Talk 3: Adjusting to life with an ICD



Aims for the session

- Introduction to Clinical Health Psychology Services
- Reactions to ICDs
- Anxiety and low mood link
- Common traps and how to overcome them

Past feedback of ICDs

"It's okay to feel apprehensive and a bit scared, it's a normal feeling and these will get easier as time goes by."

(previous attendee at ICD information morning)

 Up to 95% of people with an ICD would recommend the procedure to someone else

Impact of changes to physical health/having an ICD

Grief

Personality change

Isolation

Family

Worry about future

Fatigue

Disengagement from activities

Hypervigilance

Worry about what I can/cannot do

Physical disability

Cognitive difficulties

Employment

Emotional changes

Loss of change of identity and role

Emotion regulation difficulties

Common concerns for those living with an ICD

People have reported concerns about:

- Physical consequences of having a device (aware of device, fears of knocking it/damaging it).
- ICD giving shocks (not knowing what to do, pain, how it will feel).
- Uncertainty about the future ('device in charge', malfunction).
- Pushing myself too far (driving, physical activity, sex).

The numbers...

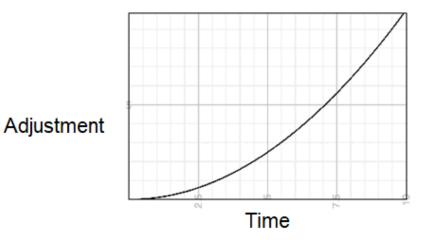
13 – 38% of people experience longer term anxiety following an ICD

24 – 46% of people experience low mood

10 – 15% of people experience PTSD type symptoms

QUALITY OF LIFE

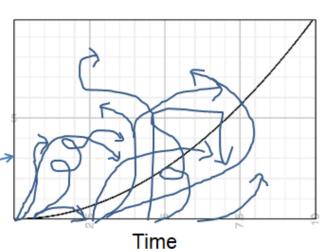
What is adjustment?



What you expect

Adjustment

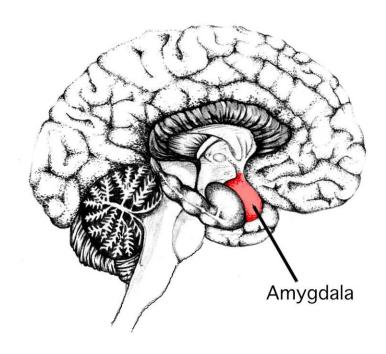
You may feel that you sometimes move between different emotional reactions (such as grief, shock, feeling hopeless)



What actually happens

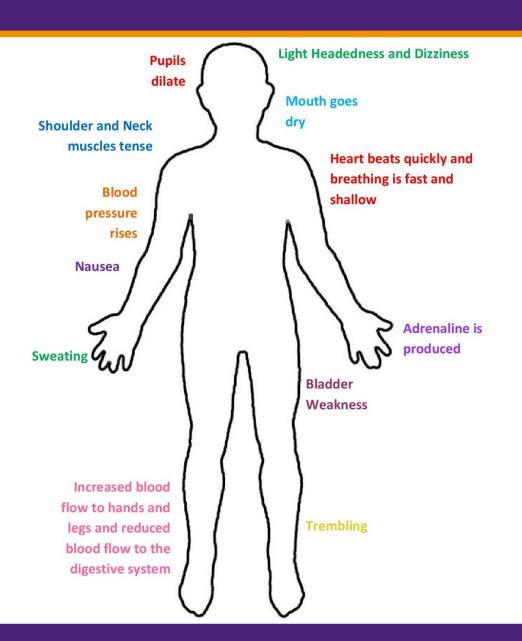
What is anxiety?

