South Thames Paediatric Network
Transforming Healthcare for Children and Young People

## An Individualised Perioperative Pathway for Children and Young People

# Network Recommendations

## Target audience

All clinical staff caring for children and young people with neurodevelopmental, learning and behavioural needs, who are undergoing elective surgical and medical procedures.

## Introduction

This document has been developed for children and young people with additional needs who are coming in for an elective admission to hospital. The recommendations aim to guide the practice of all clinical staff to manage the admission, care and discharge of the paediatric patient for whom the admission for elective procedure requires additional planning and reasonable adjustments to create a supportive and inclusive environment. We have a duty to make adjustments for a person, as part of the legislation that makes up the Equality Act, 2010 (1).

## Purpose and Scope

This document is designed to enable staff to plan the admission, care and discharge of children and young people with neurodevelopmental disorders, who have additional needs and require reasonable adjustments to ensure their well-being, comfort, safety and quality of care, therefore creating a positive healthcare experience for the patient and parent(s)/carer. It also supports the healthcare professional in their role.

## Definitions/ Language

**Neurodevelopmental disorders** (as defined by ICD-11)- are behavioural and cognitive disorders that arise during the developmental period that involve significant difficulties in the acquisition and execution of specific intellectual, motor, language, or social functions. These include (amongst others): Autism Spectrum Disorder, Developmental Learning Disorder, Attention Deficit Hyperactivity Disorder, Developmental Language Disorder, Developmental Motor Coordination Disorders (2).
**Neurodevelopmental needs-** We know that children and young people do not like the term disorder, so we will refer to this group of children as having neurodevelopmental **needs.**
**Neurodiversity-** Children with these needs are sometimes referred to as: being neurodiverse or manifesting neurodiversity.
**Autism**- Children or young people with a diagnosis of Autism often prefer to be referred to as **autistic,** rather 'having autism'.

There will be children with additional learning, behavioural or communication needs, who do not have a diagnosis, but their needs will require support all the same.

## Key Recommendations

## Pre-admission/ Preassessment

All children and young people should expect to be preassessed prior to the day of their procedure (APAGBI 2022). Your preassessment pathway should include criteria to identify groups of children who may require further preparation and support, and planning which includes: Children with anxiety or neurodevelopmental, learning and behavioural needs.

Preassessment, whether virtual or face to face, should assess the child's specific needs. As a neurodiverse child is unique, it is important to approach their care with understanding and individualised support. Preassessment should identify whether reasonable adjustments and additional planning are required to facilitate their admission, and preassessment is the opportunity to implement reasonable adjustments in the child or young person's perioperative pathway.

### Individualised Perioperative Pathway with Reasonable Readjustments

Eligibility criteria:
Any child with neurodevelopmental learning and behavioural needs or significant anxiety.
The surgeon booking a child or young person for surgery should assess for this, and highlight their patient to the preassessment team early. The use of a preassessment triage form at the time of booking can support this process Preassessment Documents | South Thames Paediatric Network

The preassessment practitioner should:

- Assess whether the child is eligible for the pathway. Explain the specialist pathway to the parent/carer.
- Complete standard preassessment documentation. Consider potential physiological risks associated with the child's condition. Assess for co-morbidities, and do not let a neurodevelopmental diagnosis distract from a good clinical risk assessment or allow diagnostic overshadowing to take place. **Diagnostic overshadowing** occurs when a health professional makes an assumption that a person's behaviour is a part of their learning disability or neuro diversity without exploring other factors such as biological determinants. There is a tendency to attribute all other problems to that primary diagnosis, thereby leaving other co-existing conditions undiagnosed (3, 4).
- Establish whether the child has had any previous admission(s) to hospital. Ascertain how they went: Were there any issues/complications/ things that went really well?
- Offer and encourage a face to face preassessment appointment, to include a preadmission hospital visit. Where this doesn't suit the child or young person, the appointment can be conducted virtually or by phone. Establish what method best suits the individual and family.
- Take a history of the child's neurodevelopmental diagnosis. Assess the specific needs, abilities and challenges for the child or young person.

