Chapter 13 Caring for the vulnerable neonate at and after discharge

Introduction [A]

Thorough discharge planning, that starts when the infant is admitted to the neonatal unit, is fundamental to the smooth transition home. Discharge planning needs to adopt a two-way communication strategy that enables a range of health professionals to provide parents with support that embraces educational, medical and emotional aspects of care. High quality discharge planning means that parents are far more like to feel able to look after their infant in the home environment, confident in the knowledge that they know who to contact, should the need arise. This chapter will discuss the specific areas that need to be considered, both prior to discharge and when the infant is at home.

Chapter learning objectives [F]

By the end of this chapter, you will:

- ✓ Understand why early and thorough discharge planning is crucial to the smooth transition from the neonatal unit to the home environment, for both parent and infant.
- ✓ Be able to identify support strategies for parents when caring for their infant in the home environment.

Critical thinking points [F]

- How would you facilitate appropriate discharge planning and the smooth transition home for the infant and their family?
- What are the key facilitators that enable parents to confidently care for their infant at home, post-discharge from the neonatal unit?

Planning for discharge home

Taking an infant home, who has been cared for in a neonatal unit, can be an exciting, but also a very daunting prospect. Discharge planning involves working with the family to ensure that the transition home is smooth and successful; it should start at the point of admission (Smith et al, 2022) with several aspects being central to its preparation (Figure14.1).

Figure 14.1 Key considerations for discharge planning from the neonatal unit to home (from Osorio Galeano and Salazar Maya, 2023)

- Discharge planning should:
    - Start from the infant's point of admission to the neonatal unit
    - Be a continuous process
    - Involve both informal and formal education
    - Acknowledge the specific circumstances of each parent (including individual, family and social situations)
    - Focus on the specific needs of the individual infant
    - Take into account the infant's clinical condition as well as how the parent(s) adapt to the circumstances
    - Embrace physical and emotional aspects
    - Consider how the smooth transition home can be facilitated
    - Be extended to the wider family

Stop and think [F]

It is easy to under-estimate the complexity of discharge planning and the range of elements involved. It is time-consuming, requiring continuity and excellent communication strategies.

One of the initial priorities is to build parental confidence so that they not only feel able to competently carry out daily care when at home but know who to contact should a health problem arise. It is important to get to know the parent(s) throughout the infant's stay in the neonatal unit, documenting key points in the notes so that these can be referred to as discharge nears and discussions become more focussed (for example, a parent may mention that they live in a high rise flat and that the lift is frequently 'out of order' – knowing this will enable bespoke information to be provided). As discharge approaches (a minimum of 48 hours beforehand, but longer, if possible), it is important to have a discussion with the parent(s) about their concerns and anxieties. Although parents may have older children, they may be very anxious about taking their vulnerable infant home; it is useful to make a list of areas that parents would like further advice about and these can then be added to the neonatal unit's generic checklist. It is also crucial to involve the rest of the family, especially siblings and grandparents (the latter who may be involved in day-to-day care activities when parents return to work). Therefore, talk to parents about who is important in their lives and who may benefit from being included in the discharge planning.

The date of discharge will be influenced by a number of factors, but primarily the infant's physical readiness; in addition, the timing needs to be as convenient as possible for the parent(s); for example, it maybe that if an infant is discharged home towards the end of a working week, there are other family members who can provide support during the initial few days at home, especially if they span a weekend (this may be even more imperative if a parent has had a multiple birth such as twins). Having a date goal to aim for also facilitates the organisation of the discharge planning arrangements.

Transition from hospital to home

Smith et al (2022) offer guidelines to facilitate discharge planning and the transition home, highlighting four key areas:

- *Basic information*: This refers to the knowledge that every family will require, irrespective of their individual and specific needs; it includes discharge education, planning tools, the team, and the process.
- *Anticipatory guidance*: This focusses on parents developing a good insight into what life will be like when they are at home with their infant.
- *Transfer and co-ordination of care*: This centres on the transition of care from the acute neonatal unit to the community.
- *Other important considerations*: This encompasses factors that may be specific to individual families and where there may be particular needs; examples include families where there is limited command of the English language, those who have disabilities, those from an LGBTQIA+ background and those in the military; but there are, of course, other circumstances too.

