

# Children and young people with chronic neurodisability: reviewing quality of care

Advances in neonatal and paediatric care have meant many more children with complex health conditions survive into adult life. While well-organized multidisciplinary teams are increasingly the norm in paediatrics, they are not generally part of UK adult practice which can lead to deficiencies in care. Some young adults with cerebral palsy have relatively minor issues with mobility and communication, but others are technology dependent and constitute one of the most complex and medically frail groups requiring hospital care.

Children, young people and young adults with cerebral palsy were chosen as exemplars for chronic neurodisability and most of the recommendations provided in a new report (National Confidential Enquiry into Patient Outcome and Death, 2018) are applicable to all young people with neurodisability. The recommendations cover a range of areas of practice and many are relevant to the everyday hospital care of this population.

As well as collecting questionnaire and peer review data, the National Confidential Enquiry into Patient Outcome and Death worked with Cardiff University to provide a report interspersed with important and novel information from routine national datasets. This provides a comprehensive picture of care in relation to utilization of health services in primary and secondary care.

The study followed work published in 2013 by the Royal College of Paediatrics and Child Health, highlighting the relatively high mortality for people with

chronic neurodisability which had improved minimally over 30 years.

National Institute for Health and Care Excellence (2017) guidance on cerebral palsy provides important quality standards across the whole care pathway for this population and *Each and Every Need* makes 35 recommendations that compliment and support these standards from strong qualitative and population-based data.

## The *Each and Every Need* study National Confidential Enquiry into Patient Outcome and Death: questionnaire and peer review data

Patients aged 0–25 years, admitted to hospital over a 6-week period with an ICD-10 code for cerebral palsy, were included in the study. Of these, 1035 were selected for inclusion in the peer review process. Questionnaires were sent to the clinician responsible for the care of the patient at the time of hospital admission and to the clinician responsible for the ongoing care in the community. Copied extracts of the case notes were requested for the 3-year period before the index admission. The mean age of the returned cases was 11.8 years, 290/531 (54.6%) were male and the majority of the sample 318/523 (61%) were admitted to a district general hospital.

## Cardiff University: routine data collection

Routinely collected health-care data for England, Wales, Northern Ireland and Scotland were linked by NHS number and anonymised before analysis. All ICD-10 and READ v2 or v3 codes available from birth to 25 years were searched for records of cerebral palsy and cases were included if they had at least one cerebral palsy code at any point in their health-care records.

## Important findings and recommendations for hospital doctors

In England and Wales, where both primary and secondary care data were used, the prevalence of cerebral palsy was found to be 3.5 and 2.8 respectively, in line with

published figures (Surveillance of Cerebral Palsy in Europe, 2000).

Analysis of national datasets proved challenging. Poor quality diagnostic coding throughout and an absence of data collection in community settings lead to underestimation of health-care utilization. Accurate and regular clinical coding is essential as it facilitates routine surveillance and allows clinical outcomes to be monitored which in turn can lead to an improvement in the quality of care. It is recommended that cerebral palsy must always be accurately recorded at all points of contact for health care.

Admission to hospital is an opportunity to maximize clinical care. There was documented evidence that 198/333 (59.5%) patients were nutritionally vulnerable and reviewers reported issues with a safe swallow for 144/311 (46.3%). However, weight was documented during the admission in only 359/536 (67%) cases; absence of hoists or appropriate weighing scales was proposed as the barrier to weight recording. Reviewers found that pain was adequately assessed in 173/281 (61.6%) cases with evidence of a pain management plan in 98/126 cases (77.8%), but reviewers also found that pain was controlled in only 78/121 (64.5%) patients. Clinicians need to consider pain as an issue in patients with chronic neurodisability whenever they are admitted.

Patients with cerebral palsy who have complex needs may require input from different specialties at different points in their care. National Confidential Enquiry into Patient Outcome and Death found that communication with the patient's wider multidisciplinary team during inpatient admissions was inadequate in 137/285 (48.1%) cases.

The Gross Motor Function Classification System is a five-point system that describes the level of mobility of patients of all ages with cerebral palsy. Monitoring these levels can inform goal setting, appropriate surveillance and intervention planning (Palisano et al, 1997, 2008). Reviewers reported variation in the documentation of Gross Motor

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Function Classification System level in the notes, with the level documented in only 155/547 (28.3%) cases. It is recommended that patients with cerebral palsy should have their Gross Motor Function Classification System level routinely recorded as a simple ‘common language’ used by all.

Patients with cerebral palsy are vulnerable to respiratory complications, especially if they have oral motor dysfunction, relative immobility and/or untreated scoliosis. These complications can be life-threatening if not managed properly. Respiratory conditions were the most common reason for primary health consultations, emergency hospital and intensive care admissions (44% of paediatric intensive care unit admissions for cerebral palsy across the UK were respiratory) and cause of death. Overall admissions to paediatric critical care were 10 times more frequent for patients with cerebral palsy than for those without.