- Establish whether the child or young person takes any regular medication that affects behaviour. Review the child's current medication and ensure they are appropriately managed before the admission. Inform the parent/carer of any restrictions.
- Ascertain what the child's communication style is. Do they use visual aids such as pictures, PECS, Makaton or communication cards? Or a technological communication device? Ask the parent/carer to bring their child's communication aids on admission, or even better, to share them prior to the admission, to be uploaded to the hospital records. It is also key to understand how the child communicates pain.
- Complete a **STPN Anaesthesia and Theatres 'All About Me' Day Surgery Passport** with the family. As an alternative, families can be asked to complete the passport in advance. This allows the team to understand the child's likes, dislikes, what comforts them, what upsets them, and take note of any particular sensory sensitivities.
- Create an individualised care plan based on the child's specific needs, including the planning of reasonable adjustments for each child or young person, alongside the play specialist and the preassessment anaesthetist(s). Ensure requirements are considered, addressed and planned and implemented prior to the admission date. Documentation is also key, so the team around the child on the day are fully informed. There is space to document the plan at the end of the Day Surgery Passport.
- Collaborate with the child's parent/carer and involve them in decision making, this will contribute to a successful hospital experience for the family.

## Reasonable adjustment planning may include:

- Preadmission Hospital Visit
- Allowing for a longer preassessment appointment
- Identifying communication aids
- Considering how to best utilise the hospital environment
    - An open bay or a cubicle?
    - Utilise play and waiting rooms pre-op, rather than a post-op environment
- Give some control to the child
    - Where name bands are placed
    - Let them wear their own clothes
    - What they will eat or drink after
- Planning for premedication or type of induction
- Considering the timing of the admission/ surgery

The reasonable adjustments should be recorded in the hospital records, and they should be marked with a reasonable adjustment flag (5). Your Trust will have their own policy for this.

## Hospital Visit

All neurodiverse and anxious children and young people should be offered a preadmission visit, either for face to face preassessment and for a tour of the children's ward or day surgery unit. It might be that this additional hospital visit just heightens anxiety and a parent/carer may opt out of

that. Alternatives may include, virtual appointments, telephone appointments or even message exchange via email, text or WhatsApp.
Hospital environments can be overwhelming for children and young people with sensory sensitivities or sensory processing differences. It's helpful for a play specialist to support the visit, allowing the child to become familiar with the environment and layout of the unit. If appropriate, equipment, that might be used during the child's admission, can be explained how it works and demonstrated using play. The preadmission visit also provides an opportunity for the child to ask any questions or express any concerns they may have; they can be provided with adequate information and can be offered reassurance. This will help alleviate anxiety and ensure that the child feels heard and supported.
A video of a hospital journey can be used to supplement a hospital visit. Links to films created by local services can be found in the appendix.
Desensitisation visits may also be offered, if that approach best meets the needs of a child. This is a series of short visits that increase in exposure each time. To support the child's preparation for the procedure, consider breaking down the steps into smaller, more manageable tasks for the child and where it is possible, offer choices which can give children a greater sense of autonomy and control. For example, in preparation for day surgery a child may be brought to the Day Surgery Unit every week for consecutive weeks, initially to meet the play team, then to be introduced to some medical equipment through play, then for the medical equipment to be used on the child, building up to managing the day of surgery. Some case studies on the desensitisation of people with learning disabilities requiring blood tests are available here: (6).

## Communication/ Visual Aids

Visual aids are highly effective for children and young people who either communicate non-verbally, or use alternative methods of communication. Children with additional needs may need extra support to understand receptive language (what is being said to them). They may use visual schedules (i.e. now & next) or social stories already, which help them to anticipate what is going to happen and prepares them for transitions. A visual representation of their admission to hospital can be really helpful. There are a number of examples of visual aid resources communicating the surgical journey on the STPN website Preassessment | South Thames Paediatric Network Some can be used as templates, to make bespoke resources for your service. You will find resources using pictures/photographs, PECS (Picture Exchange Communication System), Widget symbols, Makaton and written aids.
Ask the child's parent/carer to bring in any visual aids used at home. This will help the child understand what will happen and in what order, which will promote predictability and reduce anxiety. It is ideal if these can be shared prior to the admission and uploaded to the hospital records.

## Consultant Anaesthetist Input

Children and young people with additional needs and *any* anxiety should be referred to a Preassessment Consultant Anaesthetist. This is to create an individualised anaesthetic plan well in advance of surgery. The plan should go to the anaesthetist covering the list and the surgical team.

A contract can be drawn up in discussion with the family. See Case Study later in the document.

This appointment is to consider:

- Sedative premedications
- Distraction plan
- Anaesthetic management plan in advance
- Whether the child has been allocated the correct place on the list, or the correct list entirely

Question whether the child has been anaesthetised before, and if they already have a plan in place. Ascertain if the plan worked, and if not, find out from parents what did not work previously and why. A restorative conversation may be required, if the child, young person or family felt that it had been a difficult experience.

