

11 – Surgery, procedures and interventions

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Study Advisory Group question: *Are all aspects of care for patients with a cerebral palsy considered for those patients undergoing surgery, particularly perioperative planning and consent.*

Why is this important? *Surgery or interventional procedures are particularly common in this group of patients. It is important that these are planned carefully, communicated well and all members of the multidisciplinary team are aware of what is being undertaken.*

In this study 179/500 patients (35.8%) with a cerebral palsy underwent surgery or a procedure during their admission. This included radiological and endoscopic procedures as well as operative procedures most commonly undertaken under general anaesthesia or sedation (152/175; 86.9%). The majority (153/177; 86.4%) were classed as “planned”. This is in keeping with other recent multicentre studies showing that a relatively large number of children with a cerebral palsy undergo surgery.³¹ Patients with the cerebral palsies have also been shown in other studies to require more procedures per admission than other patients and for these admissions to generally be longer.³⁰

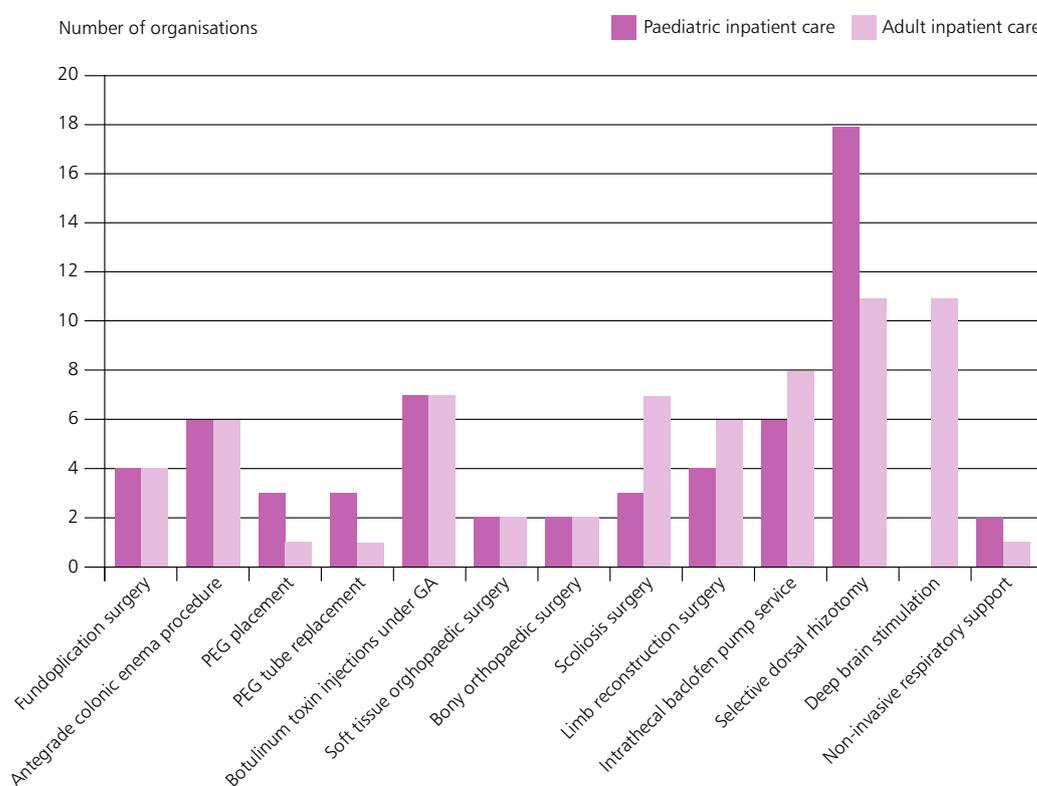


Figure 11.1 Procedures as stated by paediatric and adult inpatient leads as not available in local surgical networks

Respondents from a minority of inpatient organisations stated that they had problems with access to networks of surgical specialty care (Figure 11.1). Where there were, it seemed to be related to particular issues with access to specialist services for spasticity (including botulinum toxin injections, intrathecal baclofen and selective dorsal rhizotomy).

