



Manchester University  
NHS Foundation Trust

# Enhancing Children with Autism's Experiences in the Perioperative Period

**Perioperative Local Leads Event 2020**  
**Royal College of Anaesthetists**  
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**Fiona Armstrong, ST7**  
**Anaesthetics, HENW**





“Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.” (The National Autistic Society, 2013)

**What is Autism[ASD] ?...**



- Neurodevelopmental condition
- Spectrum – no two are the same
- Often no physical disability
- Communication difficulties
- May have normal or high IQ
- Difficulty concentrating
- Sensory needs – may be avoidant or seeking
- Difficulties with change in routine
- Anxiety +++

**What difficulties do patients on autistic spectrum have?**



## How to make someone with Autism (or anyone else, come to that) anxious...

- Disrupt routine
- Bring to a strange place
- Bring to a noisy place
- Use non-understandable language/communication (or don't even try!)
- Keep waiting for unspecified time
- Lots of people
- Lots of questions
- Invade personal space/touch
- Do unpleasant things
- Be inflexible and work to the system's timescale





- Gastrointestinal
- Endocrine
- Epilepsy
- Ophthalmological
- Mental health
- Neurology
- Dental

**Children young people  
and adults with autism  
may have multiple  
health issues**



- Don't assume because you know one patient with autism you know them all
- Several studies have shown individualised care to be the key factor in improving experience perioperatively
- *Koski et al (2016) Interventions for paediatric surgery patients with comorbid autism spectrum disorder: a systematic literature review. Archives of Disease in childhood 101(12): 1090-1094*
- *Vlassakova and Emmanouil (2016) Perioperative considerations in children with autism spectrum disorder Current Opinion in Anaesthesiology 29(3): 359-66*

## Individualisation



## Governance

- NHS Improvement Standards 2018
- Reducing the need for restrictive intervention [HM Government 2018]
- Winterbourne View (Great Britain, 2012)
- NICE Autism [2016]
- Autism Act, 2009
- Autism Strategy 2010
- Equality Act, 2010
- Health and Social Care Act, 2012

**Failure to provide  
adequate healthcare to  
patients with Autism  
[ASD] = discrimination**  
(Autism Act, 2009; Hebron, 2011)



- Elective bring in to see and find out sensory triggers/communication needs
- Use hospital passport
- Visit/tour and risk assess
- Health Play Specialist involvement
- Manage parental anxiety
- Be honest and literal
- Social story/app
- Don't add last minute as a cancellation

## Pre-operative preparation





- Reduce waiting- first on list or bring in later
- Minimise starvation
- Offer quiet area eg side room
- Liaison with Parent /carer professionals
- Use communication aids
- Be prepared to adapt eg ametop/nameband/gown
- Comfort objects eg sensory toys
- Do not lie!
- Pre med- midazolam can cause paradoxical dysphoria – nasal dexmetatomidine, ketamine another option

**On day of surgery**



- Reduce no of people to minimum
- Sensory distractions
- Be prepared to adapt
- Avoid restrictive intervention e g restraint if possible – anxieties tend to stick even further
- Stick to pre-discussed sequence if possible and allow communication aids for them to follow
- Talk to them
- Parents may know best

## Anaesthetic Room



- Consideration to potential risks
- Recover quiet area
- System for assessing pain
- Allow sensory distractions early
- Keep in hospital minimal time
- Eat and drink as soon as possible
- Be prepared for post op agitation
- Get family early

**Post op**



## Case Study – 12 year old severe non verbal ASD

- Called few days notice in for dental procedure
- Family not told would be operation under GA
- Starved from night before and brought in 11am for afternoon list
- No communication aids, no play therapist Nursed in open bay
- Anaesthetist offered premed – taken caused paradoxical dysphoria and not reassessed
- Left till 4.30pm distressed
- Distressed in anaesthetic room, told would not remember as had had midazolam and held down by 4 people for gas induction
- Now behaviour backtracked, terrified to lie down even with parents (who helped hold him down)
- Won't go near health professionals



Short, J and Calder, A (2013) Anaesthesia for children with special needs, including autistic spectrum disorder CEACCP 13(4):107-112

**Useful source**



## Autism is a spectrum condition

- Each child .young person and adult experience of autism is different
- Patient's with autism need care tailored to their needs...in order to receive health care and treatment that they are entitled to
- It can be simple solutions and a little time that make the world of difference

## Conclusion



- MDT Working
- Research options
- National guidelines
- Education programmes
- Apps/Social stories/Communication resources
- Premedication options
- Transition to adult care

## Discussion points