The threat system – 'Reptilian brain'



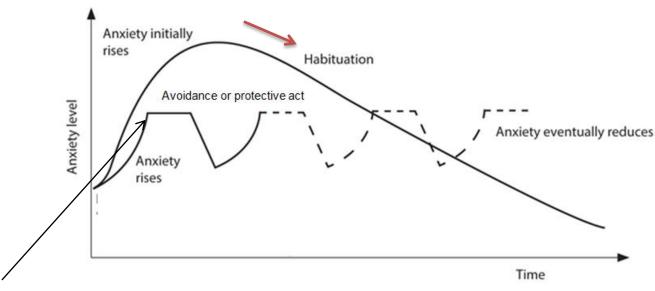
The 'old brain'

- Previously our threat system kept us safe by helping us run from predators and fight enemies (Fight or flight)
- The amygdala receives information about the threat response before we even have time to think about it. It helped us to predict threat – and respond quickly
- It employs a 'better safe than sorry' policy
 - It's not interested in being right or wrong, it's aim is to keep you safe and alive.



Fight or flight response

The fear curve



- Avoid exercise
- Avoid leaving the house
- Avoiding places/things associated with ICD shock
- Avoiding difficult emotions/push thoughts away
- Checking heart rate
- Getting reassurance from others

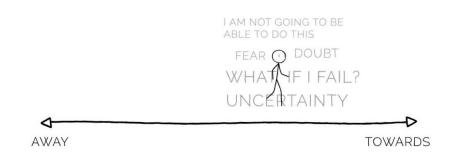
The trouble with avoidance

Avoiding situations or experiences because of anxiety has short term and long term consequences

Anxiety can 'generalise' and cause more avoidance in more and more situations, thereby making the anxiety difficulties worse.

The more you try to push anxiety away, the bigger it gets, the more control it seems to have.

Avoidance can mean that we miss out on valued and important aspects of our lives.



https://www.youtube.com/
watch?v=C-ZuqeyxULM

Panic attacks

- Panic attacks are a commonly encountered acute anxiety response (flight)
- Triggered by a specific situation
- Thoughts of losing control, passing out, dying (characterised by a high level of threat)
- They typically peak within last for approximately 10-15 minutes
- Physiological changes the role of adrenaline
- Presence of low mood following panic attacks is common

Post traumatic stress

- A response that can be triggered when there has been a real or perceived threat to life.
- Characterised by nightmares, flashbacks, intrusive thoughts/images of event, high levels of anxiety.
- These are normal responses following a difficult event.
- If these experience persist for much longer, please seek advice from your GP or health care team.

Why do we get low mood?

Lion cubs in the cave

- When presented with a stressful situation we can not resolve our brains have evolved to slow down our bodies.
- Lion cubs who can't find their parents will call out for a while, then eventually retreat to the back of a cave to conserve energy. The cubs who wandered out of the cave were less likely to survive.
- The human brain does something very similar – we can 'retreat to the back of the cave'
- However, when translated to 21st century this is not always a useful mechanism



Low mood

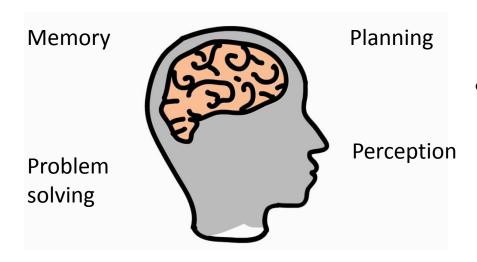
- Low mood can occur in response to threat
 - Either to yourself, family or close friends

- We may notice low mood as:
 - Changes to appetite/sleep
 - Loss of energy, feeling tired and lethargic
 - Feeling worthless, helpless or hopeless
 - Loss of interest in activities
 - Decreased motivation

Impact on cognitive skills

Language

Attention



Information processing

- Following a cardiac event, some people may notice changes in any of these domains.
- These changes can be associated with a number of things, including mood, anxiety, trauma, neurological changes, sleep, substances etc.