While patients of all ages underwent surgery and procedures a greater number occurred in children over five years, and in young people and young adults (Table 11.1). This differed somewhat from the overall paediatric surgical/ anaesthetic population where in data from UK national audits, the greatest level of activity across surgical specialties was in the under five age range much of which relates to correction of congenital anomalies and more minor ENT and dental surgery.^{51,52} Some of these issues will still occur in the cerebral palsy population but they will also have a greater number of procedures to facilitate diagnosis, manage nutrition and to treat posture and spasticity.

CASE STUDY 21

A child with a GMFCS level III cerebral palsy had a femoral osteotomy to prevent imminent hip dislocation and was re-admitted to their local district general hospital eight days post operatively with pain and vomiting. The child's mother had initially called emergency services as she had no other contacts for the (tertiary) orthopaedic team. The surgical centre was approximately 80 miles away and the patient seemed to have been discharged with only oral morphine to give as required. After a short admission requiring intravenous fluids and regular simple analgesia the patient was discharged home but with no obvious communication with the surgical centre, the multidisciplinary team or the patient's GP.

Reviewers commented that there was poor evidence of thorough discharge planning, including pain management. There was no record of regular simple analgesia being provided alongside opiates which might have meant that their side effects would have been minimised. The reviewers felt that this episode constituted poor evidence of a robust network of care.

Table 11.1 The patient underwent surgery or a procedure during the admission

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Subtotal	Not answered	Total
	n=	n=	n=	n=	n=	n=	n=	n=
Yes	18	34	39	39	43	173	6	179
No	74	87	53	47	59	320	1	321
Subtotal	92	121	92	86	102	493	7	500
Not answered	8	7	8	5	5	33	3	36
Total	100	128	100	91	107	526	10	536

When NCEPOD looked at the procedures undertaken they were in the main for orthopaedic surgery (including scoliosis surgery), management of reflux and nutritional support and alleviation of spasticity.

Preparation for surgery and multidisciplinary care

Given that most procedures and surgery were planned, paediatric inpatient centres reported whether they had a process in place for multidisciplinary team (MDT) discussion and preparation of patients with the cerebral palsies prior to planned surgery.

CASE STUDY 22

A young adult underwent revision spinal surgery for scoliosis in a major orthopaedic centre. They had a cerebral palsy and this was well documented at GMFCS level III. There was evidence of a pre-operative joint multidisciplinary team discussion including management of drugs in the peri-operative period. Consent was taken from the patient and this involved consideration of the risks of blood transfusion as well as possible surgical and anaesthetic complications.

Reviewers commented that this was the standard of care that many should expect in a “centre of excellence” and for a major procedure. However they also felt that messages were transferable for others and whether a procedure was minor or major.

Only 43 centres had routine pre-assessment clinics with medical/anaesthetic input and just 19 had a MDT discussion even for major surgery (Table 11.2). MDT preparation for major surgery was a recommendation of the 2011 NCEPOD report.⁵³ In children requiring complex surgery and many adults having all levels of surgical intervention this is now an established standard of care.⁵⁴ The advantages are that pre-assessment allows an opportunity for correction of remediable co-morbidity, and prepares the patient, their family and the team caring for them for the peri-operative pathway.⁵⁵ It also allows for timely discussion and reflection on the risks and possible complications of a procedure. The fact that MDT discussion and pre-assessment clinics were not currently the standard of care in all centres for a cohort of patients with a cerebral palsy and having major surgery requires further consideration.

There were 72/88 paediatric inpatient centres where it was stated that they had joint care of surgical patients with medical specialties, when patients were admitted for planned surgery. However, just 37 of them reported that this care was joint at all levels (Table 11.3). Very few organisations had existing guidelines and care plans specifically for peri-operative care of patients with cerebral palsies which included management of common co-morbidities. This is notable given that in some centres patients with neurodisability make up a relatively large population of patients.

