

ACT Now: Supporting psycho-social adjustment in patients who have conditions that affect their appearance

A one-day training programme for health professionals



Kristianstad
University
Sweden



**UWE
Bristol** University
of the
West of
England



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North Bristol **NHS**
NHS Trust

The day's schedule

Session 1	<ul style="list-style-type: none">• The ACT Now training project• Quiz• Communicating with patients• Patients' psycho-social difficulties relating to appearance• Introducing the ACT approach
Break	
Session 2	<ul style="list-style-type: none">• Addressing myths about appearance concerns• Identifying patients who are distressed• Having a conversation about appearance with patients• Things to consider when supporting patients.
Lunch	
Session 3	<ul style="list-style-type: none">• Using the 'ACT Map' with patients.• Applying ACT's Helpful Skills to patients: Mindful Breathing.
Break	
Session 4	<ul style="list-style-type: none">• Applying ACT's Helpful Skills to patients: Thought de-fusion.• Applying ACT's Helpful Skills to patients: Valued action.• Resources to help you and your patients
Feedback	<ul style="list-style-type: none">• Quiz and next steps

Session 1

ACT Now: Project Overview

- Funded by Erasmus+
- September 2018 – August 2020
- Collaboration of 9 countries
 - Sweden, the Netherlands, Norway, Estonia, Greece, Cyprus, Slovenia, United Kingdom and Romania.
- Overall aim:
 - Share innovative techniques with health professionals to help patients who have appearance concerns.

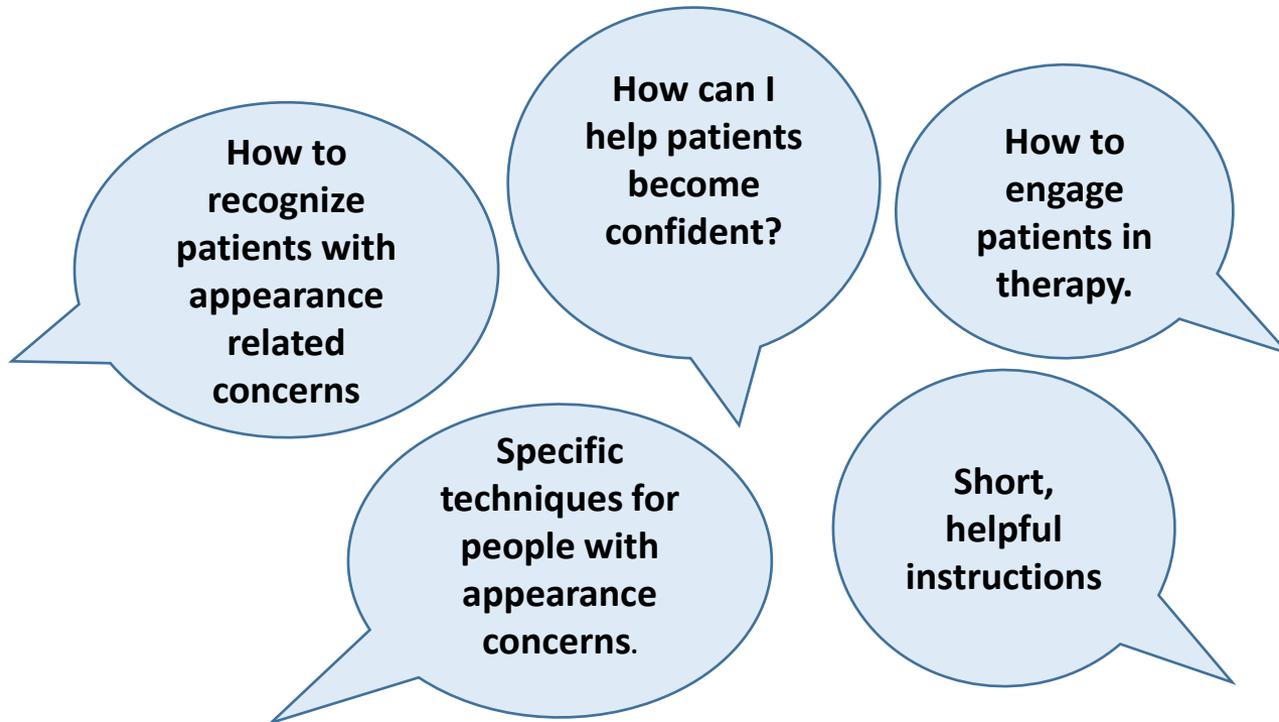
ACT Now: Project Overview

Stages of project

1. Survey of health professionals.
2. Develop innovative 1- day training programme.
3. Pilot programme in 5 countries: Estonia, Greece, Cyprus, Slovenia and Romania.
4. Evaluate and further develop programme to train more health professionals.

What health professionals want from the training

From our survey:



We need your expertise!

- Your feedback will optimise the training programme.
- We can learn from your experiences.
- Please complete the following quiz and provide detailed feedback in our session tomorrow.



Please complete the ACT Now quiz.



What we expect from health professionals in the training

1. Anything personal you share today, stays in the room.
2. Please treat each other with respect.
3. Please arrive on time after the breaks.
4. Please keep disturbances to a minimum.
 - Phones off or in silent mode, avoid separate conversations etc.
5. Please give your honest feedback.
6. Please participate as fully as you can...



Getting the most from today



TRAINEES' WORKBOOK

LEARNING OBJECTIVES

By the end of this training you should be able to:

1. Describe the common psychological and social difficulties patients can experience when they have an appearance-affecting condition
2. Use communication skills and the ACT map to help you and your patient to understand the impact of their appearance concerns.
3. Recognise common myths about appearance.
4. Help your patient to identify their values (what is important to them)
5. Teach your patient 'mindful breathing' and thought 'on-hooking' exercises to help them manage difficult thoughts and feelings about their appearance, and focus on what is important to them.
6. Work with your patient to identify a simple action plan to help them achieve what is important to them.



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Learning Objectives

By the end of this training you should be able to :

1. Describe the common psychological and social difficulties patients can experience when they have an appearance-affecting condition.
2. Use communication skills and the ACT map to guide you when discussing appearance concerns with patients.
3. Recognise common myths about appearance.
4. Help your patient to identify their values (what is important to them).
5. Teach your patient mindful breathing and thought 'de-fusion' exercises to manage difficult thoughts and feelings about their appearance and focus on what is important to them.
6. Work with your patient to set a simple goal to help them achieve what is important to them.

Tips for communicating with patients

Create a safe space:

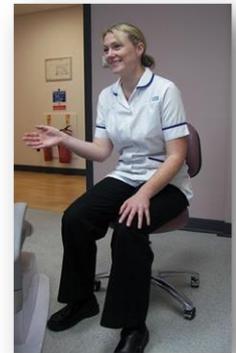
- Check the physical environment is appropriate for the type of conversation you want to have
- Check the patient is comfortable
- Reduce interruptions (e.g. from staff, visitors, phones)
- Ensure others can't hear your conversation.



Tips for communicating with patients

Use positive body language

- Adopt a relaxed posture – shoulders down, back straight, not stiff
- Smiling shows positivity and warmth
- Eye contact – keep head up and look at them when talking
- Leaning in slightly shows you're interested and listening
- Affirmative movements (e.g nodding or smiling) shows empathy
- Observe patient's body language for clue's about their feelings, are they showing signs of anxiety?



What non-verbal signs would indicate that your patient is anxious?

Tips for communicating with patients

Be a good listener

- Ask open questions (i.e. starting with: how do you feel..., tell me about...?)
- Don't rush your patients - be patient
- Don't assume what their difficulties will be
- Don't be judgmental (*You shouldn't worry about that!*)
- Avoid interrupting (when possible)
- Show empathy – show you understand their perspective
- Check your understanding - repeat back what they have said, so they know you have listened and understood.

"When you talk,
you're only
repeating what you
already know. If
you listen, you may
learn something
new."

-Dalai Lama

indpress.com

Tips for communicating with patients

Consider the issue of health literacy.

- Health literacy refers to:
 - people's knowledge, motivation and competence to access, understand, appraise and apply health information in order to...
 - make judgments and take decisions about health care, disease prevention and health promotion...
 - to maintain or improve quality of life across their lifespan



Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, Brand H (2012). Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 12(80): 1-13. doi:10.1186/1471-2458-12-80.

Tips for communicating with patients

Consider if your patient's health will be affected by a disadvantaged background.

- Are they unemployed?
- Are they living in a deprived area?
- Do they have a low education?



World Health Organization. Evidence and resources to act on health inequities, social determinants and meet the SDGs. 2019

Tips for communicating with patients

- Poor health literacy is not a problem for the minority.
- Survey results from Europe and north America show that around half of all patients cannot understand basic health care information.
- Check - Can your patient understand you?
- Throughout this workshop, consider how would engage a person from a disadvantaged group and/or who has insufficient health literacy skills.



Expert Panel on effective ways of investing in Health (EXPH), Report on Access to Health Services in the European Union, 3 May 2016

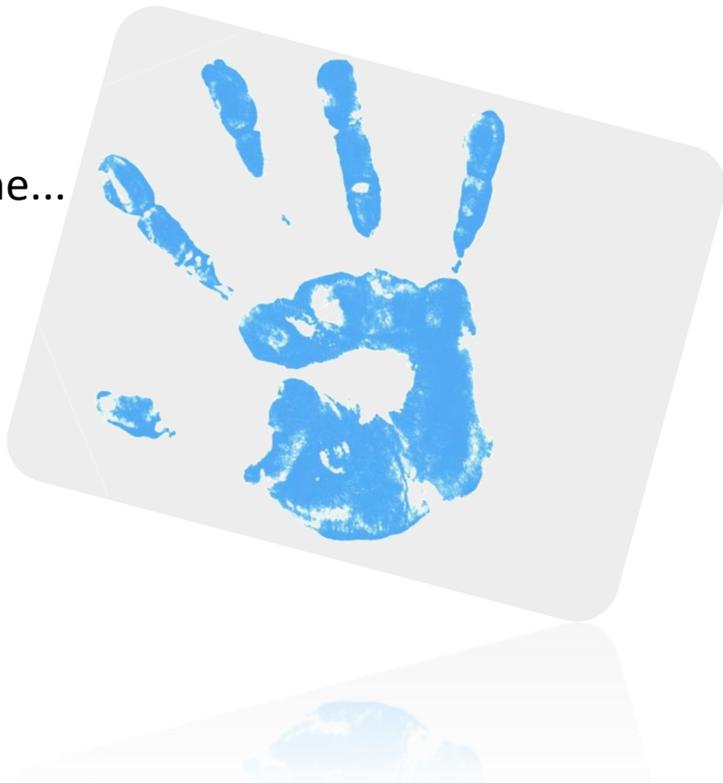
For more information;
see the **Social Inclusion
& Health Care** module
on the ACT Now website



Psycho-social difficulties
in patients with
appearance-affecting conditions

Your turn: 10 minute task

Imagine...



1. What thoughts might you have?
2. What feelings might you experience?
3. How would you react when:
 - you arrive at a new job?
 - intimate with your partner?
 - on a date?
4. How would others react

Conditions, injuries, treatment side-effects



No copyright infringement intended

Your turn: 5 minute task

In groups of 3, can you think of any more appearance-affecting conditions?