It is good practice to check if the child needs any other investigations/ procedures done whilst under general anaesthetic, e.g. blood test required for those who struggle with having bloods taken.

## Scheduling

Extra time may be required to accommodate the patient's sensory sensitivities and sensory processing differences. Often, scheduling the patient to go first on the operating list helps to reduce the waiting time, minimising their exposure to stressors and potential sensory triggers, but discuss this with the child and their family. Some children are better suited following their morning routine, then coming in for an afternoon list. A decision to prioritise a neurodiverse child should be made in collaboration with the surgeon and anaesthetist, taking into consideration the child's specific needs.

### Premedication

Neurodiverse children can experience heightened anxiety and distress when faced with unfamiliar environments or with the anticipation of surgery/medical procedures. The use of sedation pre-operatively in neuro diverse children can be useful to reduce anxiety, facilitate cooperation and ensure a smoother transition to the anaesthetic room. Ensure all planned for premedications are available on the ward.

## Environment

It is strongly recommended that Children's Surgical Wards are designed to include at least one cubicle. Ensure a cubicle is allocated for a child's admission where they have sensory needs. A cubicle may provide a more controlled and quieter environment, reducing sensory stimulation which may overwhelm or distress the patient. A cubicle also provides an enclosed space that can be made more familiar and comforting with the patient's personal belongings or sensory items that the child finds reassuring and calming.
A booking system for cubicles can be helpful to ensure all children requiring one can be offered one.

Cubicles can be adapted with sensory lights, bubble machines, ceiling light tiles, projectors and other equipment/decoration to make a calming environment. If more suited a floor mat or large bean bag could be provided in place of a bed/trolley preoperatively.
Also, in preparation of the cubicle, ensure it is free from any potential hazards. Remove any unnecessary equipment that may cause confusion or be overwhelming for the child/ young person. Where no cubicle exists, choose as quiet an area as possible, use curtains, and lights and music to distract from other sights/ noises.

### The Wider Team

Introduce members of the wider team; nurses that work on the surgery ward, and a play specialist. The **play specialist**/ play support worker is a key member of the team and has a role to support the child/young person during their admission and create a positive and child-friendly environment. Key aspects of their role include preparing the patient for the hospital admission, offering emotional support and coping techniques, individualised play interventions, play based education and behavioural support. The play specialist/support worker should support the transition between different aspects of care: pre-operative, post-operative and recovery as this will help maintain consistency and provide continuity of care, ensuring the patient's adjustment and emotional wellbeing at each stage.
Consider input from the child or young person's special educational needs school, or positive behaviour support team, or any other key workers. They are a good source of information- about the child's needs, and can also support in the preparation of the child, and even help with desensitisation. They can be part of preassessment conversations virtually, especially where the parent/ guardian needs some support.

## Day of admission- Pre-operatively

### Welcome and Relationship building

Greet the child / young person and their parent(s)/carer on arrival to the ward. An allocated nurse to show them to their cubicle, or bed space and allow time to settle. The parent/carer should also be orientated to the ward. This is a good time for a Play Specialist to introduce or reintroduce themselves.
Ensure the accompanying parent/carer has parental responsibility to consent.

### Observations

The allocated nurse should work with the parent/carer to obtain baseline observations wherever possible. This will include the patient's weight, a full set of baseline observations; TPR, BP, Oxygen saturations and PEWS score should be recorded prior to the anaesthetic or premedication administration.

Ideally these observations would be compared to observations from preassessment, acting as a baseline. Document any difficulties in obtaining the observations and make the anaesthetic team aware prior to transfer to theatre.

## Name bands

Attempts should be made for all children to wear two name and/or allergy bands, as per local policy. If the patient refuses; explore the reason why. Work with the parent/carer to establish the best option for these; e.g. Wrist, ankle, tighter, looser, placed over a sock, with the top of the sock folded over.
If it is due to sensory sensitivities or discomfort associated with wearing the name bands then document in patient's notes and alert the anaesthetic team. Ensure when accompanying the child to the anaesthetic room that 2x wristbands are present with all other required documentation.

