



Intolerance of Uncertainty

It is well understood that people with autism have a liking for sameness and struggle with change, particularly if it is unexpected.

An aspect of this preference for sameness is an intolerance of uncertainty. This means that they find any situation with an uncertain outcome extremely stressful. People with high intolerance to uncertainty (IU) will go to significant lengths to avoid any circumstance or setting where the outcome is at all unknown.

For example: Stu, a young man with autism, would love to go bowling and it was a common reward for good behaviour for him, but when his carer said they might be able to go bowling at the weekend, but they would have to wait and see (80% certain), Stu became very upset and said he didn't want to go. For him it had to be 100% sure or nothing.

We, as parents, carers or supporting professionals can often reinforce this intolerance unknowingly. By trying to reduce the individual's anxiety around change we ensure that nothing happens that they are not sure about – we plan everything to reduce their anxiety and don't allow for any deviation from the stated plan. Unfortunately, this can result in their being so conditioned for everything in their life to be under control that they are extremely fragile to any change whatsoever.

Managing anxiety around change, then, needs to be on two fronts: we implement structure and plan for change to reduce anxiety, but we also gradually increase the tolerance for not knowing how things will turn out.





So, instead of focusing on reducing change, it has been suggested that we instead work on increasing our children and young peoples' tolerance of change and uncertainty.

Following research in this area by researchers in Newcastle University¹, a programme has been developed (called CUES© – Coping with Uncertainty in Everyday Situations). The aim of the programme is to provide parents/carers with strategies to reduce intolerance of uncertainty, and therefore reduce anxiety in their children and young people. The results showed that increasing their tolerance of uncertainty was more effective at reducing anxiety than removing change from their everyday life. It also means that children and young people are more independent as they need less support to manage situations that have uncertain outcomes.

If we, as parents and carers look for safe settings in which we can deliberately introduce uncertainty in very small ways, while supporting the child/ young person and encouraging their progress in dealing with the uncertainty, we can build their resilience in these situations and help to reduce their anxiety.

An effective way of approaching this is to discuss the approach with the child/ young person and begin to gently set goals with them. They may be motivated by the goal of having greater independence, or more freedom or choice. Allow them to set the pace while reassuring them and encouraging them toward their goal. Once they have had a measure of success, they will be more confident to take further steps towards being more comfortable with change.

¹ *Towards a Treatment for Intolerance of Uncertainty in Young People with Autism Spectrum Disorder: Development of the Coping with Uncertainty in Everyday Situations (CUES©) Programme* Jacqui Rodgers, Anna Hodgson, Kerry Shields, Catharine Wright, Emma Honey, Mark Freeston. *J Autism Dev Disord* (2017) 47:3959–3966

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