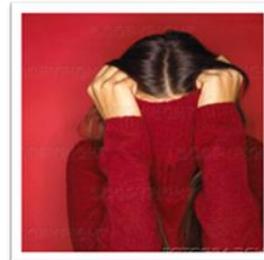
Consider: Patients in your specialty and patients in other specialties.

Anyone can have appearance concerns



No copyright infringement intended

Negative impact on physical, social & psychological health & well-being



No copyright infringement intended

Standing out from the crowd



Common difficulties for people who have any appearance-affecting condition

- Staring, comments, questions (curiosity, concern or malice).
- Being rejected or avoided by strangers, peers, family
- Being bullied, discriminated against or misjudged

(See The Oxford Handbook of the Psychology of Appearance, Rumsey & Harcourt, 2012)

Misjudged, discriminated against



The barman asked me to leave because I looked disgusting!



I'm often thought of as having learning difficulties and treated differently to other kids.

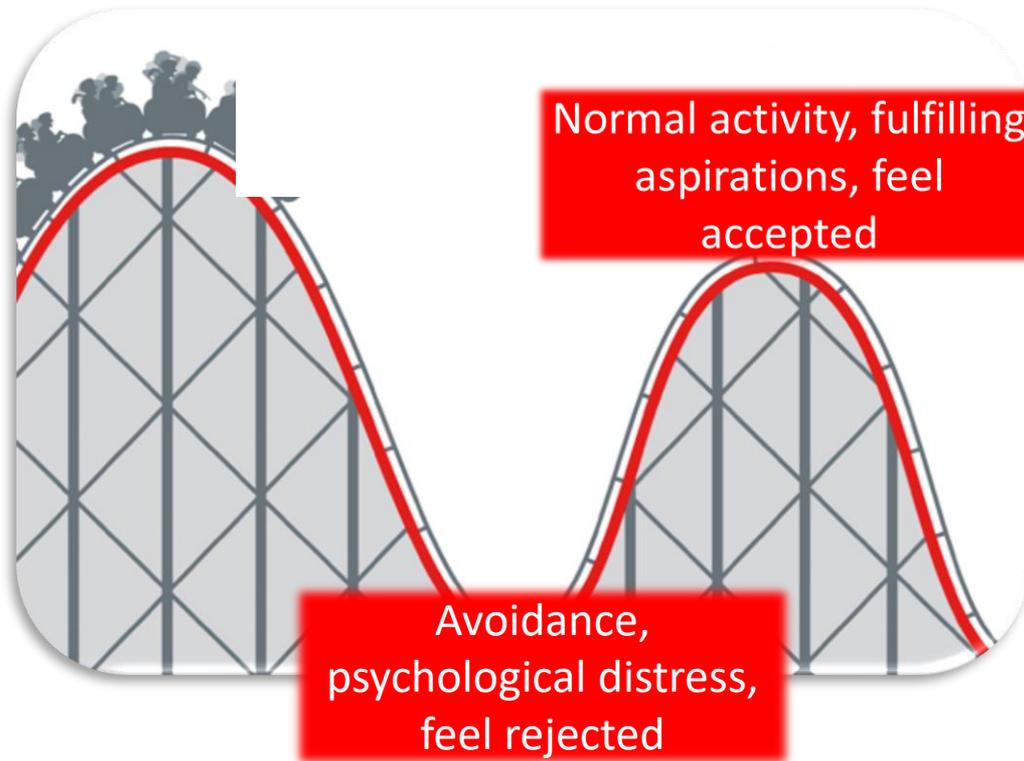
Website: carlyfindlay.com.au

Book: carlyfindlay.com.au/sayhello

Common difficulties for people who have any appearance-affecting condition

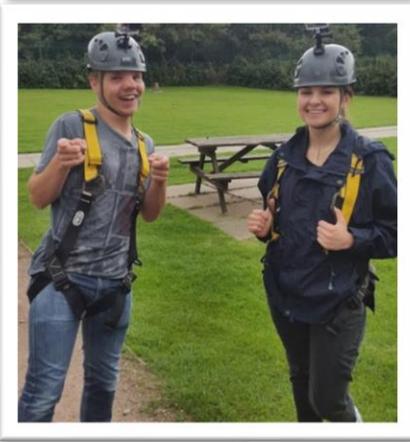
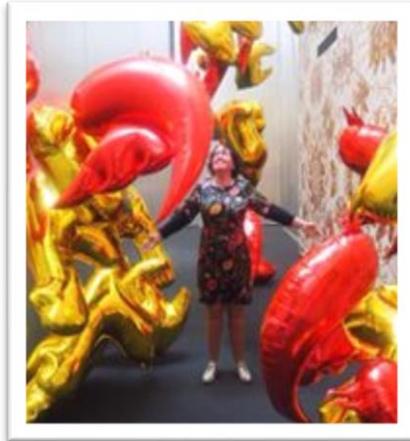
- High levels of self-consciousness.
- ***Fear*** of rejection by strangers, friends and family and fear of being judged negatively.
- Social anxiety and avoidance.
- Loss, traumatic stress, self disgust, shame, anger.

Coping fluctuates



Life events





Introducing the ACT approach

Introducing the ACT approach

- **A**cceptance and **C**ommitment **T**raining (**ACT**; Hayes et al., 1999)
- **ACT** focuses on how you **act**, so you do more that makes life good.
- Two core skills you can use to help patients:

Mindfulness:

Being aware of and open to thoughts, feelings & sensations.



Valued action:

Knowing what is important to you (your 'values'), and committing to actions that follow your values.

Why the ACT approach?

The evidence for ACT

- ACT is shown to be effective in managing difficulties common in patients with conditions that affect their appearance:
 - Long-term health conditions (Graham et al., 2016 systematic review).
 - Social anxiety (e.g. Craske et al., 2014; Niles et al., 2014).
 - Poor body image (Griffiths et al., 2018 systematic review).
- One-day ACT training for health professionals improved:
 - Evidence-based prescribing by drug & alcohol health professionals (Varra et al., 2008).
 - Health professionals' interest and confidence in using ACT with patients (Richards et al., 2011).

And from a clinician's perspective...

ACT is useful because it:

- is brief
 - You can teach patients quick and simple mindfulness and values-based skills.
- can be used with patients with **any** condition.
- doesn't try to **change** patients' difficult thoughts and feelings (which is a difficult thing to do!)
 - Instead, ACT helps patients **live with difficult thoughts and feelings** and stops them interfering with what is important in their life.
- Important:
 - 'Acceptance' in 'Acceptance and Commitment Training' does **not** mean patients need to accept everything about their situation (because perhaps they *can* change some circumstance for the better). 'Acceptance' just means accepting things that are less in their control, which include difficult thoughts and feelings.

The bus metaphor



- To help understand ACT it can be useful to think of ourselves (and patients) as bus drivers, driving the bus of our lives.
- We all have lots of disruptive passengers. The passengers represent our thoughts and feelings.
- Some of the passengers are feelings like anxiety, depression, anger and worry.
- Some passengers are thoughts, shouting things like “You’re a useless driver”, “You’re going in the wrong direction!” or other distressing thoughts.
- It is important for our health and wellbeing that we do not let our disruptive passengers dictate the direction of where we drive.
- Instead, it should be us- the bus drivers- who choose our direction.
- The right direction is determined by our values – what truly matters to us.



What do we mean by 'values'?

- Values are like a **compass**, or GPS, that we can use to direct our bus.
- They are your deepest desires for how you want to act, how you want to treat yourself, or others, or the world around you.
- Values can be said in one word, for example: loving, caring, enthusiasm, fairness, honesty.
- Or in a sentence: "I want to live with courage and kindness", or "I want to look after my health", or "I want to prioritise those I love", or "I want to develop my interests and talents as far as I can" or "I want to act with courage".



Values are NOT:

- Surface-level qualities, like attractiveness.
 - Because you cannot **act** 'with attractiveness'.
- Feelings, like happy or relaxed.
 - Because it is much easier to choose how to act than how to feel.



Your turn: Identifying your values (knowing what is important to you)

- Spend up to 10 minutes selecting your values (and/or adding your own), using the 'Knowing what is important to you' worksheet on page 2 of your workbook.
- To make it easier to relate values to your life, the worksheet is split into different 'life areas': *Relationships; Work/Education; Leisure; Health.*
- **If you can identify your own values you will be able to help patients to identify theirs.**
- Please do this exercise as a **whole person**, not just as a health professional. You do not have to share your values with other people.
- We will return to this later, and show how you can help patients put their values into real life practice, by setting goals based on their values.

VALUES: KNOWING WHAT IS IMPORTANT TO YOU

To clarify what is important to you, it can help to first choose an area of life to work on. Within each life area, a list of suggested values are given. You can also add your own.

Circle the values (or add your own) that reflect:

1. How you would like to act in your life (e.g. 'I would like to act with Courage').
2. What gives your life purpose.

Life area: Relationships (for example: with partner, children, parents, friends and relatives)	Life area: Work / Education (for example: paid work, studying, domestic duties, volunteering)
Suggested Relationship Values: Fun and humour Intimacy Genuineness Respect Gratitude Responsibility Creativity Loyalty Love Courage Wisdom Compassion	Suggested Work / Education Values: Learning Helpfulness Wisdom Loyalty Courage Self-discipline Persistence Skillfulness Creativity Adventure Ambition Open-mindedness
Your own Relationship Values: _____	Your own Work / Education Values: _____
Life area: Leisure (for example: rest and relaxation, hobbies, sport, entertainment)	Life area: Health (physical, psychological, emotional, or spiritual health and wellbeing)
Suggested Leisure Values: Fun and humour Spirituality Adventure Persistence Courage Helpfulness Skillfulness Wisdom Learning Open-mindedness Creativity Ambition	Suggested Health Values: Wisdom Spirituality Self-care Self-discipline Courage Learning Humour Open-mindedness Gratitude Ambition Persistence Compassion
Your own Leisure Values: _____	Your own Health Values: _____

