

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



Recommendations

The overarching aim of this report is to improve the care provided to children and young people aged 0-25 years with a chronic neurodisability. The cerebral palsies have been used in the study as examples of neurodisabling conditions.

The recommendations with a shaded background relate only to patients with a cerebral palsy.

The term 'clinician' has been used to encompass all healthcare professionals, although individual specialties have been listed where appropriate.

The text in *italics* after each recommendation is a suggestion as to who should be aware of / lead on the recommendation, but this will vary locally so please include all groups who need to be involved.

The **PRINCIPAL RECOMMENDATIONS** have been ranked by all involved as those recommendations of primary importance.



@ncepod #NeuroDis



RECOMMENDATIONS

Improving clinical coding and quality of routine data

1 PRINCIPAL RECOMMENDATION

Clinical coding of neurodisabling conditions in all healthcare records and routinely collected datasets must be accurate and consistent if data are to be meaningful, comparable and useful to inform health outcome reviews and patient care.

- a) Cerebral palsy and other chronic neurodisabling conditions should be added to the standard list that *“must always be coded for any admitted patient care episode (including day case patients) when documented in the patient’s medical record for the current hospital provider spell, regardless of specialty.”*^[i]
- b) Standardised healthcare data should be captured by clinicians each time a patient is seen, in ALL settings (to include community based organisations)
- c) Data collection about patients with neurodisabling conditions must include measures of clinical severity and functional abilities to enable detailed analysis
- d) Clinical coding systems should be harmonised across routinely collected datasets in England, Wales, Scotland and Northern Ireland to enable data analysis throughout the UK
- e) Patient records and routine data collections across different healthcare providers (community care, primary care, secondary care and mental health) should be linked to provide the greatest potential for quantifying healthcare utilisation and patient outcomes on a population basis. *(Responsibility for action rests with Clinicians to capture data about needs at the point of care; Chief Executives to provide easy to use electronic data capture interfaces for clinicians to achieve this; Commissioners to ensure the above are in place and the Governments or those with responsibility in England, Scotland, Northern Ireland, Wales, Guernsey, Jersey and the Isle of Man to ensure that the system specifications for electronic records are adequate for the task in all settings where clinical activity occurs.)*

As hospitals move to electronic patient records, this should facilitate better data linkage between healthcare providers. Work is underway to include SNOMED CT (Systematized Nomenclature of Medicine - Clinical Terms - a standardised vocabulary of clinical terminology) into the routine coding system for UK NHS data. SNOMED CT already captures the ‘Surveillance of Cerebral Palsy in Europe’ preferred diagnostic terms (including measures of disease and functional severity). These are incorporated into the Community Services Data Set in England and

the Community Health Activity Data in Scotland, and NHS providers are mandated to report these diagnostic data at each non-inpatient healthcare contact. However, introduction of SNOMED CT is taking a phased approach, neither SNOMED CT nor the Community Services Data Set/Community Health Activity Data is used across the UK.

- 2 Access to existing routinely collected national datasets needs to be improved. The governance and application process to the four nations should be harmonised to promote data linkage and encourage the use of population datasets more effectively and efficiently. *(NHS Digital, NHS England, NHS Scotland, NHS Wales, Northern Ireland Statistics and Research Agency, Guernsey, Jersey and the Isle of Man)*

Recommendations 1 and 2 should therefore be considered as hospital systems are planned to ensure a seamless transition from one coding system to another.

- i. National Clinical Coding Standards ICD-10 5th Edition

Clinical care - diagnosis and management

3 PRINCIPAL RECOMMENDATION

Patients suspected of having a neurodisabling condition should have an expert assessment by clinicians who have the competences to consider the range of possible diagnoses. For those patients with a cerebral palsy, the clinician must be able to recognise and describe the tone variation and distribution pattern of motor impairment, as informed by ‘NICE Guideline 62’^[ii] and the ‘Reference and Training Manual of the Surveillance of Cerebral Palsy in Europe’^[iii]. *(Clinicians, Medical Directors, Commissioners, Regulators, Royal Colleges and Specialty Associations)*

