in your worries about MD progressing, where is your attention?"

"When you back pain is really bad, where is your attention?"

"What would you say to your dad/daughter/son if they were struggling with this?"

Exercises

Mindfulness of the present moment

Perspective shifting

The diagram is identical to the top-left one, but a red circle highlights the 'Be present' vertex.

**ACT treatment/training** UNIVERSITY OF LEEDS

**Open up**

**Conversation**  
 "What if you were willing to have that feeling ...  
 Would you do things differently?"

"What does your mind have to say about that?"

**Exercises**  
 Workability exercise: noticing the cost and effectiveness of attempts to control painful thoughts, feelings.  
 Seeing thoughts as thoughts: Saying "thank you, mind" or "I am having the thought that" when caught-up with thoughts

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# Tailoring and trialling an ACT intervention for MD

**ACT for MD: Testing the concept** UNIVERSITY OF LEEDS

Research questions: "Might this help improve well-being? Do people actually like it and use it? What can we do to improve it?"

**Intervention:**  
 Remote delivery

Three-week guided self-help, comprising:

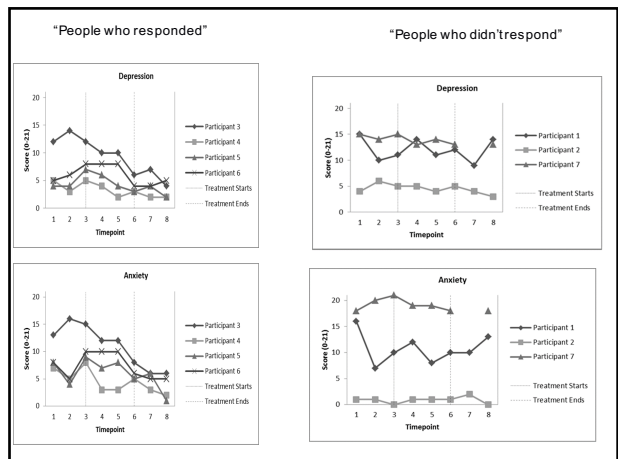
- 3 self-help booklets
- 3-5 discussions with a therapist

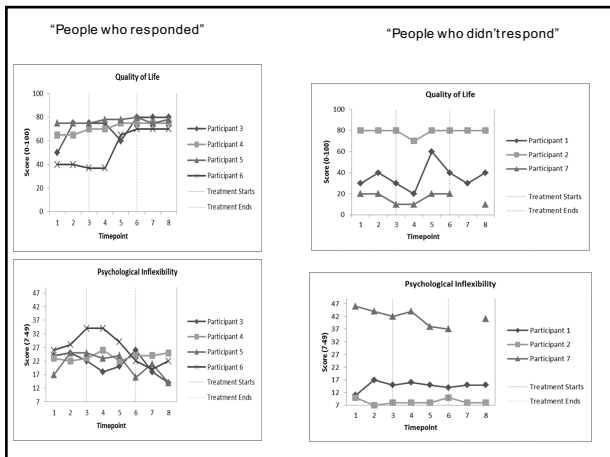
**Evaluation**  
 7 people living with MD

Questionnaires: quality of life, mood, psychological flexibility

Measured: 3 weeks before (baseline) 3 weeks during and 3 time-points after (post-intervention)

Post-intervention interview





**"People who responded"**

*"It hasn't flicked a switch and made me super happy but it has made me confident that I can live a fuller life..."*

*...I have been able to make small changes for the better.."*

*"... I find myself using the tools given now more and more. They do take practice but are effective... helped me realise that you can have a life with this illness."*

*"It helped me look more clearly at...what is important in life, and how to take small steps to achieve them.."*

**"People who didn't respond"**

*"... It was helpful in confirming that I seem to be in a fairly positive place at the moment...it was reassuring that some of the techniques ... were **not really required by me.**"*

*"... challenged myself by doing things ... (tiny things though which really don't count...)...I can't do what matters **however hard I think about it...**"*

*"...a lot of information to take in at one time. When your pain is high your levels and duration of concentration are greatly reduced..."*

ACT for MD case series

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Tailoring

One size fits all?

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ACTMuS: A randomised controlled clinical trial of (brief guided self-help) ACT for improving well-being in MD

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**Research question: Does brief self-help ACT improve quality of life and mood better than standard medical care for people with MD (reporting some distress)?**

Method  
 Participants: 154 people with FSHD, LGMD, BMD, IBM

Some evidence of moderate distress


Procedure  
 Recruited from NHS clinics, charities and registries

Participants randomized to SMC (n = 77) or ACT (n = 77)

Measurements at 3 weeks, 6 weeks, 9 weeks and 6 months


Measuring: quality of life, mood, symptom interference, psychological flexibility

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- Brief guided self-help
- Focus is on improving well-being (yet, this time we recruited those reporting a little distress)
- 4 modules (booklets and audio files) over 5 weeks.
- Supported by 4 phone calls with a clinical psychologist

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**Progress:**

3-week questionnaire (93.8%, 106/113) of **154 needed!**

6-week questionnaire (88.7%, 94/106)

9-week questionnaire (85.9%, 85/99)

The six month follow-up rate is: 69.5% (57/82)

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**Conclusions**

Psychological factors contribute to well-being in long-term conditions

There are lots of psychological therapies, each targeting different psychological factors

ACT is a newer type of treatment that uses mindfulness and behaviour change techniques to improve psychological flexibility

We developed a brief intervention to improve well-being in MD based on ACT, which we are currently trialling



## Recommended reading



### ACT & mindfulness for you

Facing the Storm – Ray Owen

The Happiness Trap – Russ Harris

Mindfulness for Health – Vidyamala Burch



### ACT for your clinical practice

Beginner: ACT made simple – Russ Harris

Intermediate: Mindfulness for two – Kelly Wilson  
The ACT Matrix – Kevin Polk

Black belt: Mastering the Clinical Conversation – Matt Villatte

## Thank you



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