Simple definitions: What is uncertainty?

- Not knowing the outcome of an event
- Being unsure
- Unpredictability

Whilst uncertainty can be difficult for everyone for some people a feeling of uncertainty can be particularly stressful and upsetting. Whilst difficulties coping with uncertainty are not specific to autism, research suggests that many autistic people find uncertain situations to be very anxiety provoking.

When people find uncertainty really upsetting and stressful they might react in a number of ways

- they may try to avoid uncertain situations completely, to try to create certainty, of course sometimes this is not possible
- they may try to prepare as much as possible for an upcoming uncertain situation, perhaps by stocking up on supplies. This may involve thinking about and preparing for every possible situation or consequence from the uncertain situation in order to try and reduce the uncertainty. This can lead to an over focus on the situation and result in increased rumination, worry and anxiety. It also means that it can be difficult to manage an unprecedented outcome, as this has not been previously prepared for or considered.
- they may try to gather as much information as they can about the situation in an attempt to increase their knowledge about it in the belief that this will reduce the uncertainty. Similar to the example above this can lead to feelings of being overwhelmed and anxious.

Difficulties coping with uncertain situations are associated with worry and anxiety and strategies designed to help people to better manage uncertainty have been found to reduce anxiety. When we try to manage our difficulties with uncertainty we are trying to create a feeling of safety and remove feelings of threat. Struggling with uncertainty can impact on our thoughts, our feeling and our behaviours and lead us to experience uncomfortable physical sensations. The first step to beginning to tackle difficulties with uncertainty can be to understand the impact that feeling uncertain might have on us. The diagram on the next page outlines some of the ways that uncertainty might impact on us. You might find it

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helpful to draw your own version of this or tick off the things that are relevant on you on the diagram.

How might Uncertainty affect us?

Vicious Cycle of Uncertainty

Trigger: Uncertain Situation or not knowing the outcome

Thoughts & Images:
- Worry
- The future is unknown: there’s always a risk, even if miniscule
- The worst could happen
- I have to be 100% sure
- I can’t tolerate not knowing
- Uncertain events are almost always negative
- I won’t be able to cope when the uncertain event happens
- I must be prepared, in order to reduce risk and increase my ability to cope when the worst happens

Behaviours:
- Try to increase certainty
- Make lists
- Plan ahead/over-prepare
- Seek reassurance from others
- Do things myself rather than ask others
- Check
- Over-protect others
- Over-inform self (internet etc)
- Avoid/make excuses
- Put things off
- Distract/Keep busy
- Decisions: make impulsive decisions/ask others to make decision/reconsider decisions already made

Emotions/Feelings:
- Uneasy
- Anxious
- Nervous
- Uncomfortable
- Stressed

Physical Sensations:
Hot, sweaty, shaky, butterflies in stomach, tingling in hands/feet, heartbeat quickens,

(adapted from https://www.getselfhelp.co.uk/docs/ViciousCycleUncertainty.pdf)
Identifying Less Helpful Strategies

It is important to identify some of the less helpful strategies, we can all use from time to time when trying to manage uncertainty. We may have certain strategies that seem to help us manage uncertainty but may not be more helpful in the long-run. These might be things like:

- Finding out more information about the situation
- Scanning for Uncertainty
- Seeking Reassurance from others
- Avoiding Situations
- Checking – avoiding making mistakes
- Making impulsive decisions
- Ruminating on information

Understanding elements of control and uncertainty:

Uncertainty can be distressing because it involves a situation that we are unable to control. There are going to be situations in life that we are not able to resolve or will be uncertain. For most of us when things are in our control we feel more at ease. When things are taken out of our control this can be overwhelming and cause us to feel distressed.

Sitting with feeling of “Uncertainty”:

When we are not able to control situations it can be helpful to develop the ability to “sit” with the feeling of uncertainty. This might sound quite strange or it might sound daunting. Especially if uncertainty makes you feel uneasy or distressed. But if you are able to manage feelings of uncertainty and you will be able to cope better when you are faced with uncertain situations. “Sitting” with the feeling of uncertainty involves beginning to focus your attention on how you are feeling internally and what is happening externally.

Use this time to “get used” to how the uncertainty makes you feel. At first, this might be a feeling of unease or discomfort but once you have recognised that these feelings are a reaction to the uncertainty, this may, in turn, help you to feel less distressed. This is because you have IDENTIFIED what those feelings are.

On the next few pages are some exercises that you might find helpful to manage uncomfortable feelings of uncertainty.
TOLERATING UNCERTAINTY

Use the **APPLE** acronym to help you deal with uncertainty.

**ACKNOWLEDGE** - Notice and acknowledge the uncertainty as it comes to mind.

**PAUSE** - Don’t react as you normally do. Don’t react at all. Just pause, and breathe.

**PULL BACK** - Tell yourself this is just the worry talking, and this apparent need for certainty is not helpful and not necessary. It is only a thought or feeling. Don’t believe everything you think! **Thoughts are not statements of fact.** What’s the **bigger picture**?