Further details of the above areas are provided in Figure 14.2

Figure 14.2 Summary of the four key areas of discharge planning and transition home (adapted from Smith et al, 2022)

Aspect	Interpretation
• Basic information	• Discharge education that includes: o Feeding o Bathing o Dressing – day and night o How to change a nappy and the frequency to be expected o Home medication information o Provision of a safe sleeping position and environment o How to recognise illness, including a pyrexia o Protecting the infant from infections o Use of any technology that may be used at home o Basic life support education o Information about immunisations o Preparing the home environment (for example, safety measures) o The journey home (for example, an appropriate car seat) o Thinking of the help that parents may need once home • Discharge planning tools that include: o A comprehensive discharge summary o Supplementary educational materials, such as resources produced by the neonatal unit or charities (for example, Bliss) • Discharge planning team that may involve: o Nurses, doctors, psychologists, social works, advance nurse practitioners o Those who will be involved in the infant's care at home o Siblings • Discharge planning process that: o Starts on the infant's admission to the neonatal unit and continues throughout their stay o Provides clear and consistent messages
• Anticipatory guidance	• Factors to be considered: o The anticipated number of medical/clinical appointments (these could include, for example, audiology, ophthalmology, cerebral scans, physiotherapy, neonatal/paediatric/community consultant, developmental checks, immunisations) o Developmental milestones and growth

<table>
<tr><td></td><td>Parental feelings about going home with their infant – this includes excitement, but also anxiety about caring for their infant by themselves without the infrastructure of the neonatal unit
How to deal with a crying infant
The type of atypical behaviour that might be encountered
Parental mental health
Potential financial implications
What to do in an emergency
Assessment of family risk factors</td></tr>
<tr><td>Transfer and co-ordination of care:</td><td>Factors to be considered:
Involvement of primary carers
Neonatal unit contact with the family post-discharge home
Community resources – who and what is available to support the transition home?
Parental emotional and mental health wellbeing</td></tr>
<tr><td>Other important considerations</td><td>Factors to be addressed:
Interpreter or computer-related services
The potential need for additional social support
Parental literacy levels
Accessibility to services, especially if parents have disabilities
Use of terminology that is inclusive and non-discriminatory
Family beliefs</td></tr>
<tr><td colspan="2"> Stop and think [F]
The four areas detailed in Figure 14.2 provide an overview of the key elements of discharge planning; however, the overriding factor is the individual family and ensuring that their specific needs are met.</td></tr>
</table>

Prior to the family leaving the neonatal unit, it is important to ascertain that all key information has been provided and that relevant procedures/policies have been appropriately followed; to facilitate that, most neonatal units have a checklist that includes similar areas to those highlighted by Smith et al (2022).

Rooming in

One strategy that is advocated prior to discharge is the rooming in of parents in the neonatal unit. Unicef United Kingdom (2022: 14) advocates that that all parents have *"the opportunity*

to room in with their baby for as long as needed and to take full responsibility for their baby's care". This enables parents to gain confidence within a safe and secure environment. Mothers have reported that rooming in aids breast feeding, enhances bonding as well as confidence, promotes 'ownership' of the baby and helps to foster a feeling of being a family (Bennett and Sheridan, 2005).

Whilst the benefits of rooming in have been well documented, it is important to recognise some of the challenges associated with it – most notably, it may disrupt parental sleep patterns, meaning that at the point of discharge, parents may already feel very tired; Bennett and Sheridan (2005) also reported mothers' having feelings of isolation. In addition, not all neonatal units have the facilities to support rooming in so it may not always be feasible. Finally, emphasis is frequently placed on the need for the mother to room in, but it is important to consider other family members, in particular, the father.

