



Topic Expert Group: Follow-up and continuing care

Coordination and integration of care after discharge home

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Target group

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

User group

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

Statement of standard

Parents receive comprehensive and integrated care for their high-risk infant after discharge home.

Rationale

Care programmes for high-risk infants may involve a range of professionals and disciplines. (1,2) Growth, feeding and development are addressed in all infants, and interventions, such as physiotherapy, (preverbal) speech therapy, dietetics, occupational therapy, or psychological support are often instituted. (3–9) Such follow-up care must also integrate with primary, secondary, and tertiary services, such as family physicians, paediatricians, neonatologists, and other healthcare professionals. Multidisciplinary collaboration and coordination of care between professionals in different healthcare settings is necessary to prevent families falling through gaps in care and to avoid needless treatment duplication. (10–13) An integrated schedule of follow-up and aftercare visits will decrease the burden of unnecessary visits.

Timely communication of the medical record is a prerequisite for coordinated care. (10,11,14) Digital systems can facilitate this. (15) Case managers will provide coordination and continuity of care and treatment goals, and facilitate access to appropriate resources. (14,16,17) As there is no uniform approach in follow-up and aftercare programmes (14,18), local guidelines need to be developed about the assignment of tasks between healthcare professionals. The focus of care changes over time from medical problems, feeding and growth, to later development, behaviour, and schooling. Case managers with different backgrounds may be required over time. Patient-centred care, close parental engagement, and shared decision making are essential in infants with complex needs. Parents are the primary caregivers and advocate for their child; they should be included as equal partners in the multidisciplinary team. (19–24)

Benefits

Short-term benefits

N/A

Long-term benefits

- Continued care (25)



- Improved post-discharge multidisciplinary care, including positive parenting interventions and other home-visits (13,26,27)
- Reduced unplanned emergency room visits and readmissions (26)
- Improved parental engagement and satisfaction (16,27)
- Improved communication between healthcare professionals involved in the care of the child (28)
- Improved access to, and use of, health and developmental services (10,16)
- Early identification of healthcare needs, e.g. need for developmental support (25)
- Improved parental advocacy skills, i.e. the parents' ability to speak up for their child (29)
- Reduced healthcare costs (30)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed by healthcare professionals about the importance of adequate healthcare for their infant, which includes attendance in follow-up programmes and the role of the case manager. (31,32)	A (Low quality) B (High quality)	Clinical records, patient information sheet
2. Parents, as the primary caregivers are supported by a professional case manager for overview and coordination of the plan for follow-on care. (23,28,33,34)	A (Low quality) B (High quality)	Audit report, parent feedback, patient information sheet
For healthcare professionals		
3. A unit guideline on follow-up management including the support of the parents by a case manager is adhered to by all healthcare professionals.	B (High quality)	Guideline
4. Training on specific needs of high-risk infants in general and follow-up management is attended by all healthcare professionals and case managers to facilitate care for individual infants and families.	B (High quality)	Training documentation
5. Case managers work with parents to facilitate parental engagement and decision making during follow-up care. (5,12,22,28,33–36)	A (Low quality) B (High quality)	Guideline, parent feedback



6. Information exchange between all involved healthcare professionals and parents is documented and monitored. (3,10,11,14)	B (Moderate quality)	Clinical records
7. Contacts as part of the local follow-up programme are planned and coordinated, and meet the specific needs of the individual infant and family. (3–9)	B (High quality)	Guideline, parent feedback
For neonatal unit and follow-up team		
8. A unit guideline on follow-up programme including the support of the parents by a case manager is available and regularly updated. (3–9)	B (High quality)	Guideline
For hospital and follow-up team		
9. Training on specific needs of high-risk infants in general, and follow-up management is ensured.	B (High quality)	Training documentation
10. Appropriate resources and facilities for follow-up programme are provided to optimise coordination of healthcare professional input for family.	B (High quality)	Audit report
For health service		
11. A national guideline on follow-up management including the support of the parents by a case manager is available and regularly updated.	B (High quality)	Guideline

Where to go – further development of care

Further development	Grading of evidence
For parents and family N/A	
For healthcare professionals N/A	
For neonatal unit and follow-up team	
<ul style="list-style-type: none"> Develop the accessibility of follow-up services, using e-health technology to support parents and health professionals. (35,36) Develop the most effective ways of communication between multidisciplinary team members and parents. 	A (Low quality) B (Moderate quality) B (Moderate quality)
For hospital and follow-up team N/A	



For health service

- Improve digital communication, integrating patient files and databases to facilitate timely handover, and ongoing care. (15) A (Low quality)
B (Moderate quality)

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about the follow-up care that is available.
- Parents are given contact details for questions about the infant's follow-up healthcare.

For healthcare professionals

- Attend training to improve knowledge on the specific needs of high-risk infants in general and especially training on case management.
- Ensure timely exchange of medical information and relevant family circumstances.

For neonatal unit and follow-up team

- Develop and implement a unit guideline for case management that starts prior to discharge.
- Develop information material about the available follow-up programme for parents.
- Develop a (paper) form to structure handover of essential medical information.

For hospital and follow-up team

- Support healthcare professionals and case managers to participate in training and education programmes to improve knowledge on the specific needs of the high-risk infants including case management.

For health service

- Develop and implement a national guideline for case management that starts prior to discharge.
- Develop and implement a policy to enable multi-disciplinary collaboration, synchronisation and necessary exchange of medical records between healthcare professionals at different levels in infant care.

Source

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