



Understanding Autism

Handout 7 - Anxiety and overwhelm



Many autistic people experience high levels of anxiety

Research has shown that autistic people often experience higher levels of anxiety than the general population. There are many factors that can contribute to this.

Uncertainty

At times the world can feel uncertain and unpredictable for many autistic people:

- Other people’s behaviour can seem confusing and inconsistent
- New situations can feel daunting, and unexpected changes may happen
- Communication differences may lead to misunderstandings

Sensory differences

For example, a person may be anxious about feeling overwhelmed in noisy / busy environments, and worry they may not be able to get away should they need to escape.

Recognising and processing emotions



Some autistic people may find it hard to recognise how others are feeling, and can also find it hard to identify and describe their own emotions. A person may at times feel ‘unsettled’ without being able to work out what they’re feeling, and what’s caused it.

Some autistic people describe not experiencing emotions connected with an event until much later afterwards, sometimes very intensely.

A protective response

Anxiety plays a key role in keeping us safe. For example, if we had no anxiety at all we might just walk out into a busy road without looking.

Anxiety becomes problematic when our high levels are out of proportion to the threat, or are ongoing. When anxious an autistic person’s need for consistency, certainty and predictability is very likely to increase, as structure helps them feel safer and in control.

For more information about anxiety go to: www.nhs.uk and search for ‘anxiety’.

Many autistic people describe having difficulties switching off. They feel they are ‘on alert’ most of the time and find it hard to relax.

Experiences of bullying



Many autistic people experience bullying at school, college and even work. These experiences can be traumatic, and result in high levels of social anxiety that have a huge impact on people’s lives.

Masking



Some autistic people ‘mask’ their autism and anxiety at college, work and at social events. A person may seem to be coping well, but may feel highly anxious inside.

Recognising overwhelm and managing emotions

Communication



Autistic people have explained that the word 'overwhelm' doesn't quite explain the intensity of the mental overload they sometimes experience.

Some people, particularly people who don't communicate verbally, may struggle to explain that they feel overwhelmed, and may show distress through their behaviour. Staff and carers can help by noticing possible triggers and helping people to find ways to communicate.

When feeling overwhelmed our ability to think clearly can be affected, making it harder to notice that we're not feeling okay.



Some autistic people may need support to recognise the signs that they are feeling anxious or overwhelmed. It can help to list these, and they may be different for different people. For example:

- I go very quiet and feel hot.
- I pace about the room a lot.

Emotional regulation

In times of stress, such as during an argument, some autistic people

may experience intense emotions they don't always feel in control of. They may become very upset, or even angry. They are likely to be feeling frightened and unsafe, but may be unable to express this clearly. People may need support to identify potential triggers, and plan strategies for avoiding those situations, or for managing them.

Having strategies to hand

It's useful to have a list of calming strategies to hand, for times when it's difficult for the person to think clearly and remember them. Each person's strategies will be different, and different strategies can help at different times.

When calmer, a person will be more able to think more clearly.

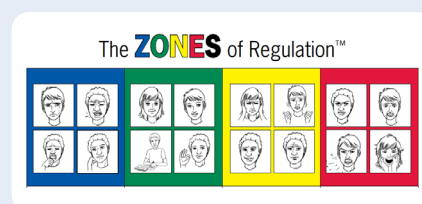
The examples on the last pages of this handout explain some of the strategies autistic people have found helpful.

Visual tools can help people to recognise feelings of anxiety and overwhelm

The Zones Of Regulation

This toolkit is widely used, and uses four coloured zones to help people identify and regulate their emotional and arousal states. Ideally people will be in the green zone, where they feel alert, relaxed and focused.

The blue zone indicates feelings such as sadness, boredom or tiredness. The yellow and red zones indicate increasing levels of anxiety/overwhelm. People list strategies to use to help them regulate back to the green zone.



www.zonesofregulation.com

Meltdowns and shutdowns

When extremely overwhelmed an autistic person may express this outwardly by showing distress and having a meltdown, or by shutting down and being unable to think clearly or communicate.



At this point the person may not feel in control of their behaviour, and may need support to keep themselves, and possibly others, safe. It's likely to have been a series of factors throughout the day that have led to this point.