### Site Marking

If the patient refuses site marking then a discussion should be held with the operating surgeon. **The operating surgeon needs to take ultimate responsibility for any decision made**. A solution could be the following:

1. Consent obtained from parent(s)/carer prior to going to the anaesthetic room with correct site verbally confirmed **AND**
2. The site is marked in accordance with a) the consent form and b) a site marking form once the patient is anaesthetised.

A site marking form is available in the appendix: A form which states that site marking is not possible. It includes: the child's identifying details, procedure and site, a body map with site marked, and a signature from the operating surgeon.

## Pain Assessment and Management

Pain is often under measured in children with neurodevelopmental, learning and behavioural needs. It is an important issue because of the medical complexity in these children and management is complicated because of communication barriers, which make it extremely difficult to assess, interpret and therefore effectively manage pain in these children.
Discuss available pain tools with the parents/carer, and the child/ young person if able. Confirm understanding of how the child/ young person expresses pain, acknowledging the parent/carer as the expert on their child. Now is also a good time to discuss a pain management plan too.
Pain assessment and management should ideally be covered in preassessment in addition and form part of the preassessment care plan, especially if it is something the child/young person/ parent/carer is worried about. If there are other pressing concerns, this may not have been prioritised (7).

### Premedication

If a premedication has been agreed, then check and administer the prescribed dose. Monitor the patient for signs that the sedative is becoming effective. It may now be possible to record vital signs, apply name bands and site mark the patient if patient refused previously. Any further difficulties should be clearly documented.

If the patient is sedated a registered nurse should accompany the patient to the anaesthetic room with the parent(s)/ carer.

### In the Anaesthetic Room

The accompanying Nurse and/or Play Specialist, should support the anaesthetic team in the distraction of the child/young person. This may include: looking at a book/ tablet/ guided imagery/ focusing on breathing/ using a virtual reality headset. The parent/carer should be supported to remain with the child/young person, until the patient is anaesthetised. The child's named Nurse should take responsibility for communicating with the recovery team, ensuring that they are informed of any important information, and should request early notification of the patient's transfer to recovery to allow early involvement of the parent/carer.

## Day of admission- Post-operatively

### Recovery

Recovery staff should call the ward to notify nursing staff that the patient is showing early signs of waking to avoid distress of the patient waking in an unfamiliar environment. The parents/carer can be escorted to recovery to reassure their child, as they wake, and the patient should be returned to the ward as soon as it is safe to do so. Re-orientate the child by talking to them about what has happened, reassuring that the procedure is finished / complete, and what will happen next.

### Ward recovery

Post op observations, should be completed as normal, as tolerated, document and share any difficulties, and listen to parental concern. Keep the child/ young person safe, and as comfortable as possible. Provide the child with familiar items; blankets, toys, food items. Ideally the Parent/carer should be updated by the surgeon post operatively. Be proactive with pain assessment and implementation of the post-operative pain management plan.

### Discharge

Begin preparing for discharge early. Ensure the discharge documentation is ready and medications to take home are available, ready for discharge when able.
The patient may be discharged home when safe to do so and parents are confident at managing their child post anaesthetic. Follow local nurse led discharge criteria (if using) to support this decision, otherwise follow local protocol of a medical discharge.
Understand the patient may not want to eat and drink in unfamiliar surroundings. Discuss with the anaesthetist/surgeon. Offer safety netting advice both verbally and give the parent/carer written information in addition. Ensure that the family know how to contact the ward/ ED if advice is required.

## Training and Education

- The Oliver McGowan Mandatory Training on Learning Disability and Autism - elearning for healthcare (e-lfh.org.uk)

- National Autistic Society, E-Learning offers: E-learning (autism.org.uk)

- PECS- Picture Exchange Communication System training, for confident use of the communication board with symbols or icons, or visual cues for specific request or actions PECS Level 1 Face to Face Training Workshop (pecs-unitedkingdom.com)

## Case Study 1

A 13-year-old boy, Jay, is referred to preassessment for dental extractions, fillings, and a scale and polish.

The nursing team ascertain the following:

**Background**

-Jay is severely autistic, is non-verbal, can become aggressive and lash out/hit

-failed attempt few months back

As well as booking the young person into a nursing preassessment, they are also referred for a consultant led appointment.