Table 11.2 MDT preparation for surgery – organisational systems in place

	n=
MDT discussion prior to all planned major surgery	19
MDT discussion for high risk patients and/or major planned surgery	23
MDT discussion for high risk patients and/or major urgent or emergency surgery	15
Routine pre-assessment clinics with medical/anaesthetic input prior to planned surgery	43
Existing guidelines and protocols for peri-operative care of children and young people with severe neurodisability	8
Specific care plans for particular surgical pathways e.g. scoliosis surgery which include management of common co-morbidities associated with cerebral palsies	15

*Answers may be multiple

Table 11.3 Joint care of surgical patients with paediatric specialists

	n=
Joint care at all levels	37
Senior advice/input as required	36
Trainee input as required	6
Subtotal	70
Not answered	2
Total	72

*Answers may be multiple

Children and young people with neurodisability often have complex medical needs. A team approach with paediatric involvement is recommended and may be particularly important when care is delivered by surgeons and anaesthetists who work predominantly in general/adult practice.⁵⁶ 

CASE STUDY 23

A young teenager with a GMFCS level II cerebral palsy, mild learning difficulty and no additional co-morbidity was admitted to a large district general hospital for elongation of tendon achilles which was performed by an ‘adult’ orthopaedic surgeon who regularly operated on children and young people with neurodisability and continued to care for them in their adult life.

Reviewers commented on the excellent care delivered for this patient, including appropriate analgesia in a day case setting. There was also discussion of opportunities within networks of better arrangements for local care of patients, and examples of specialist surgeons from tertiary centres providing a regular contractual commitment to seeing patients and operating in the DGH, and maintaining close ongoing relationships with local paediatricians and surgeons.

In the organisational questionnaire for paediatric inpatient care those units that responded stated that it was routine practice to admit children and young people with severe neurodisability for surgery or procedures through the day surgery unit in only 15/88 organisations. Where this was not possible the most common reason was surgical/anaesthetic risk (50/73) (Table 11.4). From free text comments respondents stated that disabled children requiring routine surgery were often referred to a regional tertiary centre.

Table 11.4 Reasons for non-availability of day surgery

	n=
Surgical/anaesthetic risk is felt to be too great	50
Physical facilities are inappropriate in day procedure unit (e.g. lack of access, special beds etc.)	12
Lack of nurse competencies	4
Other (please specify)	27
Subtotal	93
Not answered	1
Total	94

*Answers may be multiple

There has also been a relative reduction in availability of local surgical services for children in the DGH in the last 20 years^{51,52} and this may have impacted on care of patients with complex comorbidity.

However, there were a number of cases reviewed within this study that underwent day admission for a range of procedures under general anaesthetic (e.g. Botulinum toxin injection, MRI, PEG change), and not all were admitted to specialist centres. It may be that the decision to provide surgery or a procedure locally is also dependent on the age of the patient and competence/confidence of local providers. In practice, clinicians within some units may be more flexible in terms of individual care and admission policy than this data reflects.

National data also reflects a high level of day case activity in patients with a cerebral palsy, much of which related to procedure. 

The Association of Anaesthetists of Great Britain and Ireland states that fitness for a procedure in a day case setting should relate to the patient's health determined at pre-operative preparation and not be limited by arbitrary limits such as ASA status or age and assuming cardiorespiratory stability.⁵⁷ This is re-enforced by more recent guidance specific to children and young people which includes recommendations for adequate pre-operative assessment for complex patients e.g. in a dedicated anaesthetic pre-assessment clinic and/or as part of an MDT prior to surgery.⁵⁸

There was evidence in the case notes reviewed of a high level of engagement and input by senior clinicians on the day in those caring for patients with a cerebral palsy and requiring surgery/ procedures. 99.4% (169/170) were seen by the person carrying out the procedure prior to it occurring. The largest group of clinicians providing surgery/ procedures was trauma and orthopaedics (35.5%), with paediatrics being involved in 5.9% of cases reviewed, and general and paediatric surgery accounting for 13% of cases (Table 11.5).

Table 11.5 Specialty of surgeon/operator who saw patient prior to surgery/procedure

	n=	%
Trauma and orthopaedics	60	35.5
General surgery	13	7.7
Paediatrics	10	5.9
Paediatric surgery	9	5.3
Neurosurgery	6	3.6
Other	48	28.4
Subtotal	146	
Not answered	23	
Total	169	

Patients and /or families 125/138 (90.6%) were also seen by a senior anaesthetist prior to their procedure or operation. Since many children, young people and young adults with a cerebral palsy admitted for surgery are at GMFCS III/IV/V, and have associated co-morbidities, this senior input is essential.⁵⁹