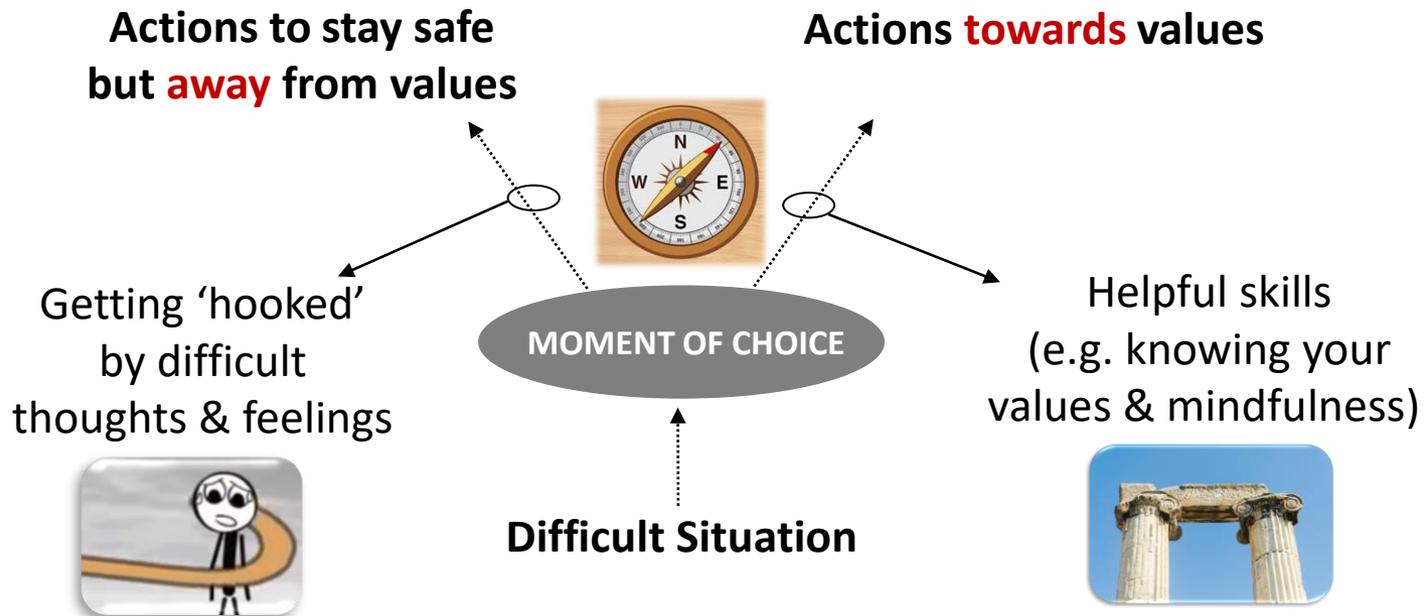
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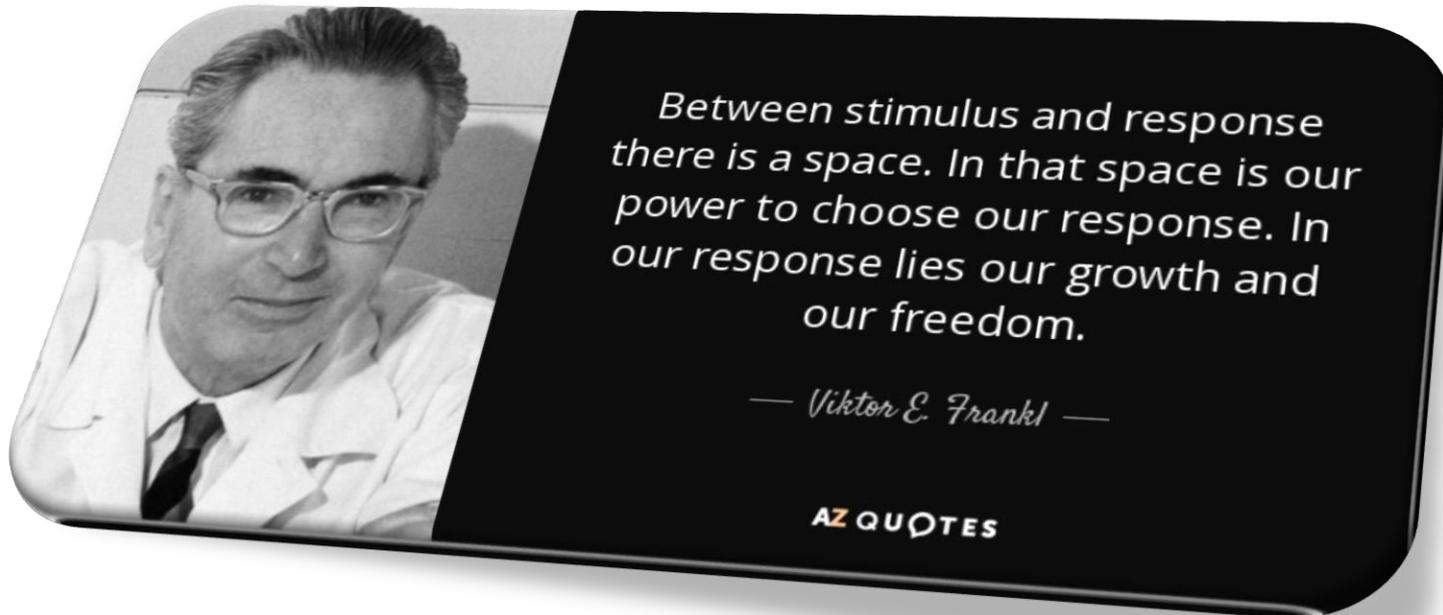
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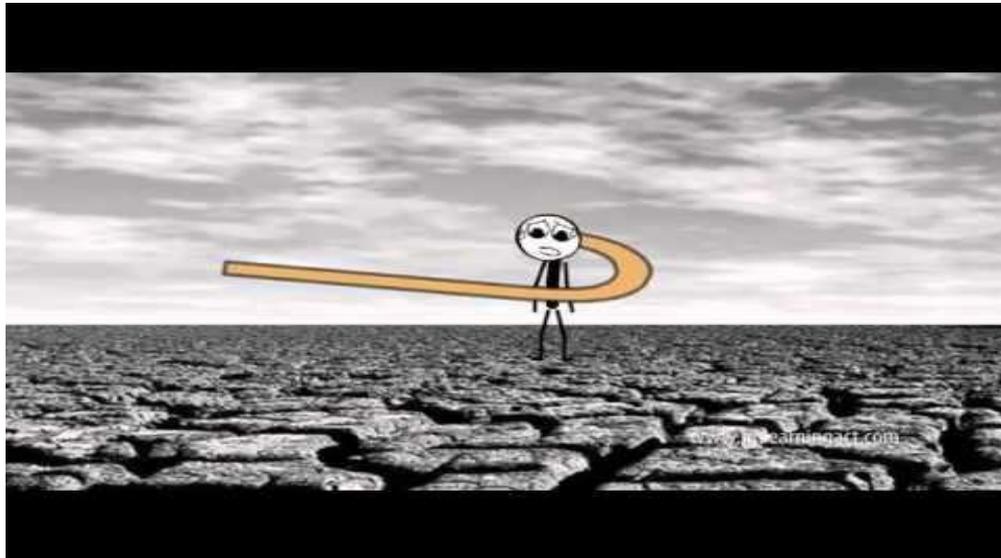
Our 'ACT Map'



The moment of choice



The moment of choice in the ACT Map: “The Choice Point”



Our 'ACT Map'

3. Actions to stay safe
but away from values

5. Actions towards values

Getting hooked by difficult
thoughts & feelings

MOMENT OF CHOICE

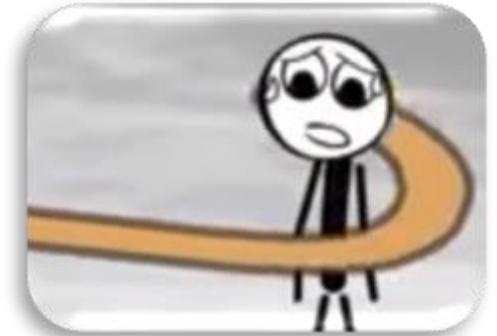
4. Helpful skills
(e.g. knowing your
values & mindfulness)

1. Difficult Situation



What do we mean by 'Getting hooked'?

- There are **two** ways in which you can get 'hooked' by difficult thoughts and feelings:
 1. **Getting caught up in difficult thoughts.**
 - Believing thoughts.
 - Taking thoughts as facts.
 - Focusing all your attention on the thoughts.
 2. **Trying to avoid or get rid of difficult thoughts and feelings (rather than accepting their presence).**
 - Trying to ignore difficult thoughts and feelings, or suppress them (push them away).
 - Trying to avoid difficult thoughts and feelings from ever showing up.
- We will cover these ways of getting hooked more throughout the training.



Teaching patients to 'un-hook'

- There are ways to take more control over our actions. To do this, **we do not need to change or get rid of these difficult thoughts and feelings.**
- Instead, ACT teaches ways of:
 - **Noticing and accepting** the thoughts / feelings , and
 - **Creating a healthy psychological distance** from them.
- These both help to '**un-hook**' from difficult thoughts and feelings, reducing their power and dominance.
- We will show you exercises in sessions 3 and 4 to teach both of these techniques to patients.



Introducing 'Actions to stay safe but away from values'

- We will look at ways that patients may avoid actions that they fear could threaten or harm them.
- We will show you how patients with conditions that affect their appearance act to stay safe in the next session after the morning break.



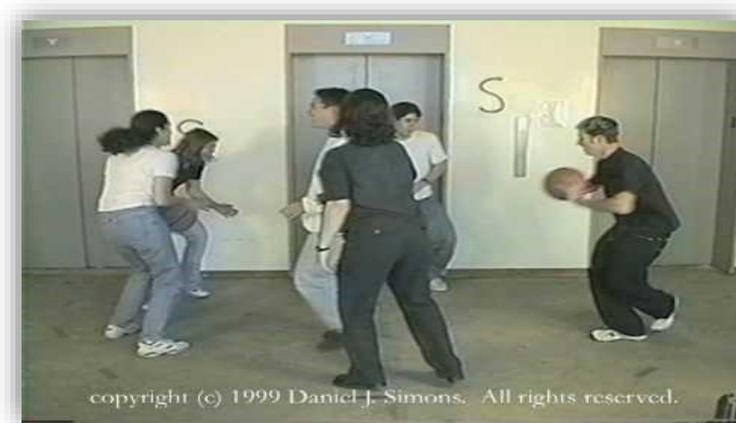


Morning Break



Session 2

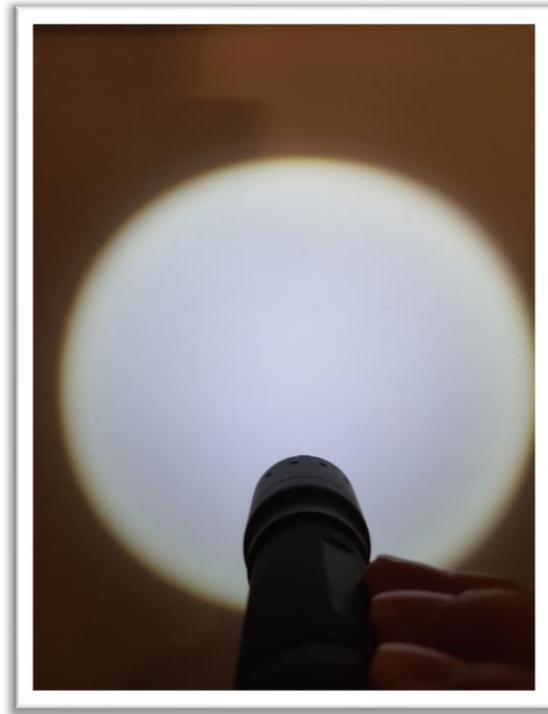
A quick attention exercise



- Hands up if you saw the gorilla?
- What was this video trying to tell us?



Fixed attention vs wide attention



Fixed attention & appearance anxiety

Evolution has built into all of us an instinct to focus our attention on perceived threats (e.g. an unusual appearance) – those who did not, got eaten by wild animals!



