



Topic Expert Group: Follow-up and continuing care

Motor and neurological follow-up assessment

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Target group

Infants born very preterm or those infants with risk factors (see preamble TEG Follow-up & continuing care) and parents

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Standardised assessment of neurological status and motor development is conducted in the first two years and repeated at transition to school.

Rationale

The goal is to evaluate neuromotor development and identify those individuals who will benefit from additional support and intervention to optimise motor development and thereby improve social and cognitive development.

Very preterm infants and term born infants with neonatal neurological morbidity (e.g. hypoxic ischaemic encephalopathy, stroke) are at risk of adverse neuromotor outcomes, including Cerebral Palsy (CP). (1–5) CP impacts on activities and participation in daily life. (6) In industrialised countries the prevalence of CP in preterm infants is decreasing, whereas it remains fairly unchanged in term born infants. (7) The prevalence of minor neurological dysfunction and motor impairment in the absence of CP continues to be high. (8,9)

Early detection of neuromotor problems paves the way for early intervention and is important for counselling of parents. (10) There is evidence that early intervention is associated with a positive effect on early motor development. (11,12) In case of CP, early interventions also aim to prevent contractures and deformities.

During infancy frequent changes in neuromotor development occur. (13,14) This implies that infants at risk may gradually move to typical development, but also that infants may develop a deficit, such as CP. By the age of two years most children with CP will have been assigned a diagnosis. For less severe neuromotor disorders, it usually takes longer before they are recognisable. Regular monitoring during infancy and preschool age is warranted. Knowledge of neuromotor status in terms of minor neurological dysfunction also serves the early detection of developmental coordination disorder (DCD), attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and specific learning disorders. (15)

Benefits

Short-term benefits

N/A



Long-term benefits

- Better guidance for families (consensus)
- Reliable and early (before two years of age) identification of those who will develop significant neuromotor problems (Cerebral Palsy, CP) (16–18)
- Early referral to community services (consensus)
- Facilitated early multidisciplinary approach to management and early intervention for those who are in need of further input (12,19)
- Identification (at pre-school and school age) of those who develop motor difficulties in the absence of CP (20,21)
- Optimised social and cognitive development (12)
- Provides feedback to peri- and neonatal healthcare providers with regards to monitoring and improving quality of care (consensus)
- Promoted and improved healthy life style by encouragement of motor activities (consensus)

Components of the standard

| Component | Grading of evidence | Indicator of meeting the standard |
|---|--------------------------------------|--|
| For parents and family | | |
| 1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including screening for neuromotor developmental difficulties. (11,12,19) | A (High quality) B (High quality) | Patient information sheet |
| 2. Parents are involved in early intervention, e.g., family-centred care. (22–25) | A (High quality) | Parent feedback |
| 3. Parents receive standardised feedback about the results of their child's neuromotor health screening in a language that is accessible to them. | B (High quality) | Parent feedback |
| 4. Children identified at risk are offered referral to the appropriate healthcare service and intervention is started in those infants with suspected abnormal neuromotor findings and motor delay (with parental consent). (11,12,22–25) | A (High quality) B (High quality) | Audit report |
| For healthcare professionals | | |
| 5. A guideline on follow-up programme including serial neuromotor assessment in the first two years (e.g. 3-6, 12, 24 months corrected age) and repeated at transition to school is adhered to by all healthcare | A (High quality) B (High quality) | Audit report, guideline |



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|---|--|--|----------------------------|
| | professionals. (14,17,20,21,26) | | |
| 6. | Children with diagnosis of CP: from 12 months corrected age onwards at each follow-up appointment standardised assessment of CP according to Surveillance of Cerebral Palsy in Europe (SCPE) criteria (27,28), and from 24 months corrected age onwards assessment of functional level of gross motor function, manual ability and communication is ensured. (29–34) | A (Moderate quality) B (High quality) | Audit report, guideline |
| 7. | Training on standardised neuromotor assessment throughout infancy to school age (e.g. General Movement Assessment at 3-4 months corrected age) is attended by all responsible healthcare professionals. (16–18) | A (High quality) B (High quality) | Training documentation |
| For neonatal unit, hospital, and follow-up team | | | |
| 8. | A guideline on the follow-up programme including neuromotor developmental health is available and regularly updated. | B (High quality) | Guideline |
| 9. | Follow-up programme after discharge including neuromotor developmental health is funded and supported. | B (Moderate quality) | Audit report |
| 10. | Follow-up rates are continuously monitored. | B (Moderate quality) | Audit report |
| 11. | Neuromotor developmental health outcomes are used for staff feedback. | B (Moderate quality) | Audit report |
| 12. | Training on standardised neuromotor assessments is ensured. | B (High quality) | Training documentation |
| 13. | Appropriate assessment facilities are provided. | B (High quality) | Audit report |
| For health service | | | |
| 14. | A national guideline on follow-up programme including neuromotor assessment is available and regularly updated. | B (High quality) | Guideline |



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| 15. A follow-up service including neuromotor developmental health is specified, funded and monitored. | B (High quality) | Audit report |
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Where to go – further development of care

| Further development | Grading of evidence |
|---|--|
| For parents and family | |
| <ul style="list-style-type: none">Offer neuromotor follow-up into school age. (4) | A (High quality) B (Moderate quality) |
| For healthcare professionals | |
| N/A | |
| For neonatal unit, hospital, and follow-up team | |
| <ul style="list-style-type: none">Integrate neonatal and neuromotor follow-up electronic systems. | B (Moderate quality) |
| For health service | |
| <ul style="list-style-type: none">Monitor CP rates on a national basis. (7) | A (High quality) |

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about follow-up including neuromotor development assessments.

For healthcare professionals

- Start a service that uses parent reports using screening questionnaires (Ages and Stages Questionnaire (ASQ) or Parent Report of Children's Abilities-Revised (PARCA-R)).
- Institute a training programme and standard schedule of assessment (screening or face-to-face assessments).
- If the findings of parent completed developmental screening questionnaires indicate delayed development in any of the domains, discuss referral to appropriate services for more detailed assessment with the family and, if appropriate, make sure it will be initiated.
- Attend training on standardised neuromotor and developmental assessments.
- Establish a structure of communication with other healthcare institutions providing follow-up.

For neonatal unit, hospital, and follow-up team

- Develop and implement a guideline on follow-up programme including neuromotor and developmental health.
- Develop information material on follow-up programme including neuromotor and developmental health.
- Establish a formal system of identifying infants who are eligible for follow-up and of keeping track of families.



- Develop a structure of standardised multidisciplinary follow-up locally.
- Establish a structure that facilitates early intervention in infants at high risk for neuromotor impairment.
- Support healthcare professionals to participate in training on standardised neuromotor and developmental health assessments.
- Provide space and resources for follow-up neuromotor developmental assessment in clinics or postal/online.

For health service

- Develop and implement a national guideline on follow-up programme including neuromotor and developmental health.

Source

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First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Hadders-Algra M, Vollmer B et al., European Standards of Care for Newborn Health: Motor and neurological follow-up assessment. 2018.