6

Consent

Consent for surgery or a procedure is an important process which involves the responsible clinician providing a clear explanation of what is proposed, the possible alternatives and any risks associated.⁶⁰ In children and young people it is important to use appropriate language and an explanation which is age and developmentally adjusted and to seek and respect the patient's view as well as to involve parent carers. In patients of all ages and except in rare and immediate life threatening situations, it should allow time for reflection, for questions to be asked and for these to be satisfactorily answered.⁶¹ Whilst it is good practice to take written consent (usually towards the end of this process to confirm agreement) this was often not done routinely for all patients where a general anaesthetic (GA) is not administered. Where procedures were carried out under a general anaesthetic data indicated that only one in five patients in this study signed the consent form themselves (Table 11.6). Given that 82/179 (45.8%) of patients in this study having surgery or a procedure were 15 years or older this appeared to be an important finding. This may be for a variety of reasons, including difficulties with communication in this population and differing consent practices across the UK countries.

6 12

Table 11.6 Person providing consent if the procedure/surgery was carried out under general anaesthetic

	n=	%
Patient	29	22.7
Parent/Carer	102	79.7
Clinician	22	17.2
Patient advocate/Proxy	1	0.8
Social services	2	1.6
Subtotal	156	
Unknown	6	
Total	162	

*Answers may be multiple

Competent children and young people may sign their consent form for surgery or a procedure. In England and Wales it is generally regarded as good practice to also ask parents to sign up to the age of 16 years. At 16 years, the young person will usually sign or otherwise indicate agreement entirely by themselves if they have capacity. However a parent carer may complete a consent form on behalf of the young person until they reach their 18th birthday if the patient lacks capacity.⁶² In Scotland, once deemed competent, the child or young person should do so alone and in practice this will generally be from age 12 - 14 in young people with age appropriate understanding.⁶³ Again a parent may complete instead and if the patient lacks capacity until the age of 18 years. In this study where written consent was not taken from 24/34 patients, this was because the patient lacked capacity, however, this was not answered in 100 cases, possibly because the patient gave consent. **6** **12**

Children, young people and young adults with a cerebral palsy may have particularly problems in completing a standard (written) NHS consent form due to either problems with motor skills, intellectual/learning disability or both. With regard to motor disability, various adaptations exist and guidance is available to clinicians on best practice when patients have degrees of motor disability and/or visual and or hearing loss. (Appendix 1)

There were just 15 patients who were aged 17 years or older who signed their own consent form prior to having a general anaesthetic for a procedure or surgery and in 12 they were the (only) signatory. A parent was the only signatory in 11 patients over the age of 16 years, and 10 of these patients were 18 years or older.

After the 18th birthday consent should be signed in the patient's best interests by the clinician undertaking the procedure/surgery. This does not preclude clinicians fulfilling the important responsibility of discussing diagnostic and treatment options and seeking agreement from parent carers/those as well as the patient for any proposed surgery or procedure. Some consent forms allow space for documentation of this discussion, but this is not the same as giving consent on behalf of the young adult.^{64,65}

The fact that in 10 cases reviewed it was identified that a parent was the only person to sign the consent form for a patient over 18 years was of concern. It was clear from these cases that there was still confusion and instances of poor practice in relation to the practical and legal application of proper consent procedures in this age group and when there are learning disabilities and/or issues with communication.

CASE STUDY 24

A young adult with GMFCS level II cerebral palsy and learning disabilities was admitted for routine surgery to correct a foot deformity on the same side as their hemiplegia. Records indicated that the patient was needle phobic and required considerable persuasion to have a premedication before attending the operating theatre. The patient's parent carer appeared to be the sole signatory on the consent form. There was no record in the notes of the patient's mental capacity and their own views on having this surgery.

Reviewers agreed that this practice was unsatisfactory and that in the absence of best interest decision making having been documented and agreed this consent was against GMC and legal guidance.

It is recommended by the GMC that clinicians taking consent should be appropriately senior in their role so that they can fully explain the procedure or surgery and any risks or complications to the patient and/or parent carers (where appropriate).

In the majority of patients (95/106) consent was taken by a consultant or senior specialist trainee (with or without CCT). It was noted that this question was not answered in 28 cases (Table 11.7).

Good practice requires attention to detail when obtaining consent, including the patient in the discussions and decision making and documenting everything clearly. Further discussion about inclusion and best interest decision making is included in chapter 6 on communication.