**Consultant-led PAC:**

**Exploring issues/concerns with care givers**

-It's very hard and distressing to have vaccinations

-sedation- will spit out

-likes: dim lights, reggae music playing on his tablet, fleece blanket/comforter, sucking thumb in buggy

- parent is concerned he will hit staff

**Reasonable adjustments**

-first on afternoon list so has breakfast

-no sedation, bring straight through to theatre from car in buggy and checks made in anaesthetic room

-dim lights, his music, comforter, both parents

-gas induction in buggy with parental hug, and team to transfer onto bed once asleep

-cannulate foot and wrap if possible so he does not see it in his hand

-parent into recovery as soon as deemed safe to

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## Case Study 2

A 5 year old boy, Jack, is referred to preassessment prior to undergoing an adenotonsillectomy on the day case ward.

The nursing team ascertain the following:

**Background**

-Jack is being investigated for likely autism and possible ADHD. Has limited language development, only verbalises a few words, or 2-3 word sentences, can become distressed and frustrated when communication in both directions is confusing.

- Starting school has been a difficult transition, but is now going well.

-Both parents are concerned about how he will cope with a hospital admission.

The preassessment team spoke to Dad on the phone, and he felt that a visit to the hospital would help, and a face to face nursing preassessment clinic appointment was arranged. A double appointment was organised, so that 30 minutes was allocated instead of 15. A date was chosen where there was a simultaneous consultant-led preassessment clinic, in case there were remaining concerns, or matters to discuss with an anaesthetist.

**Nurse-led PAC:**

-The preassessment nurse met the family, and as there were no other families in the waiting room/ play room, the appointment was held there. A play specialist also joined the appointment and focused on Jack, showing him hospital play equipment (dolls, medical sets and real hospital equipment).

-The nurse could focus on completing a systematic assessment of Jack with his parents, taking a medical and social history, using a structured proforma.

- Jack was fit and well, except recurrent episodes of tonsillitis, which meant his schooling was being disrupted, and also some early signs of tooth decay- noted by his dentist.

-Jack has never been in hospital before. He hates his trips to the dentist though and gets very wound up beforehand. He also did not cope with his pre-school boosters either.

-They also complete a 'All About Me' Day Surgery Passport to learn all about Jack.

-The preassessment nurse and play specialist learn that Jack uses PECS symbols at school, so explain to Jack using a PECS social story about coming into hospital. Then they take him to see the Day Surgery Unit, letting Jack keep hold of his communication board.

- After, they give Jack some choices about coming into hospital. What would he like to wear? What is his favourite toy, and would he/she/it like to come too? Would he like a bed in the room with all the other children, or a quieter space? What would he like to eat or drink after he wakes up?

Jacks parents are feeling much more relaxed about coming into hospital now. The nurse still offers for them to meet the Anaesthetist.

**Consultant-led PAC**

- The preassessment nurse gives a SBAR style handover to the consultant.

- The anaesthetist explains the options for putting Jack to sleep. Due to his intense dislike of needles, they all agree that induction using a mask will be the best option. Jack had been practising putting the pink mask on the dolls earlier. He is given one to take home to practise doing big breaths into.

- If Jack is particularly anxious when he arrives at the hospital, then he can have a premedication. The play specialist will meet the family though when they arrive, and they have agreed that she will organise some trucks and cars to be ready when Jack comes in.

**Reasonable adjustments**

- Longer preassessment appointment and hospital visit

- 'All about me' assessment

- Play specialist involvement along the whole pathway

- If there had still been concerns, the preassessment team could have spoken to the school, to see how they had managed Jack's transition and communication with him.

- First on the list

- PECS surgery journey chart with Jack, so he can communicate before and after his anaesthetic

- Wear his own clothes in theatre- jogging bottoms and a t-shirt

- Gas induction and pre-medication if required

- Parent into recovery as soon as deemed safe to

# Appendix

The following resources are available on the STPN Website on the Surgery in Children pages Preassessment | South Thames Paediatric Network:

### Site Marking Form

### Visual Aids/ Communication Resources

Picture Sequencing cards
PECS Surgical Journey Story
Widget Surgical Journey Story
Makaton Surgical Journey
Blank Surgical Journey- to complete with patients/parents/carers

### STPN Anaesthesia and Theatres 'All About Me' Day Surgery Passport

### Preparatory Hospital Videos- Local examples

Ashford and St. Peter's Hospital Trust
'Children's Surgery at St. Peter's Hospital'
Children's Surgery at St. Peter's Hospital (youtube.com)

Lewisham and Greenwich Hospital Trust
'Welcome to the Children's Day Care Unit - Eve's journey at LGT'
https://youtu.be/Fz_J66KjV-c?si=-2KZ4VMFEKn4oQVF

# References

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