ACT for serious health conditions

An introduction to the PSYCHOLOGICAL FLEXIBILITY approach to living with physical health conditions

Dr Ray Owen
Consultant Clinical Psychologist, Health Psychologist

Liverpool, June 2019  drrayowen@gmail.com
Goals

• Understand the principles of the Psychological Flexibility model as applied to serious physical health conditions (including CF)

• Understand the rationale and evidence for how it is used in healthcare programmes to promote healthy adjustment, behaviour change and fulfilling lives

• Practice Psychological Flexibility case formulation
Universal processes

Specific contexts
Arriving...
JAKE

• 19 year old man with Cystic Fibrosis
• At college (though attendance poor)
• Chronic low mood
• Angry outbursts

• Treatments should include daily nebulisers, tablet medications, oral/nebulised antibiotics, cardio & weights, high calorie diet
• Understands treatment suggestions; apparently poor adherence
• Often fails to attend clinic
  – “What’s the point? They just tell me off”
MAGDA

- Mid 30s: married, 8 year old son
- Always ‘positive’, energetic
- Takes condition seriously
- Made use of treatment opportunities
- Now lungs getting worse and worse
- More frequent problems
- Able to do less
- Been assessed as appropriate for transplantation
- Suddenly anxious and indecisive
  - What if suddenly die?
  - What if bed-bound?
  - Am I risking loss of couple more OK years?
  - How will I cope waiting for ‘the call’?
  - How would I cope with disappointment?
  - Why does everyone think this is easy choice?
A Mental Health service perspective

Figure 2: The overlap between LTCs and mental health problems in England

- Long-term physical health conditions (LTC): 16.5 million (30% of people in England)
- Mental health problems: 9.35 million (17% of people in England)
- Comorbid LTC and mental health problems: 5 million people with an LTC have a mental health problem, mostly depression or an anxiety disorder
Some of the challenges....

Health behaviour change
learning to pace self
dietary change
exercise
smoking cessation

Psychological impact of condition comparison to others
sense of self
fear of the future
living with uncertainty
hopelessness / ‘denial’
loss of sense of purpose
relationships

Coping with Treatment
decision-making
adherence / treatment burden
impact on life
dealing with healthcare systems
The model
Feelings are natural

Guilt  Shame
Some difficult thoughts are natural

• It’s our mind’s job to:
  • Look ahead for possible dangers
  • Try to solve problems that might come up
  • Remind us of important things in our past
  • Notice important things that are missing
  • Keep track of how other people are treating us
It’s how we REACT to these thoughts and feelings that sometimes gets us into trouble

- Giving up on things
- Getting caught up in thoughts
- Dwelling on past and future
- Trying to problem-solve things that can’t be solved
- Avoiding things that make us feel bad
Why do we struggle?

What is life? Why do we struggle so much even after knowing that ... https://www.quora.com/What-is-life-Why-do-we-struggle-so-much-even-after-knowing-
26 Jul 2015 - You can realise why the father in the picture took pain in taking care of the tree. We may leave the world empty handed but we have the option of making somebody's life easier.

Why should we struggle in life?

Why do people struggle so hard to live even when ...

Why do we struggle if everybody is going to die? Why ...

Why is there so much struggle in life?

More results from www.quora.com

Why Do We Struggle?

https://www.theodysseyonline.com/why-do-we-struggle

The question of why we struggle surely cannot be answered in one article, but this verse sums up at least one reason. Of course, you do not want to struggle, but on the other hand, maybe you should. If you were never tested and had it all together, what reason would you have to trust God? Being tested in anyway is not ...

Why we Struggle so much to Let Go of certain People. | elephant journal

https://www.elephantjournal.com/.../why-we-struggle-so-much-to-let-go-of-certain-pe...

10 Oct 2017 - Just like a drug, we will always crave the sensational highs that come with the deepest

...
Healthy, happy normality!
"...all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness."

Declaration of Independence
IN CONGRESS, July 4, 1776
• I’m not healthy, I’m not happy

• So I’m not normal
The answer has been found!

BEER
+
FOOD
=
HAPPINESS
The single most remarkable fact about human existence is how hard it is for humans to be happy.