Fixed attention & appearance anxiety

For patients with appearance concerns, other people and their appearance may be perceived as threats because:

- Patients may worry about being judged negatively (and fear being left out of the social group).
- We naturally try to establish our position in social groups, including by our appearance.
- Patients may have experiences of being stared at and/or experiencing rude questions or comments. These memories affect our expectations of future social encounters – we expect the worse!

Fixed attention & appearance anxiety: Famous experiment involving 2 groups

Kleck & Strenta (1980)

- One group had make-up applied to imitate a port-wine stain or facial scar. They were asked to go out in public, then report any unusual behaviors by others.
 - They reported being more self-conscious and noticed more intrusive behavior from others, including staring and physical avoidance.



*Example of a
port-wine stain*

Fixed attention & appearance anxiety: Famous experiment involving 2 groups

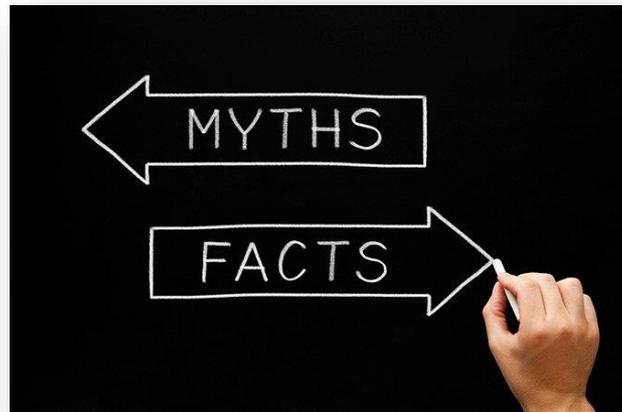
- A second group were made up in same way. But, unknown to them, a solvent rather than touch-up was applied to their face, which **removed the disfigurement**. They were asked to go out again, and report any unusual behaviors by others.
 - Despite their unremarkable appearance, participants reported the same intrusive behavior from others.
- This showed how *expectation* can influence *selective attention*:

Participants expected negative reactions, so interpreted normal behaviours as negative and related to their appearance.



*Example of a
port-wine stain*

9 myths about supporting patients with conditions that affect their appearance



Myth #1: Only patients with visible differences on their face and/or hands will struggle to cope.

Actually:

- Patients who have physical differences that are normally concealed by clothing also struggle, especially with romantic relationships and intimacy where they may have to reveal their difference (Clarke, 2012).
- Patients who have a condition that fluctuates over time (e.g. a skin condition) can also find it difficult (Moss 2005).

Myth #2: Older patients NEVER struggle with appearance concerns

Actually:

- Patients of any age can have appearance concerns (Clarke, 2012).

Myth #3: Medical intervention is the only solution to appearance concerns

Actually:

- Many patients continue to have appearance concerns even after corrective or cosmetic surgery (Di Mattei et al., 2015).
- Psycho-social interventions can be effective in improving:
 - Quality of life.
 - Appearance anxiety (Systematic reviews by Bessell & Moss, 2007; Norman & Moss, 2015).

Myth #4: Patients who have appearance concerns must be vain. They should be grateful for receiving successful medical treatment

Actually:

- Appearance concerns affect most people in high income societies.
 - Research indicates that 61 – 82% of adults are dissatisfied with their appearance (Harris & Carr, 2001; Liossi, 2003).
- Patients are typically very grateful for often life-saving treatment, but many still experience difficulties adjusting to life with scarring after acute hospital stays (e.g. in burns patients; Griffiths et al., 2019).

Myth #5: Only psychologists can help patients with their appearance concerns. There is nothing I, as a non-psychology expert, can do to help.

Actually:

- Nurses given simple training can deliver psychosocial support to patients with disfiguring disease or injury (Clarke & Cooper 2001)
- There are simple things all health professionals can do to help patients with appearance concerns.
 - And we will show you!

Myth #6: Asking patients about their appearance concerns will make things worse

Actually:

- This is a common concern for health professionals (Gee et al 2019)
- But, patients want the opportunity to talk with sensitive and empathetic health professionals
- Raising and discussing the topic of appearance can help patients feel **normal** and **understood** (Konradsen et al, 2012)

Myth #7: If patients have appearance concerns, they will tell you.

Actually:

- Patients may feel embarrassed to raise the topic, worried about seeming vain or taking up health professionals' time. (Williamson et al, 2010)
- This is why it is important for health professionals to be proactive, to normalise appearance concerns, and raise the subject themselves as if it is part of standard care.

Myth #8: I don't have time to help patients with appearance concerns.

Although most health professionals are under great time pressure, actually:

- It doesn't take long and improves outcomes.
- Happy patients won't keep coming back for more medical treatment.
- Consider the cost of not exploring concerns: for the patient, you, and your team.

<https://www.health.org.uk/sites/default/files/HelpingPeopleHelpThemselves.pdf>

Myth #9 Patients' level of distress & ability to cope is based how severe their disfigurement is

Actually:

- How noticeable patients think their disfigurement is determines distress **more** than health professionals' objective rating (Clarke et al., 2012).
- There are many research examples, including evidence that severity of facial palsy (paralysis of facial muscles) is not associated with distress (Fu et al., 2011).

Patients' level of distress & ability to cope is not necessarily related to the severity of their disfigurement

Instead, psychological well-being **is** predicted by:

- Higher levels of optimism (Clarke et al., 2012)
- Satisfaction with social support (Clarke et al., 2012)

And distress **is** predicted by:

- Getting hooked by difficult thoughts and feelings, by:
 - Trying to avoid or get rid of unpleasant thoughts and emotions, rather than accepting their presence (Zucchelli, 2019).
 - Getting caught up in thoughts, paying a lot of attention to them and believing them as facts. This is also called 'thought fusion' (Zucchelli et al. 2019).
- Preoccupation with appearance – low preoccupation is better (Clarke et al., 2012).
- Levels of fear of being negatively judged – low level is better (Clarke et al., 2012).

We cannot guess which patient will struggle just by looking at them



**Self-conscious &
struggling**

**Less self-conscious & not
struggling**

We need to find out if our patients are struggling with difficult thoughts and feelings about their appearance

How to identify patients who may be struggling:

Things they say

“I have not been going out much lately...”

“Oh, I never take my hat off...” (e.g. with alopecia)

“I am worried someone I know might see me...”

“I have no hope of being in a relationship...”

“I am not going back to work until it looks completely normal...”

“There is no point making any effort now...”

“I am fine as long as I stay at home...”

How to identify patients who may be struggling: Things they do

Making a lot of effort
to conceal the
difference.

Avoiding social
activities / work.

Worrying about the
future, feeling
anxious.

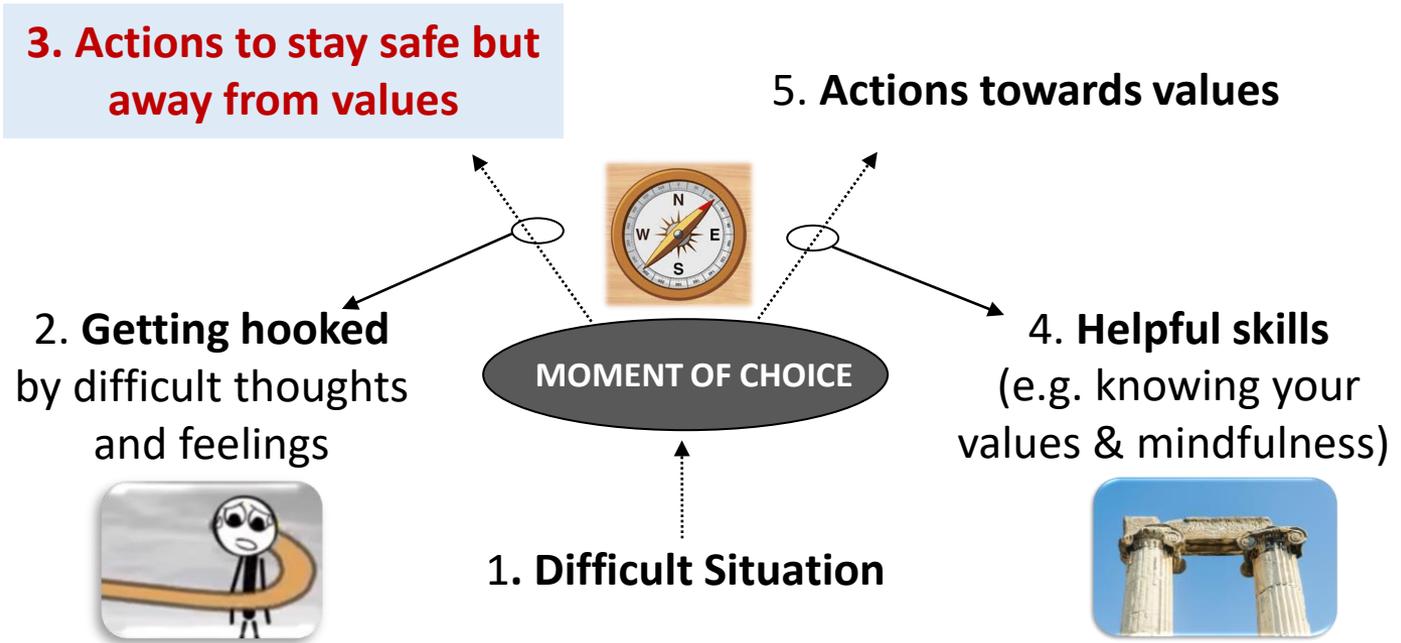
Withdrawing from
life, feeling hopeless,
having no purpose.

Attending again
and again for
further treatment.

Scratching or picking
skin or hair pulling
(e.g. skin
conditions).

- These are all examples of 'actions to stay safe but away from values'.

Our 'ACT Map'



Starting a conversation
with patients about
appearance concerns

Useful questions to introduce the topic of appearance

“How are you feeling about (the changes in) your appearance?”

“Sometimes having [patient’s condition] can make people feel self-conscious and worried about their looks. What has your experience been?”

“There is no sign of infection and everything is healing well. How do you feel about it? Have you had any questions from other people?”

“Are there any activities you have been avoiding because of your feelings about how you look?”

“Some patients say that other people give them a difficult time because of their looks, like being teased or called names. What has your experience been?”

Training video: Starting a conversation about appearance with Mary

Please embed 'Starting a conversation' video here

What to say....

Do:

- ▶ Reassure patient that concern about appearance is normal.
- ▶ If they say it is difficult / stressful, repeat it back to them calmly so they feel heard.
- ▶ Explain that psychological adjustment can take longer than physical healing.
- ▶ Ask if there are specific issues that they find difficult.
- ▶ Offer the chance to talk to you or a colleague.
- ▶ Show you are willing to help.

Don't:

- ▶ Suggest they are making a big issue about nothing (they will not feel normal).
- ▶ Say that they look fine to you (they will not feel heard).
- ▶ Tell them there are many people who have 'worse' disfigurements.
- ▶ Say they are lucky or should be grateful that the treatment has worked.
- ▶ Tell them there is nothing else anyone can do.