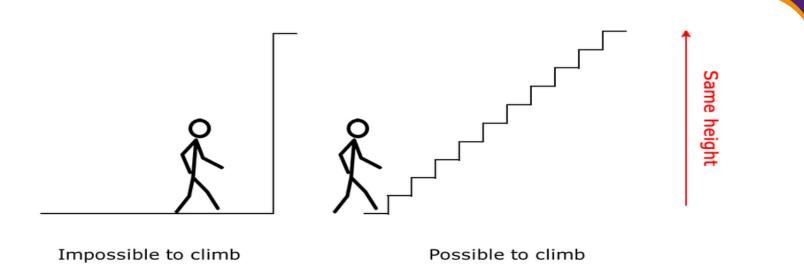
Overcoming low mood and anxiety

Tackling physiological changes: Breathing and relaxation

- Helps to slow down the systems in the body that speed up when we are anxious
- Relaxation response:
 - Reduce Heart rate
 - Improve Sleep and concentration
 - Reduce Muscle tension
 - Reduce Pain
 - Feel more in control
- By practicing the skill of relaxed breathing you are learning to cope more effectively with stress/anxiety (do it when you're not stressed too!)

Tackling avoidance/protective behaviours

- Notice times when you are avoiding / using protective behaviours
- It may be useful to make a list of the things you avoid or the behaviours you use
- Start small: identify the situations on your list that you might find easier to face.
- Ask family or friends to support you!



- Break down the task into small steps
- Start to face the thing you have avoided/used a protective behaviour for
- Remember it will feel uncomfortable at first, but it will get better!
- Small steps will lead to big changes.

Get SMART

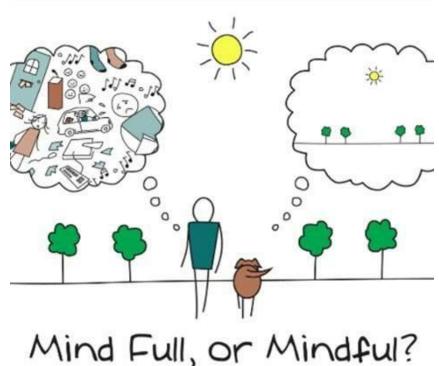
- Plan and schedule enjoyable activities, really important!
- Set SMART goals

Specific – who/where/when
Measurable – how will you know you've achieved it
Achievable - make sure the goal is actually doable
Realistic – do you have the resources (e.g. time, energy, money)

Timed – How long will you pursue this goal, how long will it take to do?

Mindfull or Mindful?

 Mindfulness means paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally.



Problem solving

- Practical coping:
 - Use your Shock Plan
 - Speak to your ICD/Heart Failure Nurse ask questions
 - Let people know you need support



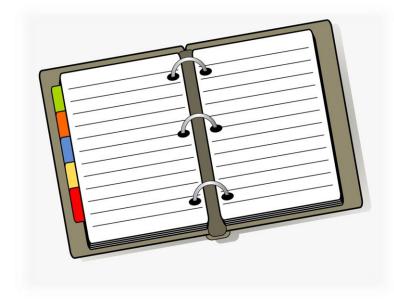
- What can you do right now in this moment that can help? Controlled breathing / distraction?
- What can you do in the future that can help?
 - Make a plan

Social/emotional support

- Remind yourself that you're in a period of adjustment most of what you are thinking or feeling is 'normal' (even though it might not be very pleasant)
- Focus on things that you CAN control
- Speak to people about how you feel and get their perspective
 - Friends and family
 - GP
 - ICD/Heart Failure Nurses
 - Clinical Psychologist (LHCH)
 - Support Groups (BHF, Arrhythmia Alliance)

Supporting cognitive skills

- Take regular breaks
- Break tasks down into small chunks
- Use practical reminders:
 - Using a diary
 - Reminders on phone
 - Calendar
 - Prompts from family/friends



Useful resources

- Mindfulness apps such as Headspace, Calm
 - https://www.nhs.uk/appslibrary/category/mental-health/
- Books on Mindfulness
 - Miracle of Mindfulness by John Kabat-Zin
- Samaritans 116 123
- If you feel that you are unable to keep yourself safe, please speak to your GP and A&E.

Thank you for listening ©

Arrhythmia Alliance www.arrhythmiaalliance.org.uk

British Heart Foundation www.bhf.org.uk

www.youngcarers.com

NHS Choices – Carers direct

Tel: 0808 802 0202

Citizens Advice Bureau—www.adviceguide.org.uk

DVLA, Swansea, SA99 1TU WWW.DVLA.gov.org Tel: 0300 790 6806

NHS Direct www.nhsdirect.nhs.uk