Anaesthesia for children with special needs, including autistic spectrum disorder

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Key points
- Learning disability affects up to 2% of the population.
- Children with special needs face many physical, psychological, and social challenges which affect their ability to cope with the routines of hospital-based care.
- A flexible, holistic approach to treatment, with good communication and individualized planning of care can create a positive experience for child and family.
- Knowledge of augmentative and assisted communication methods is useful when caring for children with language and communication disorders.
- Children with autistic spectrum disorder require special consideration, both in terms of communication and choice of anaesthetic technique.

Approximately 2% of the population are thought to have a learning disability, with an estimated prevalence in England of 75,000 children and young people whose condition is moderate to severe. For the purposes of this article, the term ‘special needs’ encompasses learning disability (IQ < 70), language and communication disorder, or any disability that prevents a child from coping well with new experiences.

Although children with learning disability may have robust physical health, developmental delay is often one manifestation of a syndrome or condition associated with other physical comorbidities (e.g. cerebral palsy, Down’s syndrome, metabolic disorders). Clinical aspects of the anaesthesia management of these conditions have been addressed previously in this journal and can be found in the archive.

Many children with special needs may attend hospital for investigations, medical management, or surgery. They may exhibit high levels of anxiety when faced with hospital treatment, and may have difficulty conforming to the usual pattern of care. In extreme cases, children may become so uncooperative that their procedure is postponed or abandoned, or can only be undertaken with the use of heavy sedative premedication or restraint. It is therefore important to find ways to meet their individual needs, particularly in areas such as information, communication, and pain assessment in order to minimize anxiety and distress and create a calm and positive experience for the child and family. These psychological and social aspects of care will be the focus of this article.

Psychological challenges
- Preoperative assessment
  - History and examination: patients may be unable to describe symptoms or give an account of their medical history; the objective view and history from the parents/carers is therefore very important. If patients also find it difficult to accept the physical contact of an examination, it may be necessary to perform an examination under anaesthesia and make an on-table decision on surgical management. Although it allows some flexibility, this approach may complicate the consent process and may require the surgeon to speak to parents while the child is anaesthetized.
  - Investigations: patients may be unable to understand the instructions required to perform investigations (e.g. pulmonary function tests) and may have difficulty cooperating with more invasive investigations (e.g. blood tests, MRI scans). Compromises may therefore be required (e.g. opportunist blood sampling while anaesthetized).
- Admission process
  - Preparation: children with special needs may have limited understanding of the reasons for being in an unfamiliar environment and for the necessity of procedures, which may, at times, be uncomfortable or even painful.
  - Behaviour: patients may be unable to communicate their distress in a way hospital staff can understand, and may demonstrate uncooperative or even disruptive behaviour.
  - Routine: children with special needs often depend on a familiar, sometimes rigid, daily routine, and find the alteration of this routine in hospital difficult to tolerate. Particular issues include waiting for long periods in crowded, noisy areas and prolonged fasting.
- Postoperative
  - Pain assessment and management: children with low IQ or language and communication disorders may not be able...
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to describe the location or nature of their discomfort or use self-rating pain scales. Validated observational scales such as the FLACC score or scales based on knowledge of individual pain behaviour may be required to ensure adequate pain management.

- Cooperation with physiotherapy: patients may be able to comply with passive forms of treatment, but may not be able to undertake self-motivated exercise and therapy that would otherwise enhance recovery.

**Social challenges**

The social impact of a visit to hospital on a child with special needs and their family is not insignificant. Surveys of families’ views have reported perceived inadequacies in care delivery which are much more related to the social aspects than the medical treatment. Examples include:

- lack of staff knowledge and understanding of the specific challenges faced by families;
- reliance on family carers in hospital;
- difficulties in ensuring patients are adequately supervised when family members are not present;
- the impact of the child’s hospitalization on carers and families;
- difficulty in coping with the routines or unpredictable nature of the hospital setting;
- the challenge of managing the activities of daily living, including feeding, moving and handling, entertainment, and hygiene needs when outside of the familiar home environment.

Understanding and minimizing some of these potential sources of frustration can greatly improve a family’s experience.

**Autistic spectrum disorder**

One of the groups of patients which may require the greatest flexibility of approach is those with autistic spectrum disorder (ASD). ASD is a lifelong developmental disability, affecting four times as many males than females, which affects how a person communicates with, and relates to, other people and the world around them. It is characterized by a ‘Triad of impairments’:

- difficulty with social communication;
- difficulty with social interaction;
- difficulty with social imagination (see later explanation).