Starting a conversation about appearance with a patient

Your turn!

15 minute practice

In groups of three:

Person 1: Patient: Use your own personal experience, or draw from your clinical experience. You can also use the ideas given on **page 4** of your workbook.

Person 2: Health professional

Person 3: Coach for health professional: Please help health professional if / when they feel stuck

- Take it in turns.
- Then feed back one observation from the exercise to the whole group.

Points to consider when having these conversations with patients

- **Seek informed consent** before trying any exercise (which we will show you in sessions 3 & 4):
 - For example “Would you be willing to try a short mindfulness exercise?”
- **Timing:**
 - It may be best to have conversations about appearance after rather than during an acute treatment phase (e.g. after a burn injury).
 - BUT, be willing to discuss concerns before planned treatment that will alter appearance (e.g. chemotherapy, mastectomy, orthognathic surgery).
- **Where possible, continue the conversation** so it is an ongoing discussion, rather than one-off intervention.
 - Things may change for the patient, or they may be more or less willing to talk about their appearance concerns.
- **Be kind to yourself:**
 - You do not need to have all the answers.
 - Remember you are just a human trying to learn about the patient’s experience

Points to consider when having these conversations with patients

If patients display distress:

- Remain calm
 - This helps patients feel that **it is OK to show distress**, and that you are able to cope with their discomfort.
- Talk about distress as being **normal** and OK in response to difficult life events.
 - This shows **openness to unpleasant internal experiences**, which is one of the Helpful skills (part of mindfulness).
- Use simple mindfulness techniques with patients to manage distress.
 - We will show these mindfulness techniques after the break in the 4th session.

Using the ACT Map with patients

Case example #1

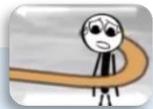
John

- 25 years-old
- Born with a cleft lip and palate that has been repaired.
- Attending a dental appointment.
- Works as an administrative assistant in a small printing office, which he finds very boring, but he feels safe because he knows and trusts his colleagues. He would love to study graphic design at university but has not yet applied, as he is worried about being around so many new people, and being rejected by his peers. He gets very caught up with these worries, and thinks they reflect the absolute truth of what would happen if he went to university.
- Would like to have a girlfriend but gets very anxious interacting with women, and when he does meet someone he likes romantically, he does not have the confidence to ask them out on a date. He hates feeling anxious around women, so tries to avoid situations where he will meet women. And when he is in such situations, he often leaves early to get rid of anxiety. He thinks that no women will be interested in dating him.

John's ACT Map

Actions to stay safe but **away** from values

1. Staying in a boring job.
2. Not applying for graphic design course.
3. Avoiding romantic advances.



Getting hooked

by difficult thoughts & feelings

1. Getting caught up in worries about being rejected by people if he went to university.
2. Trying to avoid and get rid of anxiety when around women.
3. Getting caught up in the thought: "No woman will be interested in dating me".



MOMENT OF CHOICE

Difficult Situations

1. Being around women.
2. Going to a boring job.

Actions towards values

Helpful skills

Case example #2

Mary

- 50 years-old.
- Six months ago underwent cardiac surgery for life-threatening condition. This was traumatic for Mary, as it involved spending time in the intensive care unit. The surgery caused visible scarring along sternum.
- Attending a routine check-up.
- Loved swimming with granddaughter. A few months after surgery, when she went with her granddaughter, she thought that people were staring at her scarring at the pool. She felt embarrassed, and now spends a lot of time and energy worrying that people think she looks “damaged” and “unfeminine”. She has always taken great care over her appearance, and now often compares herself unfavourably to other women of a similar age she passes on the street. Since that one experience she has not been swimming with her granddaughter again, because she hated feeling embarrassed. She tells her granddaughter she cannot go because of her heart.
- Mary has also started to cover her scar with clothes (even when it’s very hot) out of her strongly held belief that people may notice it and negatively judge her appearance, which she couldn’t bear.
- Mary attends hospital with her daughter, but asks her daughter to stay in the waiting room when she is called for her appointment. When the cardiologist / cardiac nurse asks to look at the scar, Mary asks why and is very reluctant to show it. Mary also moves her chair away from a mirror.

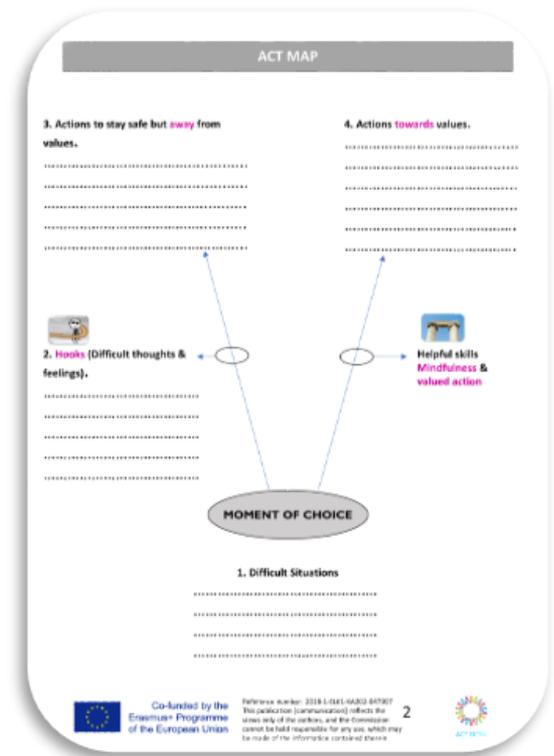
Using the ACT Map with Mary

Your turn!

15 minute practice

Using the ACT Map on page 6 of your workbook, in small groups:

1. Describe her difficult situation(s).
2. Identify how she 'Gets hooked by difficult thoughts and feelings. These are her reasons for staying safe.
3. Identify any behaviours that keep her safe but away from her values. This is what is important to her.



Mary's ACT Map

Actions to stay safe but **away** from values

1. Covers her neck, even when uncomfortable.
2. Avoids her reflection.
3. Conceals her scarring from her daughter.
4. Avoids swimming with her granddaughter



Getting hooked

by difficult thoughts & feelings

1. Getting caught up in thoughts like "I am damaged and "I am unfeminine".
2. Trying to avoid embarrassment.
3. Getting caught up in comparing her appearance to other people.
4. A desire to avoid feeling negatively judged by other people.



MOMENT OF CHOICE

Difficult Situations

1. Showing her scar to people.
2. Being around her reflection.

Actions towards values

Helpful skills

Other ways patients *ACT* to stay safe

- Wearing loose fitting clothes, scarves, hats (in warm weather), glasses, growing hair long & using it to hide face.
- Excessive use of make-up.
- Avoiding:
 - Eye-contact
 - Smiling
 - Photos
 - Socialising
 - Intimacy
- Holding head at certain angle (showing side only) or body in certain posture (leaning forward).

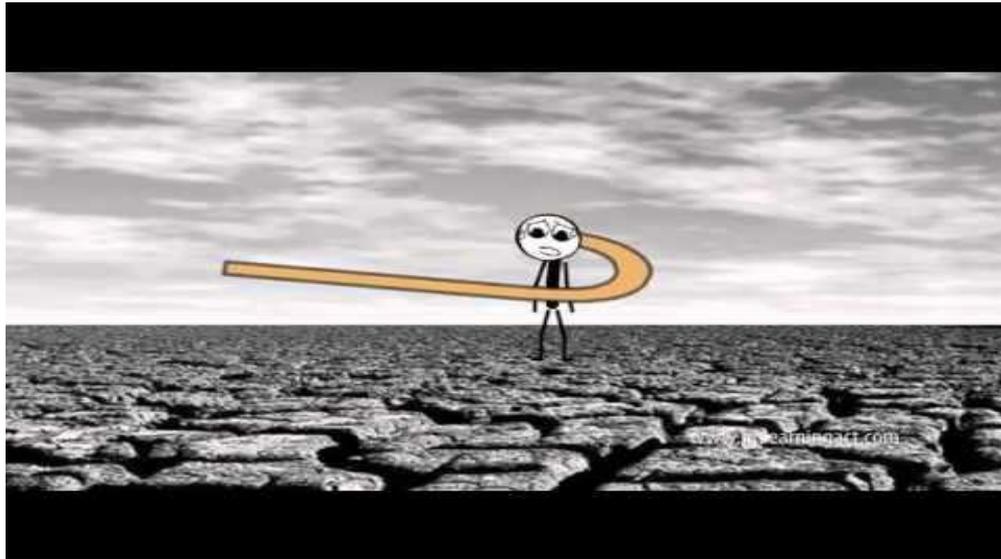


Lunch break

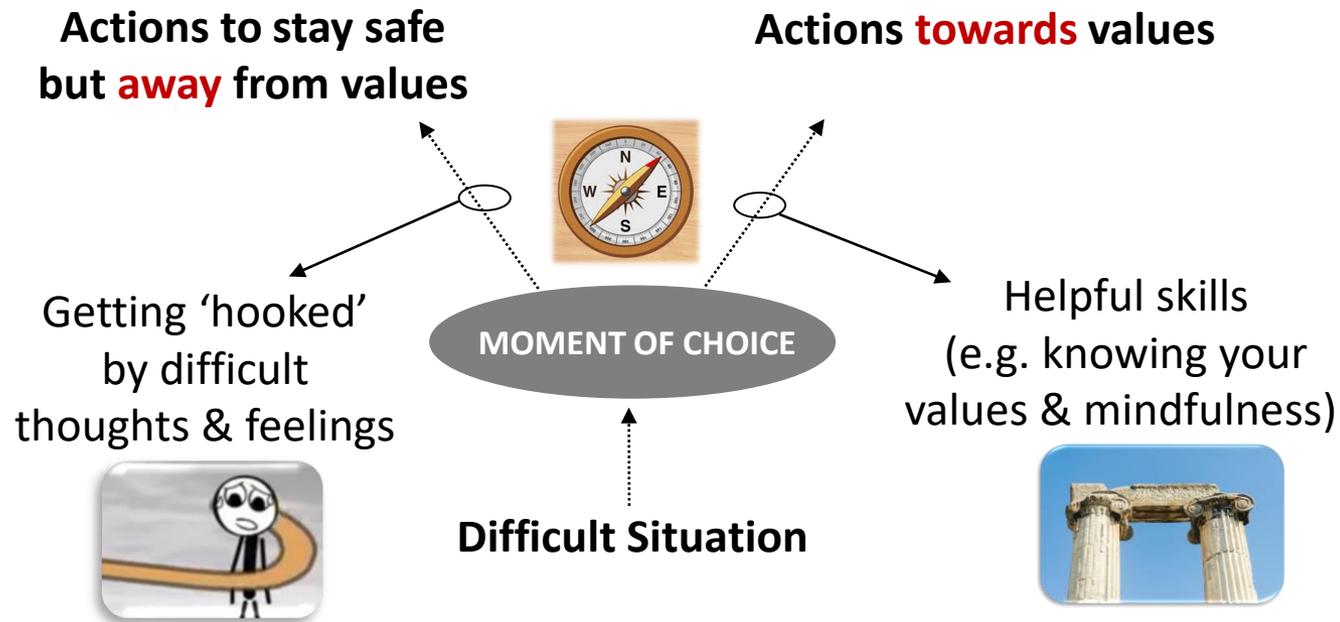


Session 3

Let's remember "The Choice Point"



Our 'ACT Map'



Training video: Using the Act Map with Mary

Please embed 'Using the ACT Map' video here

Using the ACT Map with patients

Your turn! 25 minute practice

In groups of three, practice for 10 minutes using the ACT Map to help a patient:

Person 1: Patient

- You can use your own personal experience, or draw from clinical experience. You can also use the examples on **page 7** of your workbook.