The National Autistic Society explain that "A meltdown is not the same as a temper tantrum. It is not bad or naughty behaviour".

During these times a person may temporarily struggle to process information, communicate and make choices. Ideally a person will need a quiet place to recover and not have people crowding around them.

A darkened room is often ideal as stimulation is reduced. It's important to understand that a person may struggle to process information, and will need a break from questions or choices. For example, rather than asking if a person wants a cup of tea, just make one and tell them it's there if they want it.

Have a plan in place

People may need help to be able to recognise the onset of a meltdown or shutdown, and to have a plan to follow, so that others know what they need.

It's important to recognise the signs early to hopefully avoid a meltdown or shutdown. Some people may need help both to recognise the signs and to escape from an overwhelming situation.

A plan can also outline the approach supporters should take to ensure everyone stays safe, and helpful strategies such as a weighted blanket or noise reducing headphones.

Weighted products



Weighted products, such as a weighted blanket, work by giving deep touch pressure.

People have described the feeling as similar to a hug but less intense, helping them to feel safe, calmer and grounded when feeling very anxious or overwhelmed.

There are a wide range of weighted products available, even weighted cats !

Stimming

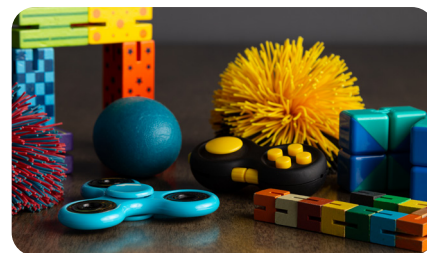
Some autistic people may use repetitive behaviours to manage uncertainty and cope in busy environments. This is often called stimming, and can include:

- rocking
- fiddling or doodling
- pacing around
- hand flapping
- repeating phrases

Stimming can be calming and is an important coping strategy for many people.

There are many reasons why a person may stim, including:

- to help make things feel more predictable
- to help them to focus better



- To block out sensory distractions in busy environments
- To release pent up energy when anxious, or even when excited
- To manage times of boredom
- Because they enjoy it !

People should not be stopped from stimming if they need to, and if their stimming behaviour is potentially harmful, they should be supported to try to find a safer alternative.

Tiredness and fatigue

Autistic people often find they need a lot of rest and recovery time. Managing uncertainty, working out communication and processing more sensory information on a daily basis can be exhausting, particularly if a person is using extra mental energy to 'mask' their autism when in public, or at work or college.

Professional support to manage anxiety

Cognitive Behavioural Therapy (CBT)

CBT is widely used to treat anxiety by helping people to change their thoughts and beliefs about themselves, and situations that cause anxiety.

Studies show that CBT can lead to a moderate decrease in anxiety for autistic people. CBT can be adapted for autistic people by using visual aids and stories to help to explain complicated social situations.

Online interaction with a therapist can be less intense than face to face meetings for some people. A therapist who understands autism, and particularly the difficulties an autistic person may have identifying emotions, is likely to be most effective.

Diagnostic overshadowing

This is where a person's symptoms are seen as a part of autism or a learning disability, rather than a separate condition that needs investigation and treatment.

"Some of my son's difficulties were simply put down to his autism. One time he was banging his head a lot, and it turned out this was nothing to do with autism, he'd actually had toothache".

A 2011 study showed that around 40% of autistic people are thought to have at least one, and often more, anxiety disorders. Autistic people need equal access to treatment for anxiety.

Safety planning



Some autistic people can be vulnerable to self harm or suicidal thoughts in times of crisis. A person may struggle to imagine solutions to a problem, and when very overwhelmed struggle to think and communicate clearly.

A safety plan is usually written and the person carries it with them. It clearly tells them who to contact and what to say. For example, 'I am feeling unsafe and need help'.

Surrey Police offer a 'Pegasus card' to people who find it hard to communicate with the emergency services. To find out more search for 'pegasus' at www.surrey.police.uk

Support to access specialist help

As well as prescribing medication for anxiety, an autistic person's GP can refer them for more specialist support. Some autistic people may have quite complex mental health needs. The Neurodevelopmental Service in Surrey and North East Hampshire provides some specialist services, and also liaises with mainstream mental health services about the needs of autistic people.