Table 11.7 Grade and specialty of the person who took consent

	n=
Consultant	70
Senior specialist trainee	12
Junior specialist trainee	8
Trainee with CCT	7
Staff grade/associate specialist	6
Specialist nurse	2
Allied health professional	1
Subtotal	106
Not answered	28
Total	134

Pain management

A policy of always asking about the presence of pain at each consultation with a patient with a cerebral palsy was reported to be in place in the paediatric outpatient care questionnaire in 29/80 organisations and in the community or disability paediatric care questionnaire in 33/80 organisations.

CASE STUDY 25

A teenager with bilateral cerebral palsy, GMFCS level III, was admitted for an elective day case orthopaedic procedure which went well and the patient was discharged home later in the day.

The case reviewer found an excellent, detailed consent form in the medical record, including detailed explanations of the procedure, its risks and benefits, and evidence of use of Makaton to assist with communication. Whilst not 'signed' by the patient there was ample evidence that they had been properly involved and agreed to surgery. The form was also signed by their parent carer.

Whilst lead clinicians for disability care stated that adequate routine enquiries about pain had been made in 159/184 (86.4%) patients, case reviewers found less frequent documentation of this (173/281; 61.6%) (Table 11.8). Where pain was present, reviewers stated that a documented care plan was in place in 98/126 (77.8%) patients and evidence that pain was adequately addressed in 78/121 (64.5%) (Table 11.9).

Table 11.8 Adequate enquiries were made about the presence of pain - reviewers' opinion

	Lead clinician for disability care		Case note reviewer	
	n=	%	n=	%
Yes	159	86.4	173	61.6
No	25	13.6	108	38.4
Subtotal	184		281	
Unknown	37		69	
Total	221		350	

Table 11.9 Where pain was present, a clear management plan made to address this - reviewers' opinion

	If pain was present:			
	Was a clear management plan made to address this?		Is there evidence in the notes that it was adequately controlled?	
	n=	%	n=	%
Yes	98	77.8	78	64.5
No	28	22.2	43	35.5
Subtotal	126		121	
Unable to answer	59		61	
Not applicable	71		60	
Not answered	94		108	
Total	350		350	

Reviewers were of the opinion that pain management could have been improved for 102/203 (50.2%) patients. They were unable to answer for 50/350 patients, found the question not applicable for 43/350 patients and did not answer for 54/350 patients. Reviewers reported that pain management could have been improved as detailed in Table 11.10.

Table 11.10 How pain management could have been improved - reviewers' opinion

	n=
Documentation of pain enquiry	85
Use of an appropriate scoring system	65
Evidence of a pain management plan	51
Referral to a specialist pain team	11
Total	212

*Answers may be multiple

Severe acute pain commonly occurs in association with procedures and surgery. In the peri-operative period pain scoring should be routinely employed in children and young people.⁶⁶ There are appropriate modifications of pain assessment scales for children of all ages and for children, young people and adults with neurodisability.⁶⁷

In this study peri-operative pain scoring was employed in three of four patients (Table 11.11).

Whilst in some cases pain might have been anticipated to be minimal (e.g. following endoscopy, change of feeding tube) there were many minor procedures in this cohort including e.g. a botulinum toxin injection where pain and discomfort can be substantial albeit generally of short duration. Pain assessment in these situations is still important, and as such procedures may need to be repeated. Pain should be monitored and addressed if longer term patient compliance is to be improved.

Pain scoring in patients with complex neurodisability and reduced cough/gag and/or respiratory drive may also be particularly important to assist with safer monitoring e.g. when delivering opiate based analgesia.

Table 11.11 The patient had regular pain scoring peri-operatively

	n=	%
Yes	100	72.4
No	38	27.5
Subtotal	138	
Unknown	29	
Not answered	12	
Total	179	

In virtually all cases where the question was answered (111/116) pain relief was felt to be adequate by admitting clinicians (Table 11.12). Without better/more routine use of pain scoring it is unclear how clinicians were able to make a decision about "adequacy" of analgesia. This might explain why for one third of patients this was unknown or was unanswered. Reviewers also felt that in 132/145 cases reviewed there was evidence that peri-operative pain relief was adequate, but again in a third of cases they were unable to answer.