- 4 Patients with a cerebral palsy should have the pattern of their motor impairment (e.g. unilateral/bilateral) and tone variation (spasticity, dyskinesia, dystonia, ataxia or choreoathetosis) assessed and recorded in the clinical notes by the clinician undertaking the assessment. *(Clinicians, Regulators)*
- 5 Patients with a cerebral palsy should have their level of motor functioning described and documented in every clinical communication, using the Gross Motor Function Classification System. *(Clinicians, Regulators)*

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- 6 Clinicians offering assessments to consider neurodisabling conditions as possible diagnoses should have timely access to magnetic resonance neuroimaging (MRI), including facilities for sedation and/or general anaesthesia if required. These may be within a network of care. MRI should not be provided without appropriate neuroradiological expertise to inform the imaging protocols used and to accurately interpret the images obtained. *(Clinicians, Medical Directors, Commissioners, Regulators)*
- 7 PRINCIPAL RECOMMENDATION**
- Patients with a neurodisabling condition should have access to an appropriate multidisciplinary team to proactively monitor their health status when their needs are complex and/or when there is a change in their functional status, physical condition or environmental situation. For those patients with a cerebral palsy, this access should reflect 'NICE Guideline 62'.**[iii]** *(Medical Directors, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 8 Patients with neurodisabling conditions should have their weight and nutritional status considered at every healthcare encounter and assessed and recorded based on clinical need. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 9 As for all patients, those with a neurodisabling condition who also have a learning disability should have this clearly documented in their clinical records by all healthcare providers (e.g. in primary and/or specialist healthcare). *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Regulators)*
- 10 Oral health and dental care for patients with a neurodisabling condition must be considered as a matter of routine by their lead clinician. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 11 PRINCIPAL RECOMMENDATION**
- All patients with complex needs and, where appropriate, their parent carers or legal guardians, should be offered the opportunity to develop a patient-held Emergency Health Care Plan/Emergency Care Summary to facilitate communication in the event of a healthcare emergency.**[iv]** This should include as a minimum:
- a) information about the patient's health conditions and treatment;
 - b) who to contact in a range of scenarios and what to do;
 - c) a statement about what has been discussed and agreed about levels of intervention including palliative care planning; and
 - d) the existence of any advance directives (for those over 18 years), lasting power of attorney or any other measure.
- The existence of this Emergency Health Care Plan/Emergency Care Summary must be recorded in all communication and case notes and this should be subjected to local audit. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators)*
- 12 Patients with a neurodisabling condition should have an assessment completed by their lead clinician to determine their risk of respiratory compromise. This should be reviewed as appropriate for the complexity of the patient's needs. Those patients at significant risk of respiratory compromise should be assessed by clinicians with expertise in respiratory medicine, in order to discuss with the patient and their family the range of interventions most likely to lead to the best outcome. 'What to do' and 'who to contact' in the event of respiratory symptoms should be documented in the patient-held Emergency Health Care Plan. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 13 As for all patients, those with a neurodisabling condition admitted to an acute general hospital as an emergency should have timely assessment and senior review within 14 hours of admission by a specialist relevant to the emergency as recommended by the Royal College of Paediatrics and Child Health in 'Facing the Future'**[v]** and the Royal College of Physicians of London in the 'Acute Care Toolkit 4'**[vi]** *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 14 Patients should undergo timely review prior to major surgery and/or if they have complex co-morbidity by key team members to ensure optimal preparation and planning. This must include senior members of the surgical, anaesthetic and medical teams. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*

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15 Pain scoring tools should be understood and used in the peri-operative/peri-procedure period for patients with a neurodisabling condition. Healthcare staff should be trained in their use. (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians*)

- ii. *NICE Guideline 62 - Cerebral palsy in under 25s: assessment and management*
- iii. *Reference and Training Manual of the Surveillance of Cerebral Palsy in Europe*
- iv. *Emergency Health Care Plan – Council for Disabled Children and Emergency Care Summary - Scotland*
- v. *Facing the Future and Emergency Care Summary - Scotland – Royal College of Paediatrics and Child Health*
- vi. *Acute Care Toolkit 4 – Royal College of Physicians*