**LET GO** - Let go of the thought or feeling about needing certainty. They will pass. You don’t have to respond to them. You might imagine them floating away in a bubble or cloud.

**EXPLORE** - Explore the present moment, because right no, in this moment, all is well. Notice your breathing, and the sensations of breathing. Notice the ground beneath you. Look around and notice what you see, what you hear, what you can touch, what you can smell. Right now. Then, **SHIFT YOUR FOCUS OF ATTENTION** to something else - on what you need to do, on what you were doing before you noticed the worry, or do something else - mindfully, with your full attention.

(taken from [https://www.getselfhelp.co.uk/options.htm](https://www.getselfhelp.co.uk/options.htm))
What am I reacting to?
- What’s happening with me: thoughts, emotions, sensations?
- What meaning am I giving it?

What are my options?

CHANGE
- What can I change?
  - Environment
  - Situation
  - My reaction
- How can I make the changes?
- What resources do I need?
- When can I do it?
- What do I do first?

ACCEPT
- It is as it is
- I don’t have to agree with it, or judge it good or bad
- I can always come back to it later
- I can keep my options open
- This is a normal body reaction
- I don’t have to fight it, or try to stop it.
- It will pass

LET GO
- Is it worth it?
- Is this something I can leave or let go of, and move on from?

What can I do that will best help me/others/the situation right now?

*When we are no longer able to change a situation, we are challenged to change ourselves* — Viktor Frankl

Taken from Get Self Help (https://www.getselfhelp.co.uk/options.htm)
PAINT Technique

Pause – don’t act straight away

Assess – Is it possible to come to a conclusion? Is it useful to come to a conclusion? What are the facts/opinions?

Is it time to stop thinking in this way?

Now, how should I focus my attention? – Park the thoughts, sit with “not knowing”, do something helpful

Tension Release

(created by co-authors of CUES-A©)
STOP!
Just pause for a moment

TAKE A BREATH
Notice your breathing as you breathe in and out.

OBSERVE
- What thoughts are going through your mind right now?
- Where is your focus of attention?
- What are you reacting to?
- What sensations do you notice in your body?

PULL BACK - PUT IN SOME PERSPECTIVE
- What's the bigger picture?
- Take the helicopter view
- What is another way of looking at this situation?
- What advice would I give a friend?
- What would a trusted friend say to me right now?
- Is this thought a fact or opinion?
- What is a more reasonable explanation?
- How important is this? How important will it be in 6 months time?
- It will pass.

PRACTISE WHAT WORKS - PROCEED
- What is the best thing to do right now?
- Best for me, for others, for the situation?
- What can I do that fits with my values?
- Do what will be effective and appropriate.
Mindfulness

Mindfulness can be a really useful approach when we find it difficult to accept that some things in life will always be out of our control or uncertain. Mindfulness strategies can also help us to identify techniques for self-care when we are feeling distressed by uncertainty.

It is really important to remember that for some autistic people who may have particular sensory difficulties mindfulness activities that promote directly paying attention to the senses should be used with caution as they may be aversive.

When practicing mindfulness we are paying particular attention to the present moment. Thoughts may come and go in our head and it is okay to be aware of these thoughts, notice that our attention has been brought to the thoughts and then to re-focus our attention back onto the breath, or the task in that present moment. When something uncertain happens, how easily do you manage to shift your focus of attention onto what is happening in that present moment? How often are you thinking about what might happen in relation to the uncertain situation?

Mindfulness is something that can take practice. But if it is a technique that appeals to you it is worth persevering as it has may have many benefits in managing distress in relation to uncertainty. Some people find it helpful to use audio recordings to help them with mindfulness activities, there are many to select from online. There are also apps which are available to download such as “Headspace”, “Calm”, “Insight Timer” and “Buddhify”. There are some specific meditations relating to uncertainty on Insight Timer.

Relaxation techniques can often be a very helpful strategy to use when you are “sitting” with uncertainty. It can be helpful to identify some relaxation strategies to use when they are trying to accept the feeling of uncertainty. These could be:

• Do some exercise (e.g. go for a walk, cycle, do some yoga)
• Read a book
• Watch your favourite TV show/film
• Listen to some music
• Do something creative (e.g. draw, paint)
• Talk to a friend or family member
• Have a bath
• Cook

Add some of your own ideas to this list. It can also be useful to review any mindful strategies as you try them out and see what is helpful about each strategy and what is unhelpful. You can then tailor the strategy to make it as helpful to them as possible.

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Useful Websites

http://psychologytools.com/technique-mindfulness.html and
https://www.getselfhelp.co.uk/mindfulness.htm and
https://www.getselfhelp.co.uk/relax.htm and
http://www.moodjuice.scot.nhs.uk/relaxation.asp and
https://www.anxietybc.com/sites/default/files/MuscleRelaxation.pdf