Being at home

Caring for an infant after discharge from a neonatal unit can be challenging and can mean that parents need professional support (Boykova, 2016). Research by Petty et al (2018) gained insight into the post-discharge experiences of parents in relation to their preparation for caring for their extremely premature infant at home. The study revealed five areas that parents felt were important to them (Figure 14.3).

Figure 14.3 Summary of findings (Petty et al, 2018)

Research finding	Interpretation
• Parental support and preparation for transition home	• Parents valued the preparation that they had had for discharge home and were generally very positive about the experience. However, when discharge planning was carried out at a late stage, or was rushed, they felt unprepared – thus emphasising the need for an organised approach
• Ongoing health needs of the baby	• Parents reported that their infants had ongoing health needs, for example, gastro-oesophageal reflux and respiratory problems; as a result, readmission to hospital was an issue. Ongoing health needs presented other challenges including financial difficulties as well as impacting on their own emotional wellbeing.
• Emotional and mental health of parents	• Parents had a range of feelings about going home with their infant – this included excitement, but also anxiety about caring for their infant by themselves without the infrastructure of the neonatal unit.
• Uncertain outcomes	• Parents were worried about what the future held in terms of their infant's health and wellbeing – this was particularly the case if the infant had had an incident such as a cerebral haemorrhage.
• Educational needs of health professionals	• Parents felt that community-based health professionals could lack knowledge and suggested a need for more focused education in terms of the specific needs of premature babies – they thought that this would facilitate a better level of support and advice for parents.

Stop and think [F]

Parents may face a range of challenges post-discharge home; these are multi-faceted and include implications for the parent, infant and wider family.

As parents may continue to be anxious about the health and wellbeing of their infant when home, different members of the multi-disciplinary team may be able to support them; however, parents need to understand their various roles and know who to contact. Figure14.4 provides an overview of some of the key personnel who may be able to support the family in the on-going care and management of their infant.

