# Guideline Framework for Neonatal Discharge Planning

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## References


TVWNODN – parental app- to be searched for on the app store.

Implications of race, equality & other diversity duties for this document This guideline must be implemented fairly and without prejudice whether on the grounds of race, gender, sexual orientation or religion.
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1.0 Aim of Guideline Framework

To provide a framework for neonatal discharge planning in the Thames Valley & Wessex Neonatal Network. Also to offer practical guidance for neonatal unit staff, on how to actively plan for and progress towards successful neonatal discharge. So that every infant is safeguarded and parent's/carer’s leave the neonatal unit with competence and confidence.

2.0 Scope of Guideline Framework

The guideline applies to all neonatal units and maternity units covered by Thames Valley Neonatal Network. This includes the following hospitals:

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<td>Western Sussex Hospitals NHS Foundation Trust</td>
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2.0 Scope of Guideline Framework

3.0 Guideline Framework

3.1 Background

For hospital staff the decision about when to discharge an infant from the hospital after a stay in a Neonatal Unit is complex, and is based largely on the infant’s medical status. However there are many complicating factors, such as parental readiness, availability of care for ongoing needs at home and system readiness to monitor and support vulnerable families, whilst safeguarding and promoting the welfare of the baby.

From the parent's perspective taking a healthy newborn baby home is an anxious and challenging time, so when a preterm baby is discharged home this anxiety will often be magnified. Literature identifies that parents experience anger, guilt, isolation and fear. In particular fear about their ability to care for their baby, concern that the baby may not feed or not sleep, and anxiety that the baby will catch an infection and be re-hospitalised.
There has been a national focus on the importance of safe and effective discharge for neonates. Three reports in particular write about discharge. These are ‘Toolkit for high quality neonatal services’ (DoH), The Bliss baby standards charter, and the POPPY report from the POPPY project. They were prompted by the afore mentioned organisational challenges for health care workers, in effectively co-ordinating neonatal discharge and the importance for parents to be supported before, during and after discharge.

Common themes arise from their documents/reports including the need for parental involvement in discharge planning, parents to be partners in their baby’s care, access to accommodation to enable full (but supported) care by parents prior to discharge, appropriate information and training for families prior to discharge, established discharge planning policy, named discharge co-ordinator.

It is with this national focus upon neonatal discharge and the evidence base developing in this area that this ‘Neonatal discharge planning guideline framework’ is being written.

3.2 Stages in Discharge Planning

Four distinct stages in discharge planning are used to direct practice and structure this guideline. This is to ensure a phased progression of discharge planning occurs throughout a baby’s admission. These four stages are:

1. **Inpatient** On admission, planning for discharge should begin.
2. **Discharge anticipated** Active planning, education and referral should begin.
3. **Discharge imminent** Outstanding issues need to be actioned and finalised.
4. **Day of discharge** Documentation is completed and baby discharged.

3.3 Inpatient

On admission, planning for discharge should begin. This is a fundamental statement in all discharge planning literature. What this means in the practice setting is to have in mind that the ultimate goal for most babies is to discharge the baby home to its parents. Think about this goal every shift to see if there are actions that can be taken to help in this process.

3.3.1 Actions to take:

1. Obtain the Red book (Parent held Records) for the baby and complete initial sections.
2. Contact the baby’s health visitor within 24 hours of admission.
3. Check social services background file and maternal history in notes, to see if there are social concerns already identified.
4. Inform baby’s parents if it is anticipated that the baby will require transfer to another clinical area as part of its transition to discharge to home. For example, to their local neonatal unit or specialist children’s ward. This should help parents to prepare for this change when the time comes. It may also help reduce the conflict that can occur when parents say they will refuse to allow their baby to be transferred to another care setting as they are happiest for the baby to stay where it is.
5. Inform parents about the App for smart phones that can be uploaded for free, and gives comprehensive information about all of the neonatal units in the Thames Valley and Wessex Neonatal Network, also general information about neonatal care, the Network and SOnet. Advise parents to search for ‘TVWNODN’ on the App store.
6. Offer parents appropriate literature relating to their baby and its care. This may include:
   - Unit booklet, including visiting and contact details
   - Bliss booklet on having a baby in a neonatal unit
   - Cot death information
   - Car seat use and selection information
   - Sources of financial help
   - Bliss going home booklet
3.3.2 Vulnerable families and ‘visitation monitoring’:

Be aware of social situations relating to the baby and its family that are already apparent, and are likely to affect discharge. For babies and families with the issues listed below:

- Concerns about the parent’s ability to care for a baby at home.
- Unstable mental health of one or more parents.
- Substance abuse by one or more parent.
- Child protection issues or social work case file already open for this family.
- Social work team request ‘visitation monitoring’. Visitation monitoring’ must be commenced, which involves comprehensive documentation of parental communication & also their interaction with and care of their baby. Parents should be informed that these records are being maintained. (See local policy for specific documentation requirements). An example of such a document in current use within the network can be seen in appendix 7).