Person 2: Health professional

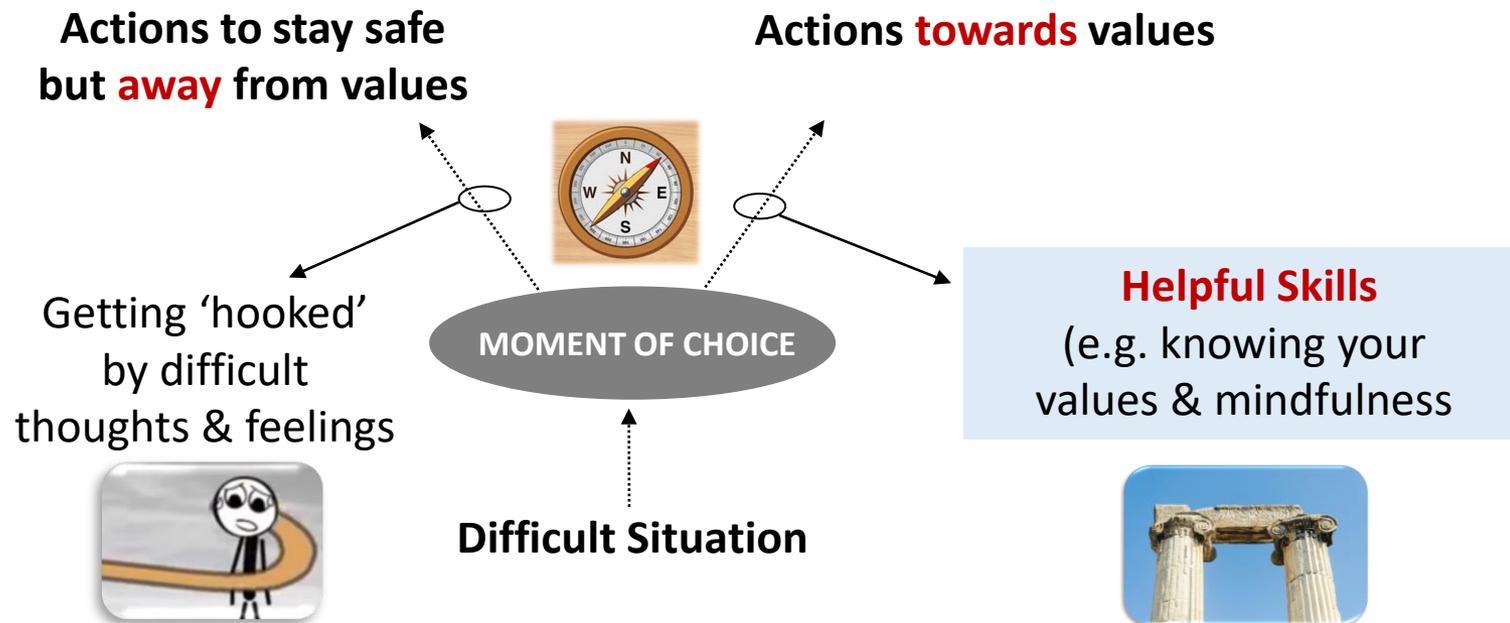
- You can use the example questions on the ACT Map on **page 8** of your workbook.
- You are just using the ACT Map to help a patient understand why they are acting away from their values: **You do not have to introduce the Helpful Skills yet.**

Person 3: Coach for health professional

- You can take notes, and offer ideas to the health professional if they feel stuck.
- Try doing two rounds, switching roles in the second practice.
- If you are concerned about doing the role play, you could act as the Coach first.
- Then feed back one observation from the exercise to the whole group.

Helping patients act
towards their values using
two Helpful Skills

Our 'ACT Map'



Let's remember the two Helpful Skills

Mindfulness:

Being aware of and open to thoughts, feelings & sensations.



Valued action:

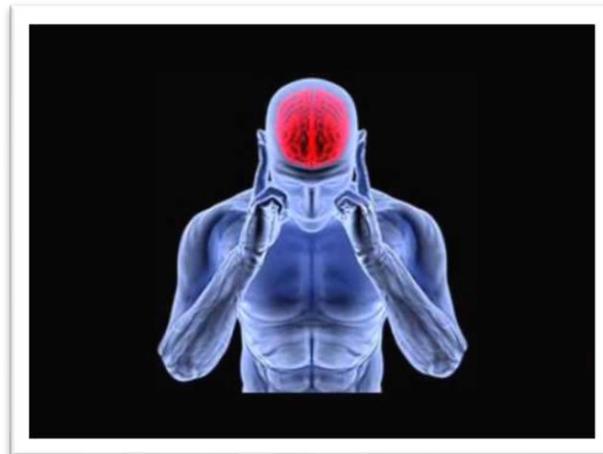
Knowing what is important to you ('values'), and committing to actions that follow your values.

What is Mindfulness?

According to Scott Bishop and colleagues (2004), there are two parts to mindfulness:

Part 1:

Paying **attention** on **purpose** to your **present experience**



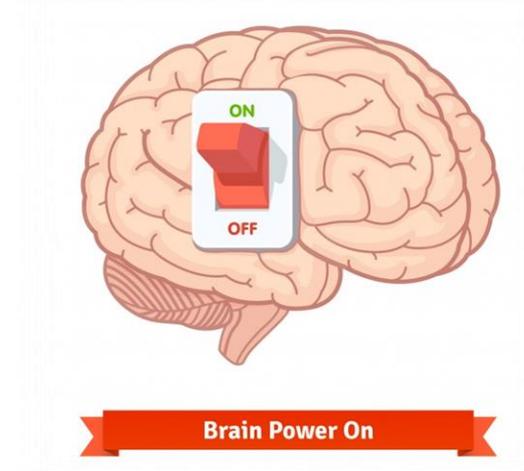
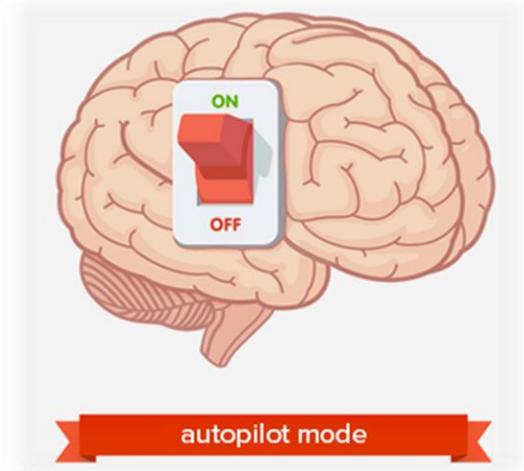
Mindfulness part 1: Paying attention on purpose

Your turn! *5 minute practice*

In pairs, tell your partner:

- 2 things you do in 'auto-pilot' (without paying attention).
- 2 things you do paying attention on purpose to your present experience.

What are the differences between these experiences?



What is Mindfulness?

Part 2:

Paying attention in a curious, open and **accepting** way.



Without this attitude of **acceptance** towards your present experience (including difficult thoughts and feelings), it is just attention training. This is not mindfulness.

Attention without acceptance

- It is possible to pay attention to your present experience and notice difficult thoughts and/or feelings (part 1 of mindfulness), but instead of accepting the experience (part 2), instead try to **push the thoughts and feelings away**.
 - In people who have conditions that affect their appearance, this tendency to try to push thoughts and feelings away is associated with distress and taking actions to stay safe but away from their values (Zucchelli et al., 2019).
- Imagine a **beach ball** filled with distressing thoughts and feelings. The tendency to try to push away thoughts and feelings is a like trying to push the beach ball under water to get rid of it. The ball will actually just keep popping up in front of your face with its distressing thoughts and feelings. Even if you manage to hold the ball underwater for some time, eventually you will get tired and it will just pop back up.
- Instead, you can take an **accepting attitude** towards the ball, and hold it gently above the water, not intruding, just letting it be.
- This is what the '**Acceptance**' means in '**Acceptance** and Commitment Training'.

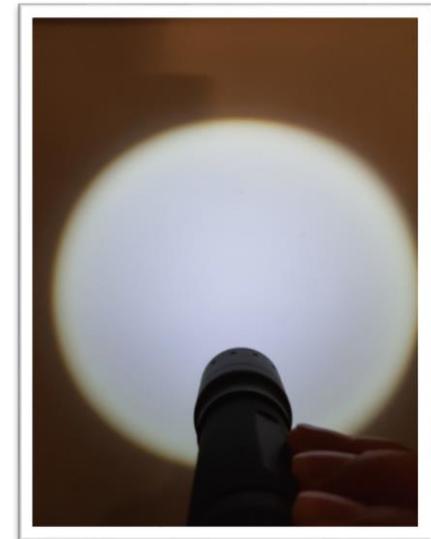


Why mindfulness?

1. **Easy and quick** mindfulness techniques can be learnt and applied.
 - Patients can use the techniques in **any** situation, as mindfulness simply involves paying attention to what is happening in any moment (good, bad, or neutral).
2. Mindfulness is focused on the **present moment**.
 - Patients often (a) worry about the future (e.g. how people may respond to their appearance) and (b) re-live past events (e.g. memories about medical treatment, or people staring at them).
3. There is **strong evidence** that mindfulness improves **health**:
 - Mindfulness helps anxiety, depression and stress (Goldberg et al., 2018; Khoury et al., 2013).
 - Large companies (e.g. Google, Amazon) are teaching mindfulness to their employees.
4. Mindfulness is **free**!
 - Patients can leave your appointment and do it anytime at no cost.

Why mindfulness?

5. Mindfulness helps us “**un-hook**” from distressing thoughts & feelings that can pull us away from doing what matters to us.
 - Mindfulness helps create a healthy psychological distance from distressing thoughts & feelings.
6. It helps **widen our attention** beyond perceived threats.
 - Mindfulness training activates the para-sympathetic (‘soothing’) nervous system (e.g. Murakami et al., 2015).
 - This means that patients have a wider, softer attention to things going on around them.



How to develop mindfulness

You and your patients can:

- Do **structured**, planned meditations.
 - E.g. Sitting with eyes closed in a quiet place, pay attention to sensations of the breath for a set period of time (e.g. 10-20 minutes).
- Bring mindful awareness to **routine daily activities**.
 - E.g. When brushing your teeth or preparing food, pay attention to sensations and sounds.
- Regularly '**check in**' with your senses, especially during **difficult** situations.
 - E.g. When feeling stressed or anxious, notice sensations in your body, and feel your whole body breathing. This can help you 'slow down'. Slowing down will help make the 'Moment of Choice' in our ACT Map grow bigger and give more freedom to make a wise, valued choice.

