Supporting patients with additional communication needs

These infographics are designed to help you support patients with additional communication needs, for example autistic or other neurodivergent people, people with a learning disability, or those with other needs.

They provide strategies and reasonable adjustment ideas to help you support these patients across the full perioperative pathway. They can be used for both adult and paediatric patients.

This resource has been co-produced with experts by experience from the learning disability charity My Life My Choice, healthcare professionals and patient representatives.

In the weeks before surgery

On the day of surgery

Recovery and discharge

In the weeks before surgery

Start planning early for maximum success.

- Once a patient with additional needs has been identified, arrange for a hospital/communication passport to be completed as soon as possible and before preassessment. This is a document that provides information about a patient's individual needs and likes and dislikes. You can view an example of a healthcare passport on the NHS England website: www.england.nhs.uk/publication/health-and-care-passports.
- Involve parents, carers, support workers, advocates and the learning disability team from the start to understand the patient's needs and any past experiences with surgery. Involve and seek advice from a play specialist at your hospital if appropriate.
- Arrange for a comprehensive preassessment, which should be face to face. You may need to allow for a longer appointment so that you have time to explain what is going to happen in detail, for example, the type of anaesthetic and induction or any premedication and equipment that will be used, for example, wristbands, cannulas, blood pressure machines, etc.
- Be flexible about how you are going to carry out the preoperative assessment. A clinic environment is not always appropriate. You might consider using the play area or the sensory room or combining the assessment with a tour of the hospital (see below). In some rare cases, a home visit via the learning disability team may be required. What is important is to get to know the patient in person because this will help you understand their needs and what strategies might help on the day of surgery.
- Consider arranging for appointments, tests, measurements and hospital visits to all be done in one day to minimise stress and repeated travel to the hospital.
- Draw up a personalised care plan with all the necessary reasonable adjustments. This should consider things like the following: best time of surgery to minimise stress; any sensory needs (dimmed lights, calming music and reduction of noise); comfort items (toys, blankets); and any likes and dislikes as per the patient's hospital passport.
- Do not assume that a sedative premedication is always necessary. Very often, with a well-thought-out care plan in place, sedatives are not required and should be explored only if there are still concerns after all the other adjustments have been considered.
- Offer a tour of the hospital and surgical ward, if the patient and carers would find this helpful (this can be scary for some). If a tour is not an option, you could provide photos of any members of staff whom they are likely to meet on the day of surgery. You could also provide equipment to take home so that they can become familiar with it, for example, a mask, a wristband or a cannula with the needle removed.
- Take note of their communication style as described in their passport. Do they need sign language, Makaton, Easy Read or visual aids, for example, for questionnaires? The RCoA offers an Easy Read leaflet to explain what to expect when having an operation, which you can view here: www.rcoa.ac.uk/patientinfo/easy-read.
- Ensure that the patient passport and personalised care plan are shared with all the teams involved (preassessment, surgery, surgical ward, recovery, play specialists, etc). The passport should be added to the electronic patient record system and be easy to access and view for everyone.

On the day of surgery

Be ready to adapt on the day and allow extra time for the unexpected.

- Follow the agreed plan, patient passports and any agreed reasonable adjustments as closely as possible. Last-minute changes can cause distress and anxiety.
- Make sure again that all healthcare professionals involved in the care of the patient have copies of the personalised plan and patient passport and that they are aware of the reasonable adjustments agreed with the patient and carers.
- Arrange for quiet rooms, if necessary, or for noise and lights to be kept to a minimum, as per the patient passport.
- Arrange for the play area or sensory room to be available to the patient and for support from a play specialist if required.
- Some patients do not like to be touched and may even refuse wrist bands and routine observations on the day. Have to hand a range of equipment and strategies to distract and reassure, for example, tablets, dimmed lights, dark glasses, fidget gadgets, ear defenders, favourite toy/comforter, virtual reality devices, etc.
- It may not be possible to mark the surgical site on the patient's body, but there are special consent forms with visual representations of a human body that can be used. The patient can then be marked once asleep.
- Consider using countdowns to signal transitions between one activity and another or to signal the end of something, for example, touching or taking a measurement.
- Allow patients to wear their own clothes, for example, pyjamas, and allow parents or carers in the anaesthetic room if required.
- People with learning disabilities often have eating difficulties or special dietary requirements. Discuss with them and their carers what food and drinks would be most appropriate for them, so that these can be arranged if possible.
- If they wear glasses and hearing aids, ensure that these are kept safe during surgery.

Recovery and discharge

Try to minimise delays and distress.

- Help reorientate the patient as soon as they come round from the anaesthetic, for example, allow parents or carers to be in the recovery room as soon as possible, and for any comfort items to be immediately available (toys, blankets, etc).
- Sensory input might be overwhelming for some patients as they wake up. Consider dimming the lights, reducing noise and avoiding unnecessary handling and touching in the recovery room. Some patients might need the sensory room during the recovery period.
- Make sure that you return their glasses or hearing aids, if they wear them, as soon as they are awake.
- Consider wrapping the cannula so that it does not cause any alarm and to protect it in case the patient becomes distressed. In some cases you might also need to add bed rails or bumpers.
- Listen to parents and carers at this critical time because the patient may not be able to express themselves. They know the patient best and will be able to warn you if distress is likely to happen or anything needs adjusting.
- Patients with additional communication needs experience and communicate pain differently. Adapt your assumptions about how someone might communicate pain and consider using a visual pain scale (you can see information about a simplified pain scale here: https://bit.ly/Simplified-Pain-Scale). Parents and carers can also help with this.
- Arrange for appropriate food and drink to be available, taking into account any dietary requirements and eating difficulties.
- Aim to discharge the patient as soon as possible by preparing discharge documentation and medications early, but only if safe to do so and parents or carers are confident in managing the patient.
- Provide patients, parents and carers with instructions for medications and recovery at home, including contact details, so that they know who to call in case of any problems or an emergency.

We hope that you have found the strategies and ideas in this resource helpful. The key thing is to listen to the patient and their carers and to remember that every patient with additional needs is different and requires a personalised approach.

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Tell us what you think

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This leaflet will be reviewed within three years of the date of publication.