It is unlikely that it will be known at this point the exact impact of such situations, but by flagging up any issues, monitoring and record keeping can begin, which will contribute to decision making about discharge. Information gathered helps social workers and the community team decide what support is required in the community or in an extreme case, whether a baby can safely be discharged home to its parents. In addition, support and education packages can be initiated early for parents with extra needs, to ensure they are competent to take the baby home when the baby is ready for discharge.

The majority of parents will not require ‘visitation monitoring’, but if an incident or episode of significant concern is noted these should be recorded in a place designated by each unit. If the problem resolves or is a single event then no further action will be required. However, if concerns continue and social services become involved, the documentation can be added to any record started.

3.3.3 Babies with specific medical or practical needs:

Babies with specific medical needs that are apparent from soon after admission e.g.:

- baby with spina bifida requiring home catheterisation
- baby with nasopharyngeal airway requiring home suction
- baby with colostomy that will be present when discharged home
- baby whose parents are deaf and may require specialist equipment for baby’s care at home
- Premature baby establishing sucking feeds- may require home tube feeding programme and teaching package.
- Baby with cleft palate or hypotonia may require long term home tube feeding programme and teaching package.

Access appropriate equipment for home care and ensuring parents/carers are competent in its use can be a long process. The sooner a need is identified then the sooner a discharge pathway can be set in place to guide staff and parents.

3.3.4 Parents:

Sensitivity will be required by staff when discussing discharge with parents, especially for the extremely preterm or critically unwell babies, as there may be no guarantee that a baby will survive in order to be discharged.

Literature identifies that the prospect of discharge is very stressful for many parents, especially those whose babies have required significant medical and nursing care. They experience anxiety relating to providing care without nursing and medical support, keeping their baby safe without hospital monitoring and...
often lack confidence in their ability to ‘parent’ their baby. With awareness of these issues, staff need to begin the process of helping parents to make a successful transition to home from the time of admission. This might be seen by:

- Encouraging parents to care for and form an attachment to their new baby.
- Reinforcing that the baby belongs to the parent’s and empowering them to make decisions about their baby, where appropriate.
- Being welcoming and keeping parents informed about their baby’s care and progress.
- Adopt a holistic role including the whole family in care.

3.3.5 Documentation:

Discharge planning is an ongoing process that happens over an extended time period. It will be normal that many health care professionals are involved in conversations, teaching and assessment and preparations for discharge. It is therefore very important that individuals carefully document all actions/care that are relevant to a baby's discharge. This needs to clear and concise and in a location known to and accessible to other team members, ideally a discharge care plan or discharge pages in medical notes.

3.4 Discharge Anticipated

Based on the 5 discharge criteria:

- Sustained pattern of weight gain.
- Adequate maintenance of normal body temperature.
- Competent baby ‘suck feeding’/ parental ‘tube feeding’ without cardio-respiratory compromise.
- Physiologically mature, with stable cardio-respiratory function of sufficient duration.
- Parental readiness for discharge - including a suitable home environment exists for discharge.

Defined as discharge is ‘anticipated’ when it becomes clear that a baby is transitioning towards achieving the five discharge criteria, but the discharge is not yet imminent.’ It is likely to be between 4 days and 1 month from actual discharge.

