

# Each and Every Need

A review of the quality of care provided to patients aged 0-25 years old with chronic neurodisability, using the cerebral palsies as examples of chronic neurodisabling conditions



## Summary sheet

The overarching aim of this study was to review the quality of care provided to patients with a cerebral palsy, as examples of a neurodisability condition. The interfaces between different care providers was assessed as well as transition from child to adult services. Children and young people with a cerebral palsy have many complex needs and whilst areas of good practice were seen, much room for improvement was identified.

At the very point of diagnosis, the term recorded in medical records to describe the cerebral palsy was often incorrect and frequently did not include specific information about the type of cerebral palsy or tone variation. From routinely collected population datasets, it was clear that although the cerebral palsies are chronic conditions, they are not coded at every contact point with NHS services.

As part of the clinical assessment to determine the cause of the cerebral palsy, the study highlighted variation in access to Magnetic Resonance Imaging, including facilities for sedation and/or general anaesthetic. There was also variation in access to neuroradiological expertise to interpret the images obtained. Important clues to other diagnoses, including developmental brain anomalies and neurometabolic conditions, will be missed if neuroimaging is not undertaken. Accurate diagnosis informs accurate management.

Despite being an internationally recognised system for describing gross motor function that informs clinical management, the Gross Motor Function Classification System (GMFCS) level of fewer than one in three children, young people and young adults with cerebral palsies was documented in their case notes.



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Good communication underpins all clinical practice and is encouraged by the General Medical Council and professional bodies, but there was lack of sufficient efforts seen to have been made to communicate directly with this group of patients in a third of the sample. There was room for improvement in the documentation of inclusion of these patients in discussions and decision-making in four out of ten cases reviewed. There was poor communication in relation to needs, support, emergency health care planning and consent for procedures.

Multidisciplinary team working is key for this group of complex patients, yet this was viewed as inadequate in 137/285 (48.1%) inpatients from the cases reviewed. Discharge summaries about episodes of inpatient care were not copied to lead clinicians for cerebral palsy care in almost half of cases and were only copied to the community physiotherapist in 30% for day case patients and 38% for admitted patients. If the wider team do not know what is happening for the patient, there can be no proactive, joined-up care. Good multidisciplinary team working depends on quality team leadership; however, our study evidenced considerable variation in clarity about who was leading multidisciplinary teams, this being especially the case for young adults with cerebral palsies.

Routine national data showed that children and young people with cerebral palsies had similar trends of 'consultation' with primary care across the age groups to those without the conditions. However, those with cerebral palsies had a higher rate of consultation and number of consultations per year compared to other children and young people in all age categories. It is important for GPs to be aware of the potential multifaceted needs of this patient group, how to manage what they can in primary care and how to access clearly published care pathways when more specialist opinions or care are needed. The data suggested that children and young people with cerebral palsies attended primary and secondary healthcare settings significantly more frequently than those without cerebral palsy. Whilst the rate of outpatient attendances increased over time outpatient attendances decreased significantly with age whilst primary care attendance increased markedly between 15-25 years of age. Peer reviewed data showed that a quarter of patients with a cerebral palsy, whose admission was unplanned, were seriously ill. Not all were seen in a timely fashion by senior clinicians, and recording of this event was poor. When appropriate, few patients had emergency healthcare planning in place.

Evidence from the case note reviews confirmed that clinical care was in need of improvement, including the recognition and management of aspects such as pain, learning disability, emotional and mental health and support needs. Weighing and measuring patients accurately to ensure adequate nutrition and accurate calculations for medication doses and fluids were inconsistent. Many patients in this study had unsafe swallows that were infrequently assessed. Hip and spine surveillance was variable, with hip status frequently not documented.

Documentation was found to be wanting in this study: the wider health needs of one in ten children, young people and young adults with cerebral palsies were inadequately described in their case notes, including their preferred communication method and level of learning ability. Documentation about adjustments required to meet needs was missing in the case notes of half of the study sample. Often it was reported that basic equipment needed to meet simple needs were absent, such as hoists, wheelchairs, weighing scales and changing places. These issues were reported by the parent carers as well as clinicians in the hospitals who responded.

Documentation of consent to procedures was found to be inadequate or inappropriate in a substantial number of cases reviewed where the patient was admitted for a procedure or surgery under general anaesthesia.

This study highlights considerable uncertainty about how and when transition to adult care occurred. NICE published guidance in 2016,<sup>10</sup> the same year that NHS Scotland set generic "gold standards" for leadership and planning of transition in healthcare.<sup>11</sup> However, translation into practice does depend on there being equivalent services for young adults "on the other side of the divide", to those available in paediatric services. Since this is hardly ever the case for patients with cerebral palsies or other neurodisabling conditions, the gap that opens up poses enormous challenges for patients and their families as well as health and social care providers, with a large burden of complex healthcare falling on to GPs. Peer review and the routine data highlighted that transition can take longer for children and young people with cerebral palsies than for those without. Also, the interface with different specialties involved throughout the transition period varied with the proportion of outpatient appointments for specialties managing mental health and learning disabilities increasing significantly between 10 and 25 years of age, but hospital admissions for the same specialties decreased with age.

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