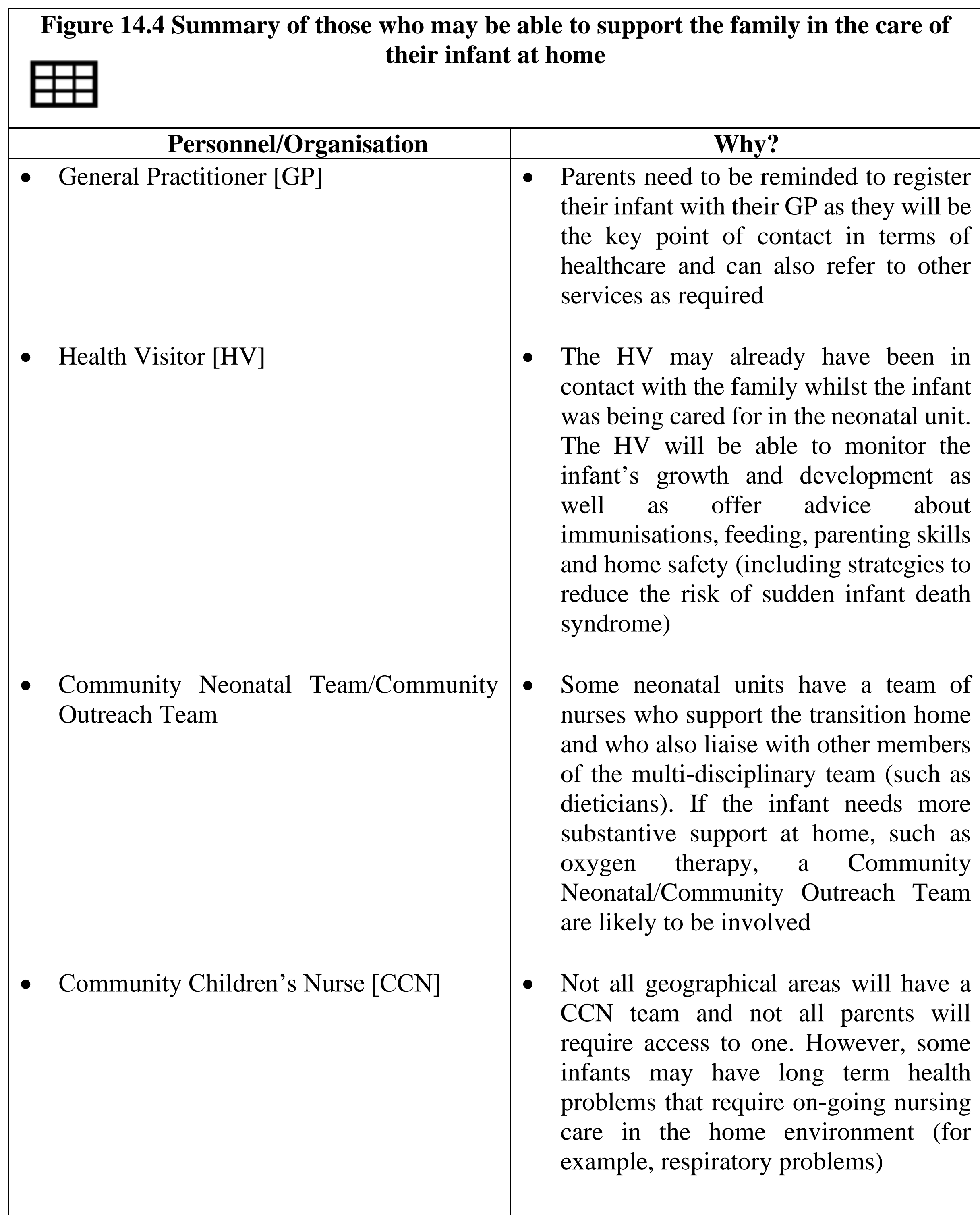
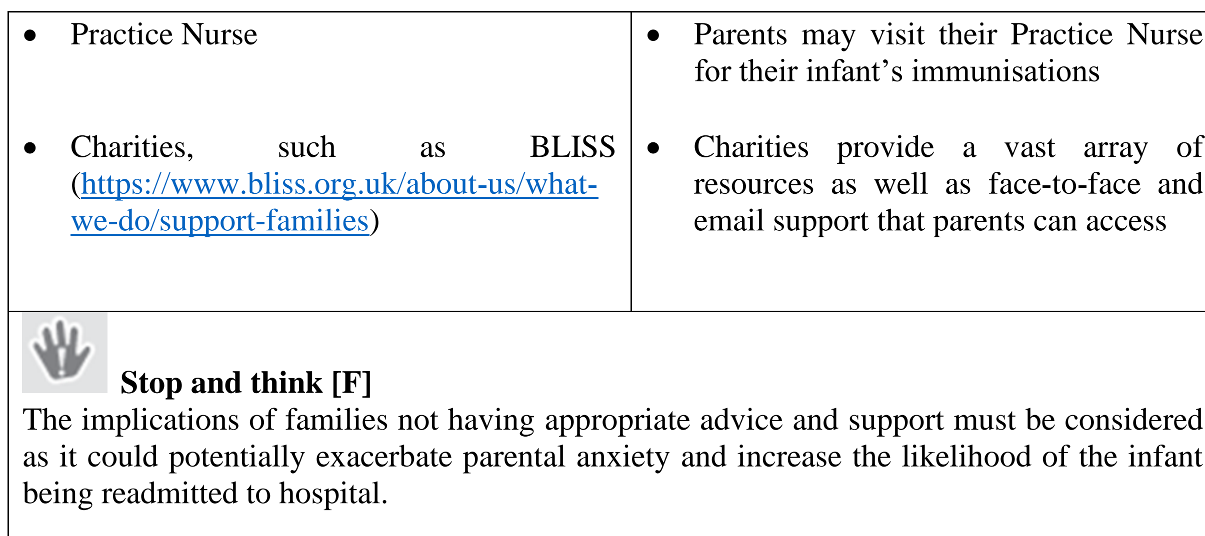