Clinical care - clinical leads and care plans

16 Patients with a neurodisabling condition who need ongoing medical and therapeutic input should always have a named lead clinician to co-ordinate care across healthcare services and all age groups. Any change in lead clinician should include planning and a thorough handover. (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators*)

17 Patients with a neurodisabling condition should be on an appropriate care pathway. For those with a cerebral palsy this should include arrangements for surveillance of hips, spine and growth until skeletal maturity and in the longer term, nutritional surveillance and the identification and management of pain. (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators*)

18 PRINCIPAL RECOMMENDATION

Patients with a neurodisabling condition should have a clear care plan that describes and addresses all of their needs. For those with a cerebral palsy this should specifically include pain, growth, nutritional status, safety of eating and drinking and other medical conditions such as seizures or mental health or behavioural issues. This care plan should be reviewed and updated when in hospital and on discharge to the community. Where the patient has complex needs this should be readily accessible to patients, their parent carers and clinicians e.g. as part of a patient-held patient passport. **[vii]** (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators*)

19 All medically frail patients with a neurodisabling condition, and where appropriate, their parent carers or legal guardians, must be offered the opportunity to discuss with their lead clinician, their care wishes in the event of serious illness or sudden collapse. This should be recorded in their patient-held Emergency Health Care Plan. This may include discussing Do Not Attempt Cardio Pulmonary Resuscitation decisions and palliative care plans, which should be validated at each point of care according to the existing legal requirements and professional guidance. This is particularly important to have in place at handover during transition to adult services. (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators*)

vii. Example of a patient-held passport

Transition and age appropriate care

20 To facilitate transition to adult services there must be a clear, documented plan developed between the young person with complex needs and their multidisciplinary team. NCEPOD supports '*NICE Guideline 43*' **[viii]** that transition planning should have begun by the age of 14. (*Clinicians, General Practitioners, Commissioners, Regulators*)

21 Healthcare organisations must better consider the needs of young people in the organisation, planning and delivery of healthcare. Age appropriate care must include dedicated physical space as well as agreed policies and procedures to be used in all clinical areas to facilitate patient privacy, dignity and inclusion. (*Medical Directors, Clinicians, Commissioners, Regulators*)

22 PRINCIPAL RECOMMENDATION

The transition plan between children's to adults' services should be co-ordinated by the lead clinicians and integrated within other multiagency plans e.g. health education, social care planning and mental healthcare services. The patient's team in primary care must be part of the planning process (*Clinicians, General Practitioners, Commissioners, Regulators*)

23 Care pathways for adolescent patients should promote dignity and independence when a hospital stay is needed and include ready access to single room accommodation, space for special equipment and the facility for parent carers to stay on-site when

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required[**ix**] and as recommended by the Royal College of Physicians of London in the 'Acute Care Toolkit 13'.

[x] (Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)

- 24 General Practitioner Networks, Federations, Clusters, Health Boards and Partnerships, should consider developing Clinical Champions for neurodisabled patients to lead and help 'bridge the gap' between specialist neurodisability teams and primary/community care. Leads could be engaged in care from the early teens and function as an essential link with the wider paediatric multidisciplinary teams. (General Practitioners, Royal College of General Practitioners, Commissioners, Regulators)

viii. NICE Guideline 43 - *Transition from children's to adults' services for young people using health or social care services*

ix. 'You're Welcome' Standards

x. Royal College of Physicians of London in the 'Acute Care Toolkit 13'.