3.4.1 Actions to take:

1. Confirm baby is registered with a GP and document correct details.
2. Confirm name, discharge address and discharge home contact details for baby/parents.
3. Review Newborn blood spot screening (Guthrie) schedule and ensure this is up to date and fully documented.
4. Review immunisation schedule, is baby well enough and mature enough to receive immunisations? Does administration of the immunisations need to be planned for before discharge, in case baby’s health status is affected by immunisations?
5. Maintain ongoing update of red book health record - according to unit policy.
6. SEND/BadgerNet computer record to be regularly updated - throughout baby’s admission.
7. Medication education can begin, with parents acting as third checker until TTO’s are obtained.
8. IBLS (infant basic life support) training should be offered and be scheduled to prevent a last minute rush and/or parents having to return after discharge to obtain training.
9. If accommodation is available, consider offering parents the opportunity to stay for one or more days and nights whilst their baby still needs to be cared for on the unit. For different families this may help in different ways. For example, to develop confidence in day to day care, to help parents visit for a longer period than usual, to help establish breast feeding or milk supply, to save one days travel for families travelling a long distance to the unit.
10. Discuss home feeding plan with parents and adjust feeding regime to try and ensure this can be achieved.
• Is maternal breast milk supply sufficient?
• If mother plans to breast feed is she putting baby to breast.
• Does the baby need to be weaned to a different formula for discharge.
• Ask parents to bring in the bottles they will be using for their baby at home, so the baby can get used to them.
• Is a breast pump available at home- if required? If not- give parents information on local arrangements for loaning, renting or purchasing a pump.
• Is a breast pump available at home - if required?
• Are supplements such as fortifier still required?
• Is the baby going home on a formula that is only available on prescription? If so the GP needs to be asked to prescribe this at least a week before discharge, so the parents can take the prescription to the pharmacy, and the pharmacy can then order the feed in. Allowing time for the feed to be collected before discharge.

11. Commence transition care practices gradually towards those which the parents will be giving when the baby is at home. Explain to parents why specific types of monitoring or forms of care are no longer necessary and that the changes are a positive thing as their baby is becoming more robust and closer to being ready for home. Also explain why new practices are being introduced and that certain ways of caring for their baby are only appropriate whilst the baby is in hospital. Gradual transitions and explanations should include:
   • Stopping saturation monitoring - directed by local policy.
   • Stopping apnoea mattress monitoring - directed by local policy.
   • Reduction, then ceasing of positioning support - directed by local policy.
   • Transition to full cot death guidelines.
   • Transition to normal lighting levels - directed by local policy.
   • Transition to normal unsupported temperature regulation.

12. Written information about the selection and use of car seat in neonates should be offered to parents. Early discussion is especially valuable as parents who have not purchased a car seat can consider the information offered, when making their selection.

13. Inform parents about the option to ‘room in’ with their baby prior to discharge so they can think about whether they would like to do this. If discharge timing can be anticipated consider booking the night (s) parents will stay in advance, so they can make plans for childcare, work arrangement. Make it clear that you cannot guarantee the baby will be ready by that date, or after ‘rooming in’. The date would be your “best guess” only.

14. For babies with life limiting conditions see Network Palliative Care Pathways/ consider referral to local hospice care.

15. Babies who fulfil one or more of the ‘at risk’ criteria should be referred for outpatient follow up. The ‘at risk’ criteria are:
   • Gestational age 32/40 and below at birth.
   • Birth weight 1500g or less.
   • Baby with Neonatal Abstinence Syndrome, that required treatment.
   • Neurological compromise.
   • Infant with anticipated early death.
   • Any other infant designated by the Multidisciplinary team (For example tube feeding at home and home oxygen babies).

3.4.2 Parental Education:

This is the stage where actively teaching, supporting and empowering parents is essential. Information giving, empowerment and education should be timely and spread out over enough time to enable parents to process information, ask questions that arise and consolidate practical skills.
Education should be offered to parents on the following and should be backed up with written information:

- IBLS
- Bathing
- Making up bottles and sterilising equipment
- Cot death guidelines, best practice at home
- Car seat, best practice in neonates
- Breast feeding and maintaining milk supply
- The ‘normal’ home environment (noise, light, heating)
- What to expect after discharge and where to seek help and advice
- Tube feeding (if appropriate)
- Administering drugs to their babies safely
- Signs of concern/baby’s ill health (For example, consider using the advice framework given in Lullaby Trust’s baby check is your baby really ill? (Lullaby Trust 2012)

When staff are teaching parents and considering signing them as ‘competent’ for a particular skill they should be:

- Demonstrating competence on more than one occasion.
- Verbalising understanding of the process and its rationale.
- Demonstrating confidence through repeated performance.

Parents as well as staff should be signing that competence is achieved. This makes it easier for parents to ask for more time and education if they are uncertain. It also ensures there is clear evidence that teaching occurred, competence was achieved, indicating parent’s acceptance of transferred responsibility for their baby as discharge becomes closer.