Figure 14.4 Summary of those who may be able to support the family in the care of their infant at home

Personnel/Organisation	Why?
• General Practitioner [GP]	• Parents need to be reminded to register their infant with their GP as they will be the key point of contact in terms of healthcare and can also refer to other services as required
• Health Visitor [HV]	• The HV may already have been in contact with the family whilst the infant was being cared for in the neonatal unit. The HV will be able to monitor the infant's growth and development as well as offer advice about immunisations, feeding, parenting skills and home safety (including strategies to reduce the risk of sudden infant death syndrome)
• Community Neonatal Team/Community Outreach Team	• Some neonatal units have a team of nurses who support the transition home and who also liaise with other members of the multi-disciplinary team (such as dieticians). If the infant needs more substantive support at home, such as oxygen therapy, a Community Neonatal/Community Outreach Team are likely to be involved
• Community Children's Nurse [CCN]	• Not all geographical areas will have a CCN team and not all parents will require access to one. However, some infants may have long term health problems that require on-going nursing care in the home environment (for example, respiratory problems)



• Practice Nurse	• Parents may visit their Practice Nurse for their infant's immunisations
• Charities, such as BLISS (https://www.bliss.org.uk/about-us/what-we-do/support-families)	• Charities provide a vast array of resources as well as face-to-face and email support that parents can access

Stop and think [F]
The implications of families not having appropriate advice and support must be considered as it could potentially exacerbate parental anxiety and increase the likelihood of the infant being readmitted to hospital.

In addition to professional support, parents rely heavily on social networks – this can include family members as well as friends and neighbours. This social support is extremely important, but it should be recognised that it can have both negative and positive consequences; for example, parents may receive erroneous advice that is not underpinned by sound evidence. This reinforces the need for the key people in the lives of the family to be involved in discharge planning whilst the infant is still in the neonatal unit.

Once home, there are many causes of concern for parents, but perhaps the ones that can be most anxiety provoking are those associated with feeding, overall development, respiration and sleeping.

Development

Infants who are born prematurely are at greater risk of developmental problems; examples include: Cerebral palsy, educational needs, motor function difficulties, speech and language development as well as learning disabilities (National Institute for Health and Care Excellent [NICE], 2017). It is therefore natural that parents may be concerned about their infant, especially as healthcare professionals may not be able to confirm whether there may be challenges ahead and/or what the severity may be. As a result, it is essential that the infant's growth and development is appropriately reviewed, via an in-person consultation; during the first two years of life, NICE (2017) suggest that this is normally at the following infant corrected ages:

- Between 3-5 months
- By 12 months

- At 2 years

The assessments provide an opportunity for an in-depth discussion with the parent(s) as well as a thorough and comprehensive assessment of the infant's growth and development; a later developmental review may be undertaken at 4 years.

One area of development that is important to consider once the infant has been discharged home is language. Infants who are born prematurely are at high risk of speech and communication problems; these can have a lifelong impact, both educationally and in terms of developing friendships; despite this, little direct attention has been given to developing early language and communication skills. In a narrative-based qualitative study (Petty et al, 2023), parents reported that they had accessed information from websites, but they had little knowledge of the core components of communication beyond bonding, skin-to-skin care and direct talking and singing with their infants. One of the main barriers to parental communication with their infants was mask-wearing, incubator care and conflicting advice (both in the neonatal unit and later, when at home). Therefore, there is a need for health professionals to provide on-going, culturally appropriate post-discharge advice that supports parents to use good communication strategies that recognise their infants' cues.

Parents need to know who to get in touch with should they have concerns about any aspect of their infant's development (please refer to Figure 14.4); therefore, providing a list of the names and contact details of key members of the multi-disciplinary team is very helpful.