(Hayes, Strosahl, & Wilson, 1999)
The Example of Suicide

• Unknown in nonhumans but universal in human society
• 6,233 deaths in UK 2013 (Source: Samaritans)
• Around 10x that number attempt (MHF)
  • Certainly underestimate
• Cuts across all psychiatric diagnoses (except dementia and agoraphobia)
  • Harris, E.C., Barraclough, B., 1997, Suicide as an outcome for mental disorders, British Journal of Psychiatry, 170, 205-228.
• Only 1 in 4 seen mental health services in previous year
  • Appleby, L. 1999, Safer Services: National Confidential Inquiry into Suicide and Homicide by People with Mental Illness, Department of Health, London.
Alternative Assumption: Painful Normality

- Normal psychological processes will often bring suffering
- We need to understand these processes and work within them to promote well-being
The culprit?

- Normal mental representation & processing
- Our behaviour is shaped by things we are not experiencing, and have *never* experienced
  - Don’t put your hand in the fire
  - Stay away from the quicksand
  - How to kill a vampire
- Role of language
- Relational Frame Theory
  - shows how we can make anything mean anything
  - and we react to things we have never directly experienced
The struggle switch

• Suppress
• Dive in & Solve
• Push away

• Quicksand
  • By trying to fight, we get more drawn in
How we get stuck...

LESS AWARE
- mind in past / future / elsewhere
- ‘inside your head’ / preoccupied with thoughts (esp stories about self)

STRUGGLING
- Trying to solve or get rid of unwanted thoughts and feelings
- Avoiding things that make us feel bad

STUCK:
pushed around by thoughts & feelings, less effective, narrower life

LESS ENGAGED
- Losing touch with what matters to you
- Stuck in unhelpful habits
Psychological Flexibility: the basic points

• As we move through life, Thoughts & Feelings will show up, simply because of how our minds work
• Some are unpleasant, but they’re not themselves harmful
• We have a natural urge to struggle (fix, get rid, avoid)
• The WAY we go about this can cause far greater problems for us than the thoughts & feelings themselves
• Goal is not to reduce the thoughts and feelings, but enable person to do things that matter in their life in the presence of those experiences
Psychological Flexibility

• The ability to move in a direction that matters to you, even if the presence of unwanted experiences (thoughts, feelings, physical sensations), and in changing circumstances

• Acceptance and Commitment Therapy
“It is not the strongest of the species that survives, nor the most intelligent, but the one most responsive to change.”

~Charles Darwin, 1809
‘Third Wave’ Approaches

• Focus on the integration & expansion of behavioral and cognitive approaches
• Particular focus on mindfulness & acceptance

<table>
<thead>
<tr>
<th>Therapy Approach</th>
<th>Originators</th>
<th>Initial problem area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance &amp; Commitment Therapy</td>
<td>Hayes et al., 1999</td>
<td>Trans-diagnostic (and non-diagnostic!)</td>
</tr>
<tr>
<td>Dialectical Behavior Therapy</td>
<td>Linehan, 1993</td>
<td>Borderline Personality Disorder</td>
</tr>
<tr>
<td>Mindfulness Based Stress Reduction</td>
<td>Kabat-Zin, 1987</td>
<td>Trans-diagnostic</td>
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<td>Mindfulness Based Cognitive Therapy</td>
<td>Segal et al., 2002</td>
<td>Repeated episodes of depression</td>
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<tr>
<td>Compassion – focussed therapy</td>
<td>Gilbert 2005</td>
<td>Shame and self-criticism</td>
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</table>
Acceptance & Commitment Therapy

• Has roots in Behavioural Therapies

• Key names: Steve Hayes, Kelly Wilson, Robyn Walser, Russ Harris

• Development during the 90s, most work since Hayes et al original book published 1999
Acceptance & Commitment Therapy – what’s in a name?

- Acceptance – of what?
- Commitment – to what?
- Therapy – always?