CASE STUDY 26

A young patient with a cerebral palsy at GMFCS level V had a laparoscopic fundoplication in a large university hospital and was transferred to a paediatric high dependency unit for post-operative care. In addition the patient had a scoliosis, very difficult venous access and a vagal nerve stimulator with relatively poor seizure control. A DNACPR plan has been temporarily suspended in the peri-operative period. Analgesia was successfully provided with a combination of regular simple analgesics, local analgesia and a low dose nurse controlled morphine infusion.

Reviewers noted that this was a case where there was very good pain assessment and management. This was carefully supervised by a paediatric pain team which included a consultant paediatric anaesthetist.

Overall quality of surgical/procedural care

Case reviewers were asked to decide how good they thought surgical and procedure care had been overall, and whether there were areas for improvement (Figure 11.2). The two groups – admitted and day case patients for surgery and procedures were looked at separately. Overall the standard of care in day case surgery seemed to be slightly better but numbers were very small.

Table 11.12 Evidence of adequate peri-operative pain control – reviewers’ opinion

	n=	%
Yes	132	91.0
No	13	9.0
Subtotal	145	
Unable to answer	50	
Not answered	17	
Total	212	

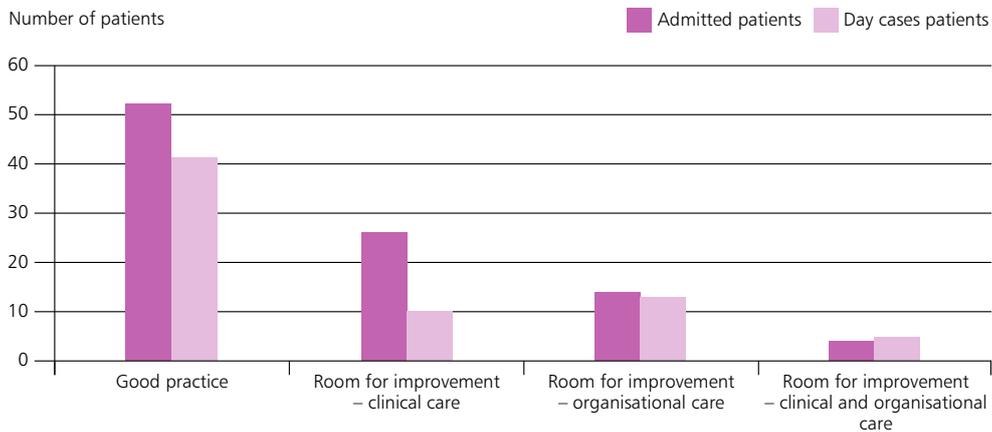


Figure 11.2 Patient underwent an operation or procedure by overall assessment of care - reviewers’ opinion

Key Findings – questionnaire, case note review and organisational data

- 179/500 (35.8%) patients underwent surgery or a procedure during their admission
- 99.4% (169/170) of patients were seen by a senior surgeon or person carrying out the procedure prior to the operation or procedure
- Where the procedure was carried out under general anaesthetic or sedation, a majority of patients (125/138; 90.6%) were seen by a senior anaesthetist prior to surgery
- Where procedures were carried out under general anaesthetic, only 1 in 5 patients (29/128) signed the written consent form themselves. In 10 cases, a parent was the only person to sign the consent form for a patient aged 18 years or over
- It was reported to be routine practice to admit children and young people with severe neurodisability for surgery or procedures through the day surgery unit, in only 15/88 organisations providing paediatric inpatient care. If not, in most organisations (50/72) this was because the surgical/anaesthetic risk was felt to be too great
- Reviewers indicated pain management could have been improved for 102/203 (50.2%) children and young people with a cerebral palsy. They were unable to answer this question or did not answer this question in 93 cases. The main areas of improvement were felt to be documentation of pain enquiry and pain scoring
- Where an operation or procedure was undertaken, 100/138 (72.4%) of patients had regular pain scoring peri-operatively
- Reviewers indicated that in 132/145 cases reviewed, peri-operative pain relief was adequate, however in a third of cases they were unable to answer.

SEE RECOMMENDATIONS**11•13•14•19•20•22•23•26•27•28
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