Feeding

One of the areas of care that can be challenging for parents to deal with in the home environment is infant feeding. Suddenly, the parent can feel isolated with no immediate access to advice or support, especially at night. Dib et al (2022) commented on the fact that challenges are common and that breastfeeding is limited in this group of infants; in their systematic review, Dib et al (2022) found that support from professionals had a significant impact on mothers' ability to exclusively breastfeed; it was suggested that an education programme (delivered whist the family are in the neonatal unit) and followed-up by weekly telephone contact after discharge significantly improved breastfeeding rates. Infant feeding difficulties are also extended to parents who are not able to, or who choose not to breastfeed, and this highlights the need for regular on-going support once the infant is at home so that parents can have any

questions addressed in a timely manner; unfortunately, this is something that can be lacking and that, as health professionals, we need to address. Petty et al (2022) found that the knowledge, skills and confidence amongst English Health Visiting students, in terms of advising and caring for parents with premature infants at home, varied and depended on individual placements and experiences. The study suggested that further education about the specific needs of premature infants and their parents was required and that more resources for community-based health professionals could optimise the support provided to parents.

Some infants may be discharged home with enteral feeding (such as a nasogastric tube), thus meaning that their length of hospital stay can potentially be reduced. Interestingly, parents may receive more support if their infant is discharged home in this situation because of the problems that can be associated with this type of nutritional support (such as tube displacement). Parents may find that they have on-going contact with the neonatal unit and/or a community neonatal or children's nursing team; this enables families to have a direct point of contact.

Respiration

Many preterm infants may have experienced respiratory difficulties and some of these may not be fully resolved at the point of discharge. Infants requiring oxygen therapy can be safely cared for at home, providing that the family have been appropriately educated, have developed the requisite knowledge and skills and that they feel comfortable to care for their infant at home. Bliss (n.d) provide an excellent resource for parents (*"Going home on oxygen"*) that they can be directed to.

Clinical guidelines provided by the Scottish Perinatal Network Neonatal and NHS Scotland (2022) suggest that infants need to meet a set of criteria to be discharged home on oxygen (Figure 14. 5).

Figure 14.5 Criteria for the infant to be discharged home on oxygen (from Scottish Perinatal Network Neonatal and NHS Scotland (2022)

- Infants should:
  - Be 36 weeks corrected gestational age or more
  - Be physiologically stable
  - Have had appropriate growth
  - Have oxygen dependency of no greater than 0.5 litres per minute, via nasal cannula
  - Be able to maintain an average oxygen saturation level of 93% or more
  - Have had stable oxygen needs for a week.
  - Have had any systemic steroids stopped at least 1 week before.
  - Have had no recent changes to medication that could impact on respiration.
  - Be able to feed orally for a minimum of 48 hours prior to discharge (unless nasogastric feeding forms part of discharge planning).
  - Not have had apnoeic episodes and have had any caffeine citrate therapy discontinued for a minimum of a week

Stop and think [F]

Whilst the above criteria are very beneficial in terms of deciding whether an infant can be discharged home with oxygen, the on-going needs of the parents are substantive, especially in terms of their potential anxiety levels. Think about the type of support that parents will need (and where this can be accessed from) to enable them to successfully care for their infant.

Sleeping

Whilst in the neonatal unit, infants may well have been exposed to an array of technology and may have become used to a range of sounds and light sources; it is not unusual for this to have an on-going impact when they are home. It is also recognised that infants who have been born prematurely may not sleep as deeply as those born at term and that they can have more active sleep – this predisposes to sleep difficulties. Lyu et al (2022) reported that both preterm and post-term birth infants experienced more sleeping problems, as well as less sleep duration, than term infants. The type of sleep difficulties can also include those associated with breathing such as apnoea and the fact that the preterm infant has a higher risk of being a victim of sudden infant death syndrome. These factors are likely to mean that parents have heightened anxiety. In addition, it is known that the parents of preterm infants are more likely to suffer from sleep disturbances themselves because of the stress that they have experienced; this then has the potential to negatively impact on their own health and wellbeing (Marthinsen et al,

2018). The consequences of poor sleeping behaviours, for both the infant and parent(s), may mean that being at home is extremely challenging, especially considering the other stressors (such as infant feeding) that parents may be exposed to. As a result, parents may need to take advantage of wellbeing services and/or counselling – it is essential to reassure them that what they are experiencing is 'normal' so that they do not feel that they are failing in the care of their infant.