- Not just ACT – RFT, FAP
- CBS
- Psychological Flexibility
Psychological Flexibility Approach / Contextual Behavioural Science

- Acceptance & Commitment Therapy (ACT)
- Functional Analytical Psychotherapy (FAP)
- Clinical Relational Frame Theory (RFT)
- Using the Hexaflex
- Using the Matrix
- Using DNAv (children & adolescents)
ACT – the evidence base

• >300 RCTs, hundreds of smaller studies
• Emphasis on establish which process change leads to outcome change (‘mediation analyses’)
• Some challenges from Ost meta-analyses (methodological differences, non-diagnosis) e.g. problem of ‘weak controls’
• Other meta-analyses have shown positive results
• No clear evidence that it is superior to (well-done) CBT
• Almost all research papers available at www.contextualscience.org
• Evidence-based practice (EBP) lists
  • Accepted as EBP on US Dept of Health’s SAMSHA list
Where being used?

• Studies reported
  • Chronic pain +++
  • Mixed LTCs
  • Epilepsy
  • Diabetes
  • Cancer
  • Cardiac
  • MS
  • Carers

• Other related
  • Weight management
  • Smoking cessation

• Probably wider clinical use than research studies
  • Lack of evidence? or
  • Appropriate use of universal model?
ACT with CF
Reducing anxiety & depression among individuals with cystic fibrosis through Acceptance and Commitment Therapy: A treatment manual including adaptation for telehealth

David S. Bennett, Ph.D,
C. Virginia O’Hayer, Ph.D.,
Winifred Wolfe, MD Candidate,
Adrienne Juarascio, Ph.D.,
Emily Winch, Psy.D.
Drexel University
Department of Psychiatry
The first 10,000 ACT trial participants
Donna

• 38 year old
• 7 year old daughter Amy
• Supportive husband Pete
• Very committed to time with her family, being loving and supportive to them, doing interesting things, achieving things at work and in the community
• Advanced cancer of the breast, with liver and bone involvement

• Very resilient and focused during primary treatment “I am sure I will beat this.”
• Constantly thinking about Amy growing up without a mother, Pete not coping
• Subsequently becomes tearful, withdrawn, unwilling to play with Amy
How we get stuck…

LESS AWARE
- mind in past / future / elsewhere
- ‘inside your head’, dominated by rules & self-stories, rather than what happens

STUCK:
pushed around by thoughts & feelings, less effective, narrower life
(inflexible, unworkable)

STRUGGLING
- Trying to solve or get rid of unwanted thoughts and feelings
- Avoiding things that make you feel bad

DISENGAGED
- Losing touch with what matters to you
- Stuck in unhelpful habits
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In a nutshell...
Psychological Flexibility Model
(e.g. ACT - Acceptance & Commitment Therapy)

**AWARE**
-of the here & now
-notice what’s going on inside you and around you

**OPEN**
- Step back & make room for thoughts & feelings
- Not getting tangled up, pushed around or running from them

**ENGAGED**
- Know what matters to you
- Do what it takes to live that way under current circumstances

More fulfilled, more effective, more resilient
ENGAGED

- Know what matters to you (Values)
- Do what it takes to live that way (Committed action)
Psychological Flexibility Model
(e.g. Acceptance & Commitment Therapy)

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More fulfilled, more effective, more resilient
Who matters most to you in the world?

How do you want to be towards them?

(How do you want to act in your dealings with them?)
Values

Client-friendly description

‘what we want to stand for in life, how we want to behave, what sort of person we want to be, what sort of strengths and qualities we want to develop’. (Russ Harris, 2009)
## Some Values

I want to behave...