Clinical care – communication

- 25 As for all patients, those with neurodisabling conditions should have their preferred method of communication clearly documented in their clinical records (electronic and/or paper) across all healthcare providers (e.g. in primary and/or specialist healthcare). (Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators)
- 26 Each consultation with patients with a neurodisabling condition should be used as an opportunity to enquire whether they and their family have the information and support they need. (Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Regulators)
- 27 All healthcare professionals who might work with patients with a neurodisabling condition should be able to make a range of reasonable adjustments to accommodate them, such as providing support for a range of communication, learning and physical access needs. 'Disability Matters' is a key resource that should be embedded in the training of all healthcare professionals.**[xi]** (Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)

- 28 Patients with a neurodisabling condition, and where appropriate, their parent carers or legal guardians should have access to information and training in optimum self-management, problem-solving and how to get the right help and support as required in line with 'NICE Guideline 62'.**[ii]** (Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)

- 29 Clinicians should be aware of, and comply with, the ethical and legal requirements for consent to surgery as defined by the General Medical Council and requirements for mental capacity assessments which will vary depending on UK country in which they live. These requirements must be communicated clearly to patients and parent carers and documented in the case notes. (Clinicians, Commissioners, Regulators)

- 30 Patients with a neurodisabling condition should be involved in all communications and decision-making about their care and management where possible, and where appropriate, with adjustments in place to support their involvement, including specialist speech and language therapists as required. Parent carers or legal guardians must also be included in these conversations as appropriate. (Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators, Patients)

- 31 After a period of inpatient care patients with a neurodisabling condition should have their ongoing function and daily needs assessed and documented. Any significant change which would necessitate a planned alteration to day-to-day care must be clearly communicated in discharge plans. The discharge plan should be sent to the patient and their parent carers and their multidisciplinary team including their GP. (Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)

ii. NICE Guideline 62 - *Cerebral palsy in under 25s: assessment and management*

xi. Disability Matters

- 32 Clinicians should be trained to be able to communicate effectively with patients with a range of communication needs. They must be able to make a structured

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assessment of overall needs alongside management of the presenting condition. (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, NHS Scotland, Regulators*)

Organisation of care

- 33 All providers of healthcare for patients with a cerebral palsy or other chronic neurodisability should have clear care pathways described for patients, parent carers and referrers which are easily available e.g. on the hospital website with named contact details.**[xii]** (*Medical Directors, Directors of Nursing, Clinical Directors, General Practitioners, Commissioners, NHS Scotland, Regulators*)
- 34 To accommodate patients with neurodisabling conditions all healthcare facilities should:
- Be fully accessible;
 - Have appropriate high quality equipment available including hoists, weighing scales, height measuring facilities, places to allow changing and wheelchairs to support participation in everyday activities and proactive independence. These should be easily available and maintained regularly. (*Medical Directors, Directors of Nursing, Clinical Directors, Commissioners, NHS Scotland, Regulators*)
- 35 Hospitals should review their day-case facilities and policies to ensure they are inclusive for neurodisabled patients with complex needs. (*Medical Directors, Directors of Nursing, Clinical Directors, Commissioners, NHS Scotland, Regulators*)

xii. *British Academy of Childhood Disability – Quality Principles for Paediatric Disability Services*

Whilst each recommendation should be read to determine if it is relevant to you or your organisation, the table opposite summarises a quick glance view of which ones should be looked at depending which 'audience' you are. A gap analysis tool, by audience is available on the report study page at www.ncepod.org.uk

Audience	Recommendation number(s)
Chief Executives	1
Clinical Directors	7,8,9,10,11,1,13,14,15,16,17,18,19,23,25,26,27,28,30,31,32,33,34,35
Clinicians	1,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21,22,23,25,26,27,28,29,30,31,32
Commissioners	1,3,6,7,8,10,11,12,13,14,16,17,18,19,20,21,22,23,24,25,27,28,29,30,31,32,33,34,35
Directors of Nursing	8,9,10,11,12,13,14,15,16,17,18,19,23,25,26,27,28,30,31,32,33,34,35
General Practitioners	11,16,19,20,22,24,25,32,33
Guernsey	1,2
Isle of Man	1,2
Jersey	1,2
Medical Directors	3,6,7,8,9,10,11,12,13,14,15,16,17,18,19,21,23,25,26,27,28,30,31,32,33,34,35
NHS Digital	2
NHS England	1,2
NHS Scotland	32,33,34,35
NHS Wales	1,2
Northern Ireland	1,2
Patients	30
Regulators	3,4,5,6,7,8,9,10,11,12,13,14,16,17,18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35
Royal College of General Practitioners	1,2
General Practitioners	24
Royal Colleges	3
Specialty Associations	3