Patients with ASD may have a lower than average IQ, but they may, in contrast, have normal or even high intelligence. There are many psychological theories which attempt to explain the altered social functioning in people with ASD, including lack of ‘theory of mind’; this may help us to understand some of the challenges faced in providing anaesthesia care to patients with ASD. Theory of mind is the ability to attribute mental states, beliefs, intents, and knowledge to oneself and others, and to understand that others’ beliefs are different from one’s own. People with autism have a theory of mind deficit—they have difficulty seeing another’s perspective, difficulty in determining the intentions of others, and lack understanding of how their behaviour affects those around them.

Some perceptual deficits seen in autism include:

- **Mental physical distinction**: the difference between thinking and doing.
  - If told that Peter is thinking about a dog and James is holding a dog, a child with ASD will be unable to judge which boy can actually stroke the dog.

- **Functions of the brain**:
  - Autistic children tend to know that the brain can make you move, eat, drink, etc., but lack appreciation that it also has higher mental functions—thinking, dreaming, wanting, keeping secrets.

- **Appearance—reality distinction**:
  - Children from the age of 4 yr are usually able to distinguish between appearance and reality—for example, when shown a candle in the shape of an apple, they will understand that it is an apple-shaped candle. Children with ASD will say it is an apple or a candle but will not capture its dual identity in their description.

- **False belief**: lack of understanding that people’s minds do not hold the same information.
  - The classic test for false belief is the Sally–Anne test. The child is introduced to two dolls, Sally and Anne. Sally has a marble, which she puts in her basket; she then leaves the room. Anne enters, sees the marble and takes it, hiding it in her toybox. Sally then comes back. The child is asked where Sally will look for her marble. The child passes the test if they say the basket, acknowledging that Sally thinks it is still there. Eighty-five per cent of clinically unimpaired children and 86% of children with Down’s syndrome pass the test, but 80% of children with autism fail it by saying the toybox, because they believe that Sally knows what they know. This lack of understanding may explain why children with ASD may become confused by repeated questioning or a lack of appreciation of their wants and needs.

- **Lack of social imagination**: deficits in flexible thinking regarding interests, routines, perspectives, and rules.
  - The child with ASD may struggle to reflect on an unreal world that exists only in the mind, viewing the world in a very literal way. They cannot generalize information and have very little imagination or understanding of fantasy or fiction. They may be confused, therefore, and gain little benefit from the use of ‘magic’, imagery, or metaphorical language in the anaesthetic room.

Children with ASD are often very reluctant to be touched or examined and may display repetitive patterns of behaviour (sometimes becoming distressed if their opportunity for such behaviours is limited by the situation). They may have a limited range of
preferred food and drink, be reluctant to make eye contact and be non-verbal, or, conversely, demand repeated complex factual explanations of every stage of the procedure.

There is emerging evidence that, in a proportion of children, ASD is associated with biochemical and metabolic abnormalities. These may include mitochondrial dysfunction, increased lactate, general B-vitamin complex deficiency (associated with the limited dietary choices of ASD children and/or intestinal dysfunction), and increased oxidative stress, associated with membrane lipid abnormalities. Although anaesthesia and sedation do not present a major problem for most children with ASD, unpredictable regression in skills and behaviour is noted in a small number of patients after general anaesthesia. It may be appropriate therefore to adopt an anaesthetic technique suitable for patients with mitochondrial disease. Recommendations include good hydration, minimal fasting, care with Hartmann’s solution (due to elevated blood lactate levels), maintenance of normal blood glucose, body temperature and acid–base balance, and avoidance of oxidative stress.

**Anaesthesia strategies for the child with special needs**

A flexible and holistic approach to care should be adopted. Where possible, efforts should be made to coordinate interventions required by multiple specialities so that they can be carried out during the same anaesthetic. Careful consideration should be given to the family’s needs and patient’s particular requirements for communication, explanation, preparation, and premedication.

**Preoperative care**

- **Assessment:** it is essential that a system is in place to allow the ward and anaesthetist advanced notification that a child with special needs will be attending for surgery, so that their particular requirements can be assessed and met. Ideally, a checklist should be completed before admission to explore the child’s physical and psychological needs, including information on mobility, communication methods, likes, dislikes, and phobias. This can be carried out by telephone, or by a parent/guardian attending the hospital without their child before the admission. An example checklist is provided in Figure 1. Measurement of weight, height, and baseline observations can be obtained in the community setting if necessary. Gathering such information in advance is invaluable to help plan the logistics of the day of surgery. For example, provision of a quiet waiting area, and placement first on the operating list to minimize the fasting time. Families should be encouraged to bring to the hospital any activities toys or other familiar ‘comfort’ objects which they know will calm their child and keep them entertained. If the child has a ‘communication passport’ listing information about their needs, routines, and communication strategies, it is very helpful to have this available during the admission.

- **Preparation:** conventional patient information resources may be inappropriate or inaccessible to the child with special needs, even those designed specifically for children and young people. It is therefore important to take time to explore the individual child’s level of understanding and communication needs to facilitate smooth perioperative care. For children with low cognitive ability, the presence of a familiar carer and maintenance of physical comfort are particularly important.