<table>
<thead>
<tr>
<th>Respectfully</th>
<th>Honestly</th>
<th>Gratefully</th>
</tr>
</thead>
<tbody>
<tr>
<td>Irreverently</td>
<td>Caringly</td>
<td>Self-challengingly</td>
</tr>
<tr>
<td>Co-operatively</td>
<td>Adventurously</td>
<td>Playfully</td>
</tr>
<tr>
<td>Competitively</td>
<td>Creatively</td>
<td>Respectably</td>
</tr>
<tr>
<td>Independently</td>
<td>With curiosity</td>
<td>Flexibly</td>
</tr>
<tr>
<td>Usefully</td>
<td>With appreciation of beauty</td>
<td>Taking other perspectives</td>
</tr>
<tr>
<td>Generously</td>
<td>Openly</td>
<td>With originality</td>
</tr>
<tr>
<td>Loyally</td>
<td>Spiritually / religiously</td>
<td>With awareness</td>
</tr>
<tr>
<td>Kindly / compassionately</td>
<td>With commitment</td>
<td>Healthily</td>
</tr>
<tr>
<td>Dependably</td>
<td></td>
<td>Nurturingly</td>
</tr>
<tr>
<td>Helpfully</td>
<td></td>
<td>Effectively</td>
</tr>
<tr>
<td>Sociably</td>
<td></td>
<td>Enthusiastically</td>
</tr>
<tr>
<td>Consistently</td>
<td></td>
<td></td>
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- "some other way, that’s not on this list?"
Values are...

• Ongoing
• Not the same as Goals (compass points, not destinations)
• Not the same as Actions (ways of acting)
• Chosen (the person I want to be, not what I’m stuck with)
• Not dependent on others’ approval (if no-one else ever knew)
• Not right or wrong
• Ends in themselves, more or less… (intrinsically reinforcing)
• About fulfilment, not happiness:

  • “a life well-lived is a life lived according to your Values”
Accessing Values

• List
• Values card sort
• Funeral address / dinner in your honour
• **as they show up**
  • In vitality
  • in pain ("inside your pain, you’ll find your Values")
Not a unique concept

- “Everything can be taken from a man or a woman but one thing: the last of human freedoms - to choose one's attitude in any given set of circumstances, to choose one's own way”

- “He who has a why to live for can bear almost any how”

Viktor Frankl, V. (1959) *Man's Search for Meaning*
Video here: Michael Jr – Amazing Grace
https://www.youtube.com/watch?v=-HW8rEeCX94
The Bullseye: place an ‘X’ in each section of target for where you stand today

- Purposeful activity (e.g. paid work, child-rearing, education, volunteering)
- Leisure (e.g. hobbies, interests, things done for fun)
- Self-care (e.g. health, personal development)
- Relationships (e.g. intimate, friendships)

I am living fully by my Values

I am acting very inconsistently with my Values

Adapted from Lundgren
BUT.....

• What happens when we move towards our goals?

• Stuff shows up and gets in the way
  • External stuff
  • Internal stuff
    • Thoughts, emotions, physical sensations, habits, rules, self-stories etc

• Then we react to that
  • E.g. fusion, experiential avoidance
Experiential avoidance video here

• https://youtu.be/C-ZuqeyxULM
OPEN
- Step back & make room for thoughts, emotions, sensations
- Not getting tangled up, pushed around or running from them

(Defusion & Willingness)
Psychological Flexibility Model  
(e.g. Acceptance & Commitment Therapy)

**AWARE**
- of the here & now  
  - notice what’s going on inside you and around you

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**ENGAGED**
- Know what matters to you  
- Do what it takes to live that way

More fulfilled, more effective, more resilient
Struggle
Struggling with thoughts

- Whatever you do....
- Thought on a piece of paper
- Passengers on a bus

- Concept of Fusion
Fusion: the general process

• Losing the distinction between thought and reality
• Seeing the world *through* your thoughts, rather than seeing the thoughts as part of your world
• Tinted specs
See, *that’s* what I’m talking about!
Defusion

• Noticing
• Back to that piece of paper
• Thanks, mind..
Video here: Our common fate (the stories we carry round)

• https://www.youtube.com/watch?v=XHGBeg6AnMo
Everyone you meet is fighting a battle you know nothing about. Be Kind. ALWAYS.
1. This is Smelly Velcro Cat. It’s not your fault he’s arrived. But you cannot get rid of him.

Imagine Smelly Velcro cat as your difficult thoughts and feelings.

2. You can obsess over how to get rid of him...

3. Go away!

You can struggle and try to push him away... but can you focus on what matters to you when all your energy is here?

4. So could you allow him to be here? You don’t have to want him or like him but here he is anyway and there is no way to get rid of him...

5. So could you drop the struggle? Make room for him and allow him to be there while you move your arms and legs and take action to follow what matters to you deep in your heart?
Emotions: experiential avoidance
Exercise

• An uncomfortable experience..
‘Getting rid’ of unwanted emotions

NEVER

IN THE HISTORY OF CALMING DOWN.
HAS ANYONE EVER CALMED DOWN
BY BEING TOLD TO CALM DOWN.

CALM DOWN
How else do we ‘get rid of’ unwanted emotions?

- Suggestions?
- Argue with self
- Distract self
- Alcohol
- Other drugs
- Self-harm
- Kill self
EA -> acceptance / willingness

- Aunt Irma
- Physicalising
- Practice sitting with ‘in the moment’
  - Nb occasionally need some prep work, e.g. DBT style
- Dropping anchor
- Connection to Committed Action / “the price I’m willing to pay”
  - Chemotherapy
  - A ticket to the Bahamas
MAGDA

- Early 30s
- Born in Poland, came to UK seasonal agricultural work
- Settled in UK, moving into hospitality / hotels
- Was fit, enjoyed sports, socialising
- Hoping to train & qualify in exercise, settle down
- Increasing pain problems
- Diagnosed fibromyalgia
  - Hard to work long shifts at hotel
  - No sport
  - Weight gain
  - Anxious preoccupation with pain
  - Constant worry
  - Activity avoidance
Acceptance?

• A difficult word..
  • Especially in physical health
  • In a lot of frames

• Willingness
• Making Room
Psychological Flexibility Model
(e.g. Acceptance & Commitment Therapy)

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Mindfulness?

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**Engaged**
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More fulfilled, more effective, more resilient
Anna has emptied her mind and is just listening to the world around her.

She can hear the neighbours arguing, two ambulances, a burglar alarm, a child crying, and the sound of dubstep coming from a Subaru Impreza.

She is also concentrating on her own feelings, like her cystitis.
Today me will live in the moment, unless it’s unpleasant, in which case me will eat a cookie.

- Cookie Monster
Do you know why your dog is happier than you?
Mindfulness ISN’T about achieving this...
Some mindfulness exercises aim for this...
This is what we’re really aiming for
Mindfulness in ACT

• It is more then just relaxing
• Do you have to ‘meditate’?
• Is it dangerous?
  • Backlash – MacMindfulness &/or Harmful
  • Little relevant data of actual harm from e.g. MBSR
    • Needs closer study
    • Hurt vs harm
• Like physical exercise
  • Dose / intensity
  • Vulnerabilities of individual
  • Quality of instruction

  • Baer & Kuyken Oxford Mindfulness Centre

So what ARE we using present Moment Awareness for?

• Get better at noticing..
• Context (external) – environment, cues / stimuli
• Context (internal) – incl sensations, thoughts, feelings
• Consequences of actions – tracking outcomes

• Defusion, willingness
An exercise...
Video here: Here Comes a Thought

https://www.youtube.com/watch?v=rds7V5Sxu-4
‘Focus’ and ‘Awareness’ video

https://www.youtube.com/watch?v=TpIU3WN0ggQ
How we talk to people about their experience

• As we move through life, Thoughts & Feelings will show up, simply because of how our minds work
• Validate experience +++
• Some are unpleasant, but they’re not themselves harmful
• We have a natural urge to struggle (fix, get rid, avoid)
• The WAY we go about this can cause far greater problems for us than the thoughts & feelings themselves – can get in the way
• Goal is not to reduce the thoughts and feelings, but enable person to do things that matter in their life in the presence of those experiences
Basic behavioural principles

A \rightarrow B \rightarrow C

Antecedent \rightarrow Behaviour \rightarrow Consequences

wtf?

What’s the function?
Bringing It Together

• Antecedents: feelings of anxiety and sadness, thoughts such as “I am a loser” and “life sucks”, environmental factors including a TV, a fridge full of beer, and being alone.

• Behaviour: watches TV and drinks large quantities of beer until falls asleep, intoxicated

• Consequences: a) short term: relief from painful thoughts and feelings b) long term: damages physical health, increases emotional pain
• Easy for consequences we have experienced before
• ‘Selection by consequences’ – Skinner
• BUT..
• What about things we’ve never experienced before?

• How do you kill a vampire?
• “If you do that now, you’ll receive a **financier**”
  • A financier is a heavy fine
  • A financier is a type of sponge cake
Relational Frame Theory

• A scientific account of how human language develops, enables us to learn, understand and problem-solve flexibly

• AND

• Ruminate, worry, react as if we’re in danger when we’re not, reach conclusions about ourselves that don’t help, get stuck in rules that aren’t working

‘Learning RFT’ (2010) - Torneke
Workability

• Is it working to give you a rich, full and meaningful life?
  • If yes, keep doing it.
  • If not, would you consider doing something different?

• What works short term to get rid of unpleasant thoughts & feelings, often does not work long term to give us a rich and full life
I often tell clinicians that they only need to learn how to do three things really well:
• Know how to increase a client's openness to experiences;
• Know how to train the client to be located in the present moment in life and
• Know how to engage the client in his or her valued life directions.

You don't have to know how to deliver 16 different evidence based treatment packages;

you just need to learn how to do those three things really well, in the heat of the moment in the clinical conversation

Kirk Strosahl
AWAY FROM VALUES

HOOKS, e.g.
- Lack of awareness of Values
- Urge to avoid discomfort
- Desire for short-term gains
- Old habits
- Hooked by thoughts
- Stuck in a story

TOWARDS VALUES

HELPERS, e.g.
- Awareness of Values
- Skills:
  - Awareness
  - Defusion
  - Acceptance
  - Flexible perspective taking
  - Effective goal-setting

'EXTERNAL' FACTORS
- Improved symptom management
- Improved function
- Improved social context

Adapted from Ciarrochi, Bailey & Harris 2013
Over to you
Psychological Flexibility Model
(e.g. Acceptance & Commitment Therapy)

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More fulfilled, more effective, more resilient
RAKE

- 19 year old man with Cystic Fibrosis
- At college (though attendance poor)
- Chronic low mood
- Angry outbursts

- Treatments should include daily nebulisers, tablet medications, oral/nebulised antibiotics, cardio & weights, high calorie diet
- Understands treatment suggestions; apparently poor adherence
- Often fails to attend clinic
  - “What’s the point? They just tell me off”
MAGDA

- Mid 30s: married, 8 year old son
- Always ‘positive’, energetic
- Takes condition seriously
- Made use of treatment opportunities
- Now lungs getting worse and worse
- More frequent problems
- Able to do less
- Been assessed as appropriate for transplantation
- Suddenly anxious and indecisive
  - What if suddenly die?
  - What if bed-bound?
  - Am I risking loss of couple more OK years?
  - How will I cope waiting for ‘the call’?
  - How would I cope with disappointment?
  - Why does everyone think this is easy choice?
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Losing touch with what matters to you
Stuck in unhelpful habits

STUCK:
(inflexible, unworkable)
Live demo

- Real play / role play
- NOT about fixing/curing.. About exploring
compassionate
respectful
curiosity
Everyone you meet is fighting a battle you know nothing about. Be Kind. ALWAYS.
Taking it further

• One website:
  • contextualscience.org

• One self-help book:
  • Oliver, Hill & Morris - Activate your Life

• Two books for professionals:
  • Bennett & Oliver – Acceptance & Commitment Therapy (100 Key Points)
  • Hayes & Ciarrochi – the Thriving Adolescent

• Further training
  • Contextulscience.org
  • Birmingham ACT week
Shameless plug

Both ‘Highly Commended’ in BMA Popular Medicine Book of Year

Available from Routledge or usual suppliers

Contact me: drrayowen@gmail.com

Twitter @mindfulprimate
Social media

• Twitter:
  • @myACBS
  • @mindfulprimate
  • @thinkpsychol
  • @morriseric
  • @contextconsult

• Facebook groups
  • Acceptance and Commitment Therapy
  • Association for Contextual Behavioural Science

• YouTube
  • Acceptance and Commitment Therapy
What next?