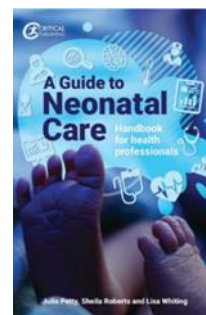


Chapter 15 Community based family care

A Guide to Neonatal Care - Handbook for Health Professionals
Petty J, Whiting L and Roberts S (2024) Critical Publishing



Supplementary information

Taking a premature baby home after an often-protracted period on the neonatal unit can be stressful for parents and they are often confronted with an unexpected reality. The transition to motherhood and parenthood has occurred in the neonatal unit, under the watchful eye of neonatal nurses. When the baby goes home, parents are expected to take on the full-time caregiving role of a baby who may require around the clock care with medications, home oxygen, feeding issues and monitoring. The level of preparation for the transition home of the premature baby can impact on how the family survives and thrives. It is not surprising that parents may find this challenging because the growth and development trajectory of extremely premature babies can be markedly different from a term infant requiring tailored support.

Optimum community support (via peers and / or health professionals or both) is therefore essential for parents, to minimise the potential longer-term effects of the traumatic experiences that they may have encountered during their time on the neonatal unit.

The NICE (2017) guidance on developmental follow-up recommends.....

Provision of 'enhanced developmental support'.

Provide parents or carers of a preterm baby having enhanced developmental support with a single point of contact within the neonatal service for outreach care after discharge.

Use a range of approaches when providing enhanced developmental support and tailor the support to take account of individual preferences and needs.

Approaches may include:

- face-to-face meetings, in clinics or in the home
- a telephone helpline
- text messages, emails or similar.

Providing enhanced developmental surveillance up to two years (corrected age)

For all children born preterm who are having enhanced developmental surveillance, provide as a minimum:

2 face-to-face follow-up visits in the first year that focus on development, at the following corrected ages:

- between 3 and 5 months **and**
- by 12 months
- and**
- a detailed face-to-face developmental assessment at 2 years (corrected age)

To add, the research undertaken below by Petty, Whiting et al (see the Extra Reading content articles x4) recommends the following.....

- Primary care health professionals (eg GPs, Health visitors, School nurses, Community nurses / teams) have specific training and / or resources about the specific needs of the premature neonate in terms of expected growth and development patterns, adjusted / corrected gestations and altered milestones, differences in feeding patterns and specific clinical needs including recognising when a premature neonate is becoming unwell.
- Education resources are developed for both parents and health professionals in relation to these areas.
- Parents are signposted to parent / peer support groups via social media, charities and or local neonatal units, that are tailored to the specific needs of the premature neonate and family.

- Our recommendations concur with the NICE (2017) guidance on Developmental follow-up, that states the following.....
Care, support and follow-up after discharge
- *Healthcare professionals providing postnatal care and support in the community for babies born preterm should have the skills and knowledge to recognise and manage problems in these babies, including:*
 - *providing feeding support*
 - *addressing concerns about sleeping*
 - *helping parents or carers to interact with their baby.*

Glossary

GP: General practitioner – a doctor who provides care and treatment for a local population.

Hospice: A hospice, within a neonatal context, focusses on the multifaceted care and support that is required by both the infant and the family.

Neonatal: The period of life up to 28 days post-term.

Premature: Relates to babies who are born alive before 37 weeks gestation.

LGBTQIA+: Lesbian, gay, bisexual, transgender, queer/questioning, intersex, asexual.

Together for Short Lives: A UK charity that that focusses on children's palliative care. <https://www.togetherforshortlives.org.uk/>



EXTRA READING – Read more about issues relating to the community care & support of parents after discharge home from the neonatal unit.....

- Petty, J, Whiting, L, Fowler, J and Green, J (2021) **Exploring the knowledge of community-based health professionals in supporting parents of premature babies at home: A survey-based study.** *Nursing Open*.
 - Green, J, Fowler, C, Petty, J and Whiting, L (2021) **The transition home of extremely premature babies: An integrative review.** *Journal of Neonatal Nursing*. 27(1), 26-32.
 - Petty, J, Whiting, L, Mosenthal, A, Fowler, C, Elliott, D and Green, J (2019) **The knowledge and learning needs of health professionals in providing support for parents of premature babies at home: A mixed-methods study.** *Journal of Neonatal Nursing*. 25(6), 277-284.
 - Petty, J, Whiting, L, Green, J and Fowler, C (2018) **Parents' views on preparation to care for extremely premature infants at home.** *Nursing Children and Young People*. 30(4), 22-27.
-