References

Bennett. R. and Sheridan, C. (2005) Mothers' perceptions of 'rooming-in' on a neonatal intensive care unit. *Infant.* 1(5), 171-174.

Bliss (n.d) *Going home on oxygen.* Available from: https://www.bliss.org.uk/parents/going-home-from-the-neonatal-unit/going-home-on-oxygen Accessed on 16th October 2023.

Boykova , M. (2016) Life after discharge: what parents of preterm infants say about their transition to home. *Newborn and Infant Nursing Reviews*. 16(2), 58-65.

Dib, S., Kittisakmontri, K., Wells, J. C. and Fewtrell, M. (2022) Interventions to Improve Breastfeeding Outcomes in Late Preterm and Early Term Infants. *Breastfeed Medicine*. 17(10), 781-792.

Lyu, J., Groeger, J. A., Barnett, A. L., Li, H., Wang, L., Zhang, J. Du, W. and Hua, J. (2022) Associations between gestational age and childhood sleep: a national retrospective cohort study. *BMC Medicine.* 20(253) https://doi.org/10.1186/s12916-022-02443-9

Marthinsen, G. N., Helseth, S. and Fegran L. (2018) Sleep and its relationship to health in parents of preterm infants: a scoping review. *BMC Pediatrics*. 18(1), 352. doi: 10.1186/s12887-018-1320-7.

National Institute for Health and Care Excellent (2017) Developmental follow-up of children and young people born preterm. Available from:
https://www.nice.org.uk/guidance/ng72/resources/developmental-followup-of-children-and-young-people-born-preterm-pdf-1837630868677 Accessed on 22nd October 2023.

Osorio Galeano, S. P. and Salazar Maya, Á. M. (2023) Preparing Parents for Discharge from the Neonatal Unit, the Transition, and Care of Their Preterm Children at Home. *Investigación y Educación en Enfermería*. 41(1), e04. doi: 10.17533/udea.iee.v41n1e04.

Petty, J., Whiting, L., Green, J., Fowler, C., Rossiter, C. and Elliott, D. (2018). Parents' views on preparation to care for extremely premature infants at home. *Nursing Children and Young People.* 30(4), 22-27.

Petty, J., Whiting, L., Green, J. and Fowler, C. (2022) Exploring the knowledge of community-based nurses in supporting parents of preterm babies at home: A survey-based study. *Nursing Open*. 9(3), 1883–1894.

Petty, J., Harding, C. and Whiting, L (2023) Exploring the parent perspective on the enablers and barriers to communication with their preterm infants: a narrative study. *Journal of Child Health.* In press.

Scottish Perinatal Network Neonatal and NHS Scotland (2022) *Home Oxygen Therapy for Neonates.* Available from:
https://www.perinatalnetwork.scot/wp-content/uploads/2022/04/National-Neonatal-Network-Home-Oxygen-Guideline-V1.0.pdf Accessed on 16th October 2023.

Smith, V.C., Love, K. & Goyer, E. (2022) NICU discharge preparation and transition planning: guidelines and recommendations. *Journal of Perinatology.* 42(Suppl 1), 7–21. https://doi.org/10.1038/s41372-022-01313-9

Unicef United Kingdom (2022) Guide to the Unicef UK baby friendly initiative neonatal standards. Available from: https://www.unicef.org.uk/babyfriendly/wp-content/uploads/sites/2/2022/03/UNICEF-UK-Baby-Friendly-Initiative-Guide-to-the-Neonatal-Standards.pdf Accessed on 17th October 2023