A frequently identified source of stress from parents is that discharge information is often inconsistent; in particular the date that their baby will be going home. It is not easy to anticipate in advance the exact date/week a baby will be ready for discharge, however anticipated date/week of discharge should be estimated on admission and reviewed weekly, keeping parents fully informed to reduce parental disappointed and potential feelings of being let down by staff if the anticipated discharge date/week is delayed. Ensure parents/carers understand the criteria that their baby will have to be achieving before discharge.

3.4.3 Documentation:

As discharge is coming closer, the need for accurate and thorough documentation becomes more important still. All team members need to document:

- Teaching given to parents/carers
- Competence achieved
- Gaps in knowledge or skill still required for discharge
- Plans made to teach/support parents/carers
- Conversations about discharge, including any specific plans or plans in progress
- Documentation of leaflets given to parents/carers

3.4.4 Social Concerns/Vulnerable families:

Babies and parents/carers should already have been identified who require ‘visitation monitoring’. It is important that records are maintained on every shift.

Staff are not required to ‘spy’ on parents/carers, however as part of the care for the family and their responsibility for the safety of the baby, staff are responsible for acting upon any parental behaviours or interactions they observe that cause them concern. Even if ‘visitation monitor’ has not formally been commenced, any behaviour causing concern must be clearly and objectively documented in the location agreed by local policy and the nurse in charge informed. It is the responsibility of the nurse in charge to...
ensure further investigation and escalation of concerns as required. In most cases, further parental support will be the outcome required.

For babies and families with identified social concerns they will be followed up community social work team. If these babies do not require follow up for medical reasons after discharge then their care after discharge will be co-ordinated by the community social work team. The hospital nursing and medical team will take an active role in supporting and preparing a baby and its family for discharge. Joint discharge planning meetings are likely to be required with likely attendees including but not limited to: Community Midwife, Health Visitor, Unit Nurse, Unit Doctor, Social Worker, Family Support Worker, Parents. The outcomes of such a meeting will often include:

- Clear discharge plan
- Criteria that the parents have to meet before discharge will be considered.
- Additional support and resources to be offered by community or social services.
- Planned date for discharge to be agreed, in order to ensure goals are achieved and resources prepared.
- Agreed allocation of tasks outstanding, to MDT members.
- Where relevant, visitation arrangements for confidential foster placements.
- The social work team will usually identify when parents/carers, the home situation and support services are ready for a baby to be discharged. Under no circumstances must these babies be discharged before confirmation has been given that it is safe to do so.

3.4.5 Babies with a Specific Medical or Practical Need:

For babies and families/carers with identified medical or practical needs, the hospital nursing and medical team will need to take an active role in supporting and preparing a baby and its family/carer for discharge. However it would be usual for the community team (usually neonatal or paediatric nursing teams) who will be co-ordinating the baby’s care in the community, to oversee and dictate the major details of discharge.

For infants with complex needs it is usual to arrange a multi-disciplinary team discharge meeting. Local policies will dictate who normally arranges and coordinates these meetings to ensure optimal communication and a well-co-ordinated discharge. Likely attendees including but not limited to; Community Neonatal Nurse, Community Paediatric Nurse, Health Visitor, Unit Nurse, Family support to ensure a well-co-ordinated worker, Parents, Physiotherapist, Speech and Language Therapist, Occupational Therapist, Specialist Nurse or Doctor relating to the child’s condition. The outcomes of such a meeting will often include:

- Equipment training or procedure education that the parents have to meet before discharge can safely occur.
- Additional support and resources to be offered by community or social services.
- Planned date for discharge to be agreed, in order to ensure goals are achieved and resources prepared.
- Agreed allocation of tasks outstanding, to MDT members.
- The specialist equipment needed will be decided, and then the MDT can decide who will order/access it, in preparation for discharge.

It is very rare that a baby will be being discharged home, who is going to receive ongoing medical care. For example home ventilation. Such discharge planning is beyond the scope of this guideline. However it can be anticipated that a wide group of people will need to work closely together to achieve a safe and satisfactory outcome for the baby and its parents. Basic principles of discharge planning will need to be applied which include highest quality communication, documentation, co-operation, negotiation, education and co-ordinated care.
3.5 Imminent Discharge

'Within 72 hours of anticipated discharge'.

3.5.1 Actions to take:

1. Ensure parents are aware of the baby’s imminent discharge, and the planned/ expected date for this.

2. Ensure baby