- **Patients with limited spoken communication may already use a form of augmentative and alternative communication (AAC)** and providing information using their familiar communication method can aid the child in navigating the steps in the anaesthetic process. Examples of AAC are discussed below.

- **Premedication:** local anaesthetic cream to facilitate i.v. cannulation should be encouraged, but may not be tolerated by all patients. In this situation, cannulation may be avoided until the patient is anaesthetized after an inhalation induction. Children with special needs may require sedative premedication to alleviate anxiety and promote cooperation with anaesthetic procedures. Good communication and preparation can aid in encouraging the child to take oral medicine, but it may be necessary to disguise it in cordial or even a teaspoon of a favourite food, such as jam or yoghurt. Very occasionally, by individual arrangement, and with close liaison and planning with a parent/carer, premedication may be necessary before arrival at the hospital. In these circumstances, lorazepam may be a suitable option. Midazolam is a commonly used premed, although some children with ASD may occasionally become paradoxically dysphoric rather than sedated. For children with challenging behaviour, ketamine or a combination of ketamine and midazolam is often successful. Premedication options are suggested in Table 1.

Patients may be taking regular medication to modify behaviour, which should be taken into consideration on an individual basis. Such drugs may include stimulants, anti-psychotics, and nocturnal melatonin.
Table 1 Premedication regimes for children with special needs

<table>
<thead>
<tr>
<th>Drug</th>
<th>Administration route</th>
<th>Dose</th>
<th>Maximum dose</th>
<th>Onset time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Midazolam</td>
<td>P.O.</td>
<td>0.25–1 mg kg⁻¹</td>
<td>20 mg</td>
<td>20–30 min</td>
</tr>
<tr>
<td>Ketamine</td>
<td>P.O.</td>
<td>3–5 mg kg⁻¹</td>
<td>20 mg</td>
<td>30–60 min</td>
</tr>
<tr>
<td>Midazolam +</td>
<td>I.M.</td>
<td>1–2 mg kg⁻¹</td>
<td>3–5 min</td>
<td></td>
</tr>
<tr>
<td>ketamine</td>
<td>P.O.</td>
<td>0.5 mg kg⁻¹</td>
<td>20 mg</td>
<td>~30 min</td>
</tr>
<tr>
<td>Clonidine</td>
<td>P.O.</td>
<td>3 mg kg⁻¹</td>
<td>150 µg</td>
<td>45–60 min</td>
</tr>
<tr>
<td>Lorazepam</td>
<td>P.O.</td>
<td>4 µg kg⁻¹</td>
<td>150 µg</td>
<td>45–60 min</td>
</tr>
</tbody>
</table>

Table 2 Autism dos and do nots

- **Dos**
  - Minimize waiting times
  - Warn before making physical contact
  - Get information from parents and carers
  - Speak quietly and gently
  - Recognize that the patient may not wish to communicate
  - Offer preferred foods when possible
  - Give clear explanations
  - Minimize disruption to normal daily routine
  - Provide a clear plan for the day ahead

- **Do nots**
  - Allow prolonged waits in noisy environments
  - Initiate physical contact without the patient’s assent
  - Make assumptions about a child’s understanding or cooperation
  - Raise your voice
  - Assume that a lack of communication indicates a lack of understanding
  - Spring surprises—routine is very important
  - Use complex language such as metaphor or imagery

- **Patient care**: some general strategies for managing a child with ASD are suggested in Table 2. The anaesthetic room should be a calm environment facilitated by the presence of a parent/carer, low-level lighting (compatible with safe working practices), minimal extraneous noise, and the fewest healthcare personnel possible. If the child is very uncooperative despite preparation, premedication, or both, re-sedation or postponement of surgery may be necessary.

- **Restraint**: physical restraint should be avoided if at all possible, although it is important to acknowledge that a degree of restraint may be a usual element of the daily lives of some children with special needs to promote their safety; if parents or carers are skilled in holding their child, it may be considered acceptable for therapeutic holding to occur to facilitate induction. If physical restraint is considered unavoidable as a last resort, adequate members of trained staff should be available to control the situation as quickly and effectively as possible. Parents should be forewarned about what to expect. It is good practice to record how the child acts during induction and after the operation to aid future anaesthetic management.

**Peroperative care**

While sedative premedication may have been necessary to allow induction of anaesthesia, there are advantages to keeping the anaesthetic plan as simple, straightforward, and flexible as possible. Good analgesia is essential, with liberal use of local anaesthetic techniques, paracetamol, and non-steroidal anti-inflammatory drugs. There should also be a low threshold for administration of an antiemetic agent and an isotonic crystalloid fluid bolus to minimize postoperative nausea and vomiting. These measures are particularly important in children with special needs, as it may be very difficult to assess and distinguish between the potential causes of postoperative distress—pain, nausea, numbness due to local anaesthetic, emergence delirium, unfamiliar nurses, residual disorientation from preoperative sedation, etc.