Case review confirmed that 337/509 (66.2%) of patients were admitted urgently, and 75/321 (23.4%) of these patients were seriously ill with a range of associated conditions including respiratory and airway issues.

Overall there was poor evidence of emergency health care planning in the medical notes for cerebral palsy patients, with a plan present in just 24/305 (7.9%) cases. Consequently *Each and Every Need* calls for all patients with complex needs to be offered the opportunity to develop a patient-held emergency health-care plan or emergency care summary to facilitate communication.

Patients with neurodisability are more likely to be admitted for a range of surgery and procedures and this was reinforced in the national data analysis. These admissions need good planning and multidisciplinary team preparation. Where procedures were carried out under general anaesthetic, only 29/128 patients signed the 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 is essential that hospital doctors fully recognize the rights of a young person with altered abilities to be included in decision making, using communication aids where needed, and assess and document capacity where applicable.

Communication with the wider multidisciplinary team at discharge is particularly important in patients with complex needs. Questionnaire data indicated

discharge communication contained input from relevant members of the inpatient team in only 210/391 (53.7%) cases. There was variation in the adequacy of communication on discharge and reviewers found this to be better with patients and families than with lead clinicians.

Coordinated transfer between paediatric and adult services is particularly important when a patient has complex needs. The analysis of routine data showed that for patients with a neurodisability transfer to adult services happened later than for other patients of the same age. After the age of 18 years patients with cerebral palsy were less likely to have an identified lead clinician for their neurodisability care (31/133; 23.3%), and not all those undergoing transition had a lead GP (39/53 patients) as recommended by National Institute for Health and Care Excellence (2016) guidance.

### Conclusions

Admission to hospital presents an opportunity to maximize the care delivered to the child or young person with neurodisability. All clinicians should be aware of the National Confidential Enquiry into Patient Outcome and Death (2018) report recommendations and take each and every opportunity to meet each and every need. **BJHM**

*This editorial has been written on behalf of the authors of Each and Every Need (National Confidential Enquiry into Patient Outcome and Death, 2018).*

National Confidential Enquiry into Patient Outcome and Death. 2018. *Each and Every Need*. National Confidential Enquiry into Patient Outcome and Death, London

National Institute for Health and Care Excellence. 2016. Transition from children's to adults' services for young people using health or social care services. Clinical guideline NG43. (accessed 26 March 2018) [www.nice.org.uk/guidance/ng43](http://www.nice.org.uk/guidance/ng43)

National Institute for Health and Care Excellence. 2017. Cerebral palsy in under 25s: assessment and management. Clinical guidelines NG62. (accessed 26 March 2018) [www.nice.org.uk/guidance/ng62](http://www.nice.org.uk/guidance/ng62)

Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol*. 1997 Apr;39(4):214–223. <https://doi.org/10.1111/j.1469-8749.1997.tb07414.x>

### KEY POINTS

- Admission to hospital presents an opportunity to maximize the care delivered to all patients with neurodisability.
- Poor quality diagnostic coding, and an absence of data collection in community settings lead to underestimation of health-care utilization. Patient records also revealed very poor recording of important descriptors of motor disability such as the Gross Motor Function Classification System.
- Communication was highlighted as an issue across all parts of the patient pathway in both acute and community care settings.
- Respiratory conditions prevailed as the most common reason for primary health consultations, emergency hospital and intensive care admissions and cause of death. While nearly 25% of patients admitted urgently were seriously ill, there was poor evidence of emergency health care planning in the medical notes.
- There was often poor evidence of patients having a planned transition of care from paediatric to adult services and less than a quarter of patients over 18 years of age had an identifiable lead clinician.

Neurol. 1997 Apr;39(4):214–223. <https://doi.org/10.1111/j.1469-8749.1997.tb07414.x>

Palisano RJ, Rosenbaum P, Bartlett D, Livingston MH. Content validity of the expanded and revised Gross Motor Function Classification System. *Dev Med Child Neurol*. 2008 Oct;50(10):744–750. <https://doi.org/10.1111/j.1469-8749.2008.03089.x>

Royal College of Paediatrics and Child Health CHR-UK Programme of Work at the MRC Centre of Epidemiology for Child Health, University College London Institute of Child Health.

2013. Overview of Child Deaths in the four UK countries. (accessed 26 March 2018) [www.rcpch.ac.uk/system/files/protected/page/CHRUK\\_Module%20A%20low%20res%20\(2\).pdf](http://www.rcpch.ac.uk/system/files/protected/page/CHRUK_Module%20A%20low%20res%20(2).pdf)

Surveillance of Cerebral Palsy in Europe. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Dev Med Child Neurol*. 2000 Dec;42(12):816–824. <https://doi.org/10.1111/j.1469-8749.2000.tb00695.x>

To find out more about the practicalities of providing acute care for patients with chronic neurodisabilities, see p C108.

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