How to develop mindfulness

Think of mindfulness as a **muscle of the mind**. Like a muscle in your body, the more you exercise it, the stronger it gets.

- Structured mindfulness practice is like going to the gym.
- Doing routine activities mindfully is like doing physical activity, e.g. gardening.
- 'Checking in' during difficult situations is like running for a bus (so when you really need to use your muscles).



Training Video: Mindfulness practice #1 Mindful Breathing

Please embed 'Mindful breathing' video here

Mindful breathing

Your turn! *10 minute practice*



Training Video: Patient's feedback on Mindful Breathing

Please embed 'Patient feedback on Mindful breathing' video here

Your feedback on the Mindful Breathing practice

- What was the mindful breathing exercise like for you?
- What thoughts and emotions did you notice?
- If any difficult thoughts and emotions came up, how did you react to these?

Adapting the Mindful Breathing practice for some patients

The mindful breathing exercise may not be suitable for all patients, for example:

- Some patients with **physical disabilities**. You could instead suggest they:
 - Follow their breath through sensations just in their (a) nose, (b) chest and/or (c) abdomen, or (d) their whole body.
 - Mindfully listen to sounds (with eyes close), observing sounds coming and going, as if they were a microphone.
- Patients with a history of **psychological trauma** or **breathing problems**. Instead, they could:
 - Mindfully listen to sounds.
- For people with **tinnitus** or any **hearing problems**, mindfulness of sounds can be distressing so mindful breathing may be better.

Afternoon break



Session 4

Mindfulness practice #2: Thought 'de-fusion'

- **Thought de-fusion** is a specific aspect of mindfulness, that helps patients create a **healthy psychological distance** from difficult thoughts.
- Examples of unpleasant thoughts from patients with appearance-affecting conditions include:

"I'm a freak"

"My arm is a complete mess"

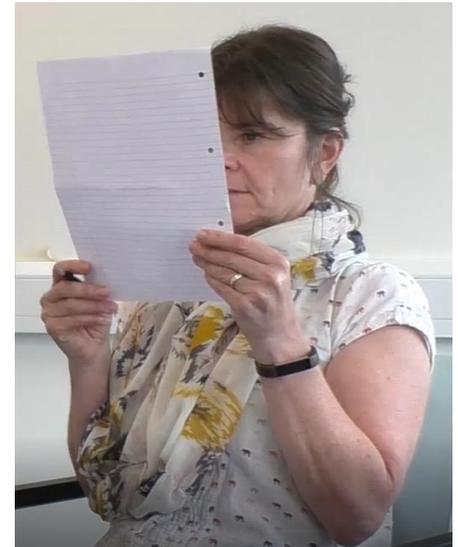
"My stomach is disgusting"

"I'll never be able to have a relationship again"

"I'm ugly"

Mindfulness practice #2: Thought 'de-fusion'

- In people with conditions that affect their appearance, the tendency to get caught up with, or 'fused', with difficult thoughts is associated with distress and taking actions to stay safe but away from their values (Zucchelli et al., 2019).
- Imagine one of your difficult thoughts is written on a **sheet of paper**. Getting caught up with the thought is like holding the paper right up against your face. The thought takes up most of your view, and it is very difficult to see anything else in front of you, including the people and other things that are important to you. **Your attention is caught up with the thought.**
- Thought de-fusion is a way of creating healthy distance from difficult thoughts, so you are less caught up in them and have a clearer view.
 - **It does NOT involve trying to change the thoughts, or argue with the thoughts.**
 - Thoughts de-fusion involves just noticing the thoughts and viewing them in a clearer, more detached way.



Training Video: Thought De-fusion exercise

Please embed 'Thought de-fusion' video here

Thought De-fusion exercise

Your turn! 15 minute practice

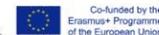
- In pairs, take turns to act as:
 - Health professional
 - Go through the thought de-fusion exercise, using the instructions on page 10 of your workbook.
 - You will also need a sheet of paper and pen.
 - Patient
 - Use a thought that **really** does come up for you. This will make the exercise more real and effective.
 - For this exercise, your thought **does not have to be about appearance**.
 - You do not have to share your thought with the health professional if you do not want to.
- You can also practice the adapted version of the exercise for patients with **literacy difficulties**.
 - This version involves holding up a sheet of paper to represent the thought, without the patient needing to write on the paper.

THOUGHT DE-FUSION EXERCISE

1. Ask patient if they would be interested in trying a technique which can give their difficult thoughts about appearance less influence over their actions. This is a technique they can use in any situation. And explain they can stop at any point if they do not want to continue for any reason.
2. If patient agrees to try technique, give patient a paper and pen. Ask patient to draw a horizontal line in the middle of the page. Then ask them to try to bring to mind a thought they have about their appearance that they have been noticing recently. It may be best not to choose a thought that is highly distressing, and instead choose a thought that is about 5 out of 10 for how distressing it is. Ask the patient to write down the thought on the line.
3. Now, ask the patient to hold the paper close up to their face, and read the thought as if it was a fact. [wait 5 seconds]. Ask patient how it makes them feel, in their mind and in your body?
4. [Acknowledge the patient's feelings] Continuing to hold the paper where it is, ask the patient to imagine that the people and activities they care about are directly in front of them, about a metre ahead. Ask if they can see those things, with the thought so close to their face.
5. Explain how being so close to their distressing thought is also getting in the way of the things they care about.
6. Explain to patient that one very understandable way to try and deal with the distressing thoughts is to try to push them away. To show what this is like, ask them to push the paper out in front of them, with your arms stretched out straight. [wait 5-10 seconds]. Ask the patient how their arms feel, and whether they can see the things they care about directly in front of them (a metre ahead)?
7. Now ask the patient to rest their arms and place the paper on their lap (or table). For the next step of the exercise, ask them to write the words in front of their thought: "I'm noticing the thought that". You can also ask them to draw a speech bubble around the phrase. Ask them to take a few seconds to read it, and notice how it makes them feel in their body and mind [wait 5-10 seconds]. Ask if there is any difference in how it feels now compared to before, and how easy is it to see the people and activities that you care about now.
8. Explain that this exercise shows us is that sometimes just by reminding ourselves that these are thoughts, and not necessarily facts, it gives us some healthy psychological distance from the thoughts. And this also allows us to use less energy in trying to push away the distressing thoughts.
9. Explain to patient that in any situation, when they notice a distressing thought, they can just say in their mind "I'm having the thought that..."

For patients with literacy difficulties

- You can ask the patient to say the thought out loud, rather than writing it on the paper.
- You can still use the paper, and ask them to imagine that their thought is on the paper. This way, you can still ask them whether they can see the things they care about in front of them, and to hold their arms stretched out.



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10



Core skill #2: Valued action

- Valued action has two parts:
 - Part 1 is knowing what matters to you ('values').
 - Part 2 is taking **actions** that follow your values.

There is evidence that valued action helps people with appearance-altering conditions:

- Burns patients who were clear about their values and committed to doing things that fitted their values were less distressed than those who were not clear or committed (Shepherd et al., 2018).

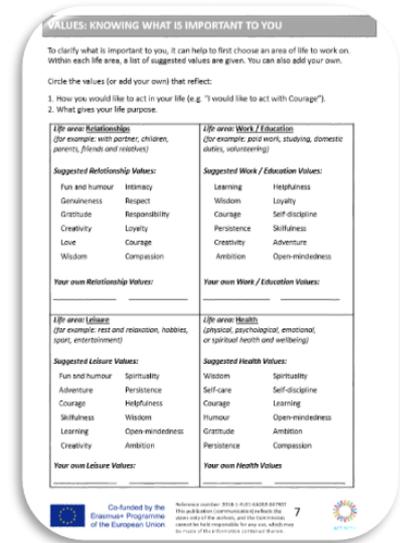
As you learned earlier, values refer to how you would like to act in daily life: e.g. "I would like to act with **Courage**".

- Values are like a **compass** that directs our actions.

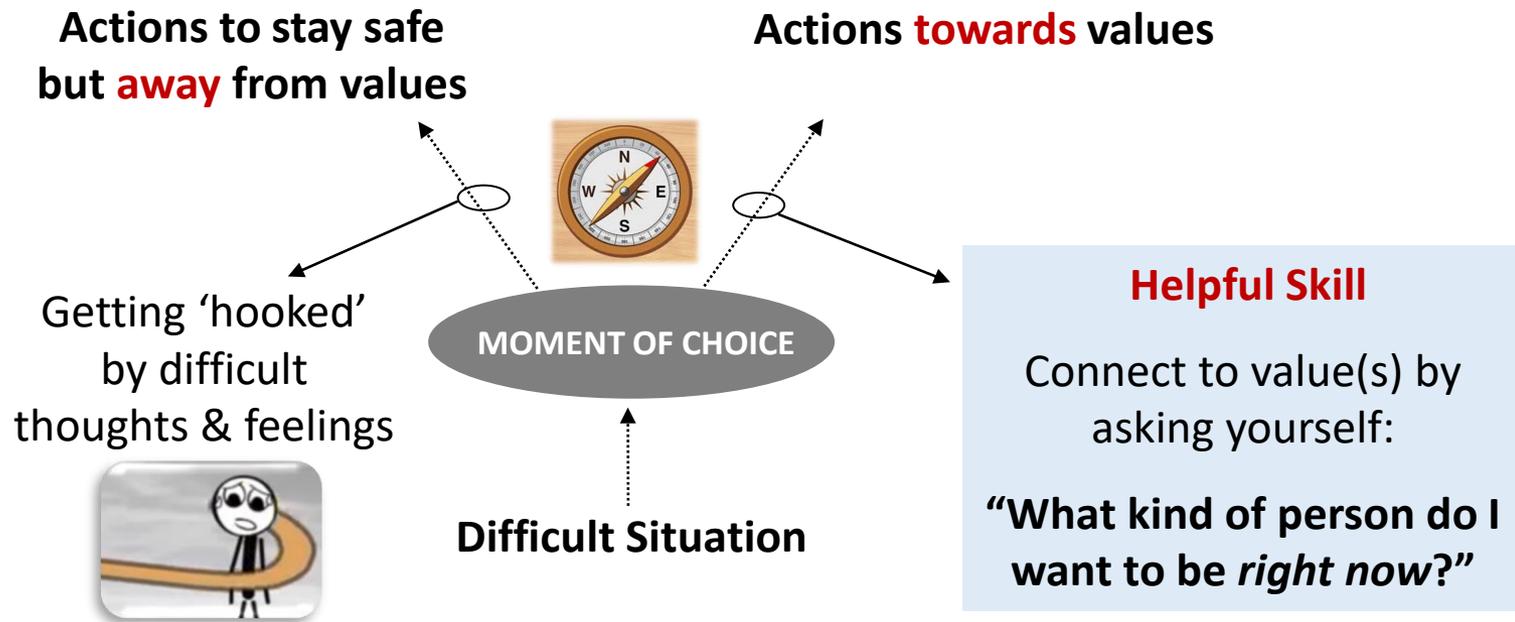


Helping your patients identify their values

- Earlier you identified your values- what is important to you.
- You can also use this worksheet with your patients.
- It will help your patients find the **motivation** and **direction** to choose actions that might be challenging, but will lead to a more meaningful and fulfilling life.
- Patients can use values in **two ways**:
 - **In any difficult situation**, at the ‘Moment of Choice’ of the ACT Map, by asking themselves: “What kind of person do I want to be right now?”
 - For example, a patient with burn scarring on her face notices unwelcome attention from other people while eating at a restaurant with her friend. She wants to leave immediately without finishing her meal, but asks herself “What kind of person do I want to be right now?”, and decides she wants to be a friend. So she switches attention to what her friend is saying, and finishes her meal.
 - **When making plans**, setting goals or considering decisions (we will show this in the next exercise).