**Postoperative care**

A rapid smooth recovery and early discharge should be the aim for physically well special needs patients who have had straightforward day surgery. I.V. cannulae often cause distress and should be removed as soon as possible once it is clear that the patient has full control of their airway and there is no obvious need for further i.v. medication. To minimize disruption to the patients’ daily routine, and after discussion with carers, they may be discharged once they have regained their usual baseline in terms of orientation and mobility, without necessarily meeting the usual discharge criteria (e.g. to have eaten, drunk, or passed urine). Advice and instructions should be offered to carers regarding regular appropriate analgesia at home. Vigilance should be advised in helping a child to protect an area which has been infiltrated with local anaesthetic (e.g. avoiding lip biting after dental surgery).

Pain management in non-verbal children may be challenging and the use of behavioural pain rating scales and the assistance of the parents and carers may be required. As many children with special needs are unable to manage patient-controlled analgesia systems after major surgery, they may benefit from nurse-controlled protocols allowing for background infusion of opioid with the facility for bolus administration in response to pain scoring. Any i.v. cannulae, nasogastric tubes, or other clinical or monitoring apparatus may need to be well secured and bandaged to prevent their dislodgement.

**Communication**

One of the most important aspects of high quality healthcare is good communication. Many strategies are available for communicating...
with unimpaired children, to provide explanations, or influence behaviour, including descriptions, stories, training in coping strategies, distraction, metaphor, imagery, and modelling. Some of these options may be appropriate for children with lower IQ, but alternative methods may be more suitable for children with language and communication disorders, for whom conventional communication is difficult or impossible.

Patients with limited speech may benefit from the use of sign language, such as Makaton (www.makaton.org), symbol charts, or the Picture Exchange Communication System (www.pecs.org.uk).

Patients with ASD and limited social understanding may benefit from practical coping strategies, concentrating on how to manage a new situation. Examples would be symbol timelines, social stories, and behavioural management programmes. Some familiarity with the communication aids used by patients at school and home can help in providing information and encouraging discussion in hospital.

When speaking to a patient with special needs, it is helpful to use simple words and language, to speak clearly and directly, to make eye contact if possible, and to avoid complex forms of

**Fig 2** Symbol selection for anaesthesia; Widgit Symbols & Widgit Software 2002–2012 www.widgit.com.
language such as jargon, abbreviations, acronyms, sarcasm, or metaphor. For patients with little receptive or expressive language, various alternative forms of communication exist (AAC).

**Augmentative and alternative communication**

AAC includes methods which supplement the usual use of speech/writing and which help expression as well as understanding. They may be:

- **Unaided**
  - methods which use only the body to enhance communication;
  - body language, facial expressions, gestures, signing.
- **Aided**
  - methods which require the use of equipment or resources;
  - low tech: writing, drawing, picture boards, symbols, objects;
  - high tech: require a power source: message devices, computers, electronic aids.

Symbol timelines may be particularly useful to break down the process of admission to hospital and subsequent treatment into discrete manageable steps. This can reduce anxiety by allowing activities (such as being weighed and having a name band put on) to be rehearsed in advance and then prompted individually when required during the hospital stay. If the steps are illustrated in a way which is familiar (e.g. Widgit symbols used in special needs education), children may be empowered by recognizing a system they understand and by exercising some choice in the order in which some of the steps are tackled. It is important to emphasize a clear benefit to completing the sequence, such as eating, drinking, and going home. Examples of anaesthesia-related symbols are shown in Figure 2; a day-case admission timeline is available for free download from the RCoA patient information website children’s pages (http://rcoa.ac.uk/childrensinfo), along with other anaesthesia information resources for children and young people.

Social stories are a powerful way of assisting people with ASD to cope with new social situations. By explaining the context and providing information about the perspective of others and missing social cues, they can help people with ASD to model their reactions and behaviour appropriately. An example of the style of a social story is shown in Table 3. Social stories must be carefully written and individualized, and may be best prepared in conjunction with the child’s carers. If a child has been prepared for a hospital admission using a social story, it is important to try to work within the child’s understanding on the day.

**Table 3** Example of a social story for the application of local anaesthetic cream

<table>
<thead>
<tr>
<th>The nurse will put some cream on my hand</th>
</tr>
</thead>
<tbody>
<tr>
<td>The cream is cold</td>
</tr>
<tr>
<td>It is held on by a plaster</td>
</tr>
<tr>
<td>When the nurse asks to put the cream on my hand, she will be very pleased if I hold my hand still</td>
</tr>
</tbody>
</table>