Anxiety and overwhelm - our strategies



I rely much more on my calendar, lists and timetable when I'm overwhelmed. They give me certainty, and help things to feel less chaotic and out of control.

Physical exercise helps me manage my anxiety. Doing heavy work like lifting weights or even digging the garden helps me feel grounded.



I've learnt to plan very carefully to avoid becoming so overwhelmed that I have a meltdown.

I once combined an unfamiliar bus journey with my first day at a new college class - never again!



It helps me to visualise my social battery which can run low quite quickly. I have a list of activities and how much energy they cost me. For example, going to a party uses 75% of my daily charge, so I make sure I have very few other demands on that day and the next, which helps me recharge.



Self care is really important. I used to be very critical of myself when things went wrong, or I felt overwhelmed. These days I have two rules: 1) If I wouldn't say it to a friend I won't say it to myself, and 2) I don't give myself a hard time, when I'm already having a hard time.

I recover much more quickly than I used to by being kinder to myself.



Alison needs to do things in her own time. She's very meticulous. If she feels rushed she can get very stressed, so it's important that, as her supporters, we understand this.

As a reasonable adjustment at work I am allowed a 15 minute break between meetings. This has helped me manage my anxiety and overwhelm. I also have a time out card I can show to colleagues if I urgently need a break.



If I'm stressed I've learnt not to game against other people. I get really upset if I lose. I just play against the computer in easy mode.



I wear my noise cancelling headphones and weighted vest when I go to an appointment, as they help me feel calm and secure.

I carry a notebook with me which says on the front "I can't communicate verbally at present. Please write in here instead". This takes the pressure off and gives me time to process the information.



I 'lose it' sometimes if I have an argument, or feel I'm being treated unfairly.

I get really upset, and it takes me time to recover and see things clearly again.



Lawrence has a support plan which explains likely triggers for his anxiety and overwhelm, and the support and strategies that are helpful. The plan is used by all his support staff and ensures that they are supporting him in a consistent way.



I have a checklist to go through when I'm not feeling right. Am I hungry? Am I cold or hot? Do I need a drink? When did I last eat? Do I need the toilet? Sometimes it's one of these simple things that stops me feeling on edge.



My partner and I developed a 'meltdown plan'. We use a colour chart to help me explain when I'm starting to feel overwhelmed. When this happens we follow the agreed plan, and he knows that I need a quiet, dark room, ideally with my weighted blanket and a cup of tea until I feel calmer.



If something's making me anxious I list what I can do. If there's things I can do now I do them and if not I try to distract myself by absorbing myself in my passion for aircraft, which feels safe and certain.

One of my stims was skin picking, which can be painful as my hands end up really sore. At school I used to get told off for rocking on my chair, so I started picking my skin under my desk at school instead. I now try to use a fidget cube as an alternative, and carry it with me wherever I go, so it's always to hand.



I keep a diary of things that happen each day to help me identify what I might be reacting to, and how I am feeling. I tend to mask my anxiety and autism at work, so when I get home sometimes it all comes out and I have a meltdown.



My support worker can tell when I'm stressed before I notice. She helps me to stay calm by helping me to find a quiet place to go, and to play a game on my iPad. If I have an activity to get absorbed in it distracts me from my stress.

When I was feeling unsafe I went to the Police station and showed my Pegasus card. The officer was great. She read my notes and knew exactly who to contact. My notes mention that I love cats, so we chatted about my cat which really helped me calm down.

Mindfulness techniques and yoga help me to feel grounded and relaxed. We're all different though. For some people a nice warm bubble bath helps, and for one person I know it's cold water swimming.



I do everything I can to avoid overwhelming situations:

- If a bus is crowded I wait for the next one
- I always sort my outfit out the night before
- I do my shopping at 9pm when it's quieter



When I first went to university I didn't make any friends, and put on a lot of weight. My mentor helped me recognise that the empty feeling in my stomach was loneliness rather than hunger. Things got better when I joined some clubs.

I keep a list of calming activities with me at all times. When I am stressed I can't think what to do, so this list really helps. I've learnt that when stressed the priority is to regulate myself instead of focusing on the problem I'm struggling with. Once my mind is calmer I can usually sort it out.