The 1st way to use values: In any situation, at the Moment of Choice



The 2nd way to use values: Making Plans

Training video: A simple values-based goal

Please embed 'Setting a simple goal' video here

HOW VALUES AND GOALS WORK TOGETHER

- Values and goals are different, but work together.
- Values **direct** goals.

Values are a compass



Goals are **places** that you choose to go on your route.



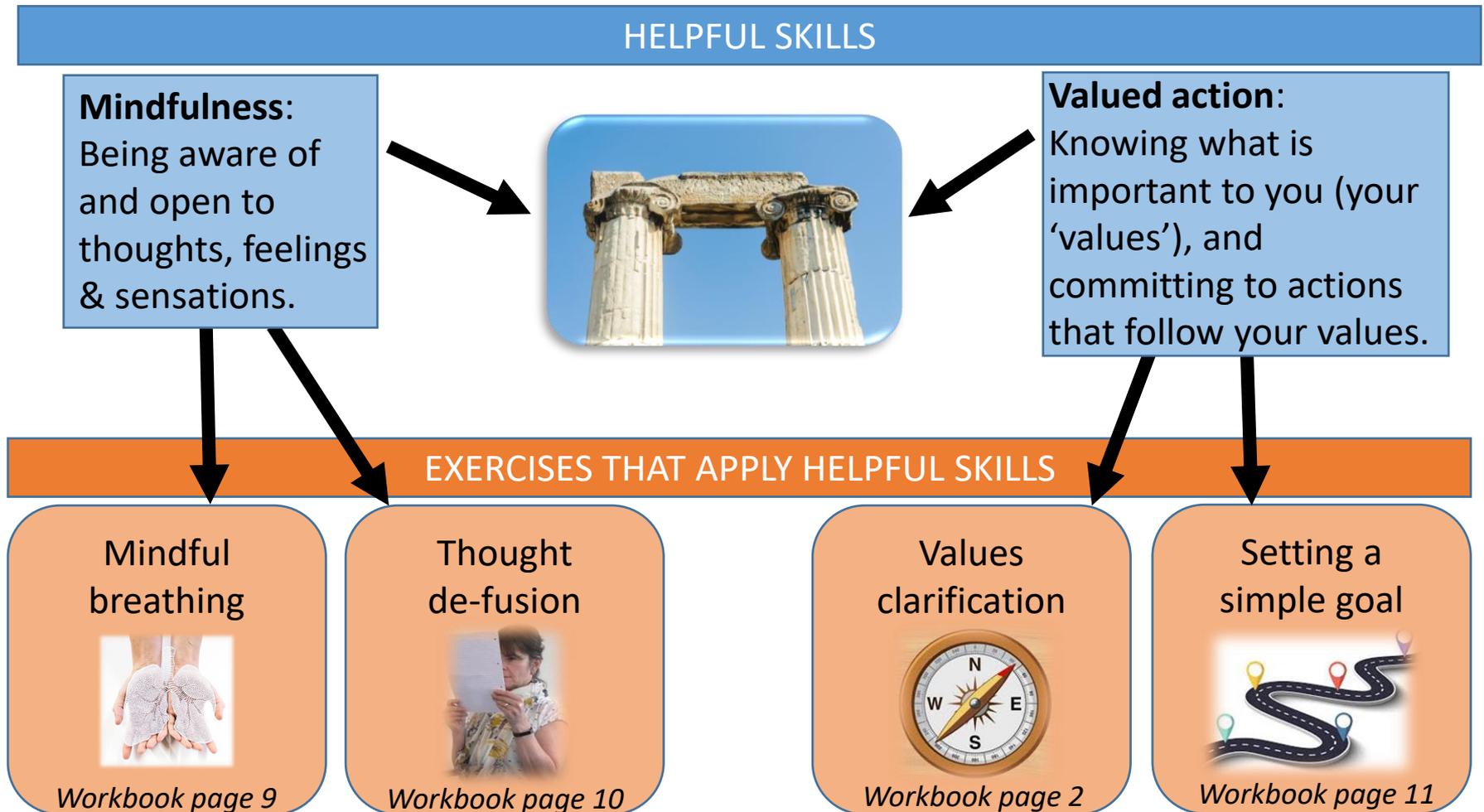
- For example, the patient in the video has a value of being close to her granddaughter. This value directs her goal of reading to her granddaughter.

Setting a values-based goal

Your turn! 10 minute practice

- Spend up to 10 minutes setting a values-based goal using the ‘Setting a values-based goal’ worksheet on page 11 of your workbook. You can use the value(s) you chose earlier in the ‘Knowing what is important to you’ worksheet on page 2.
- Try to chose something **real** for you. It does not have to be about appearance. It could be in any of the four life areas.
- You do not have to set a goal in area of life that is very difficult for you – just something you would like to work on.
- You can help patients set a values-based goal, either by talking it through with them (if you have the time), or giving them the worksheet.
- If you feel comfortable, you can share your goal with the group.

A summary of how to apply the Helpful Skills with patients



Extra skills: Dealing with negative reactions

Guidance is given in patients' resource

MANAGING OTHERS – PATIENT HANDOUT

Posture

Most of us don't think about our posture, but it's an important part of how we communicate. Our posture refers to the way we hold our body and gives other people clues as to how anxious or confident we are. Standing or sitting with your shoulders back and your head up gives a strong message that you're confident, even if you don't feel it. If you look confident, people are more likely to respond to you positively. If you stand with your shoulders bent forwards and your head looking down at the floor, people will know that you don't feel comfortable. This will make others feel uncomfortable too - and they're less likely to engage with you.

Task. Think about how you're sitting and try to straighten your back and keep your shoulders down. Make an effort to practice this position at least once a day. When you're walking around in the next few weeks try looking up instead of at your feet, with your shoulders back. This should help you to look and feel more confident. Ask family and friends to walk with you to improve your posture.

Gestures

Our gestures - the little movements of our hands and head - aren't always very obvious, but they tell us a lot about a person.

Nodding your head whilst someone is talking to you is just as important as keeping up eye contact. It shows that you're interested and that you understand what they are saying.

Hand gestures. Moving your hands about to make a point shows confidence. Standing with your hands in your pockets can make you appear anxious or even bored. It's important to use hand gestures because they show energy and enthusiasm for the topic you're talking about. This can be particularly useful if your difference makes facial expressions difficult.

If your hands are not affected, shake hands with people, even if they don't initiate the interaction. Look them in the eye and smile. This will show that you're confident and comfortable with your appearance. If you're unable to shake hands nod, use eye contact, smile, say hello and explain that you have a condition that prevents you from shaking hands.

Making the most of your appearance

A common response to an altered appearance is to think that it's new not worth bothering with other aspects of your appearance. But, people do make assumptions based on appearance. Good grooming and good personal hygiene are often considered a sign of being organised and efficient and can help us fit into our peer groups. It can help to have your hair cut or styled regularly, dress in a way that is appropriate for your lifestyle and look tidy and clean. Women especially find it difficult to put themselves first and look after their own self-care needs. **Task.** Take some time to consider ways in which you might be able to focus on self-care activities.

However, sometimes clothes or make-up designed to disguise a feature can have the opposite effect. Bearded hats and hoodies may be particularly unhelpful in certain contexts as some societies associate them with aggressive behaviour and people can easily look threatening, especially if wearing them is associated with poor eye contact. Similarly, wearing very large jackets in the summer draws attention to people rather than disguising problems, and unadvised use of camouflage patterns can make facial changes more obvious.

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11

MANAGING OTHERS – PATIENT HANDOUT

Verbal skills

Tone of voice

Have you ever had a conversation with someone where you picked up more about how they were feeling from their tone than from what they actually said? Your tone of voice tells people a lot about your thoughts and feelings. Probably the most important thing to remember is that your voice gives away emotion. If your tone of voice is aggressive or depressed, then you're going to put people off. If you sound too nervous, people will feel uncomfortable.

Tone of voice can easily make or break a situation. If you're feeling anxious, aggressive, depressed, or even bored, your tone of voice can give this away. Many people often don't realise they're using a flat voice, but just by thinking about the way you talk, you can make sure that you use more variety. If you do use a flat tone it sounds boring and suggests that you aren't that interested in them or that you aren't that interesting! It increases the chances that others will switch off when listening to you.

Task. Spend a couple of minutes now saying the following sentence out loud in different tones: for example in a happy, sad and angry tone. "Hi, how's it going? I'm having a great day!"

1. Can you tell the difference?
2. Listen to the way that other people around you talk.
3. What do different tones tell you about the way someone is feeling?

Slow down your voice

Another important part of voice control is speed. If you're feeling anxious or annoyed, it's easy to talk more quickly and your voice may also shake. People find it difficult to understand if you're speaking quickly. It's important to remember to slow down. This makes your speech clearer and gives the other person a chance to take in what you're saying. Even if you don't feel very confident, sounding as though you are can make you feel better and will result in others reacting more positively towards you.

Speak clearly

Remember to speak clearly. If you speak too quietly, people will find it hard to hear you and will lose interest in what you are trying to say. BUT, avoid shouting! There is nothing more irritating than someone who is shouting at you when they are standing right next to you. With practice you'll be able to get the right volume, which will help you to speak more clearly.

Active listening

Active listening is about hearing what someone says and showing that you've understood them. It's a good skill to encourage conversation and to show that you're confident. Skills that can be used to show active listening include agreeing, commenting and repeating back. Let's explain those.

Agreeing

Saying "yes" or "umm" "uh huh" whilst someone is talking to you shows that you're listening

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12

What you have learned today: 10 minute task

Group activity

- Identify 3 things that you know now that you did not know before the training.
- What are 3 things you will do in practice as a result of the training?

Personal activity

- Identify something(s) that you would like to find out more about.
 - *What will be your first action(s) in doing this?*

Key learning points from today

Today you have learned that:

1. It is worth starting a conversation about appearance with patients who have an appearance-affecting condition.
2. Not all patients are distressed by their appearance.
3. Communication skills help start a conversation with patients.
4. The ACT Map can be used to guide you when discussing appearance with patients.
5. You can help patients to 'un-hook' from difficult thoughts and feelings using brief mindfulness exercises: (a) mindful breathing, and (b) thought de-fusion. These involve bringing open, accepting attention to thoughts and feelings, rather than trying to avoid or change them.
6. You can help patients (a) identify their values and (b) set a simple goal based on their values.

Please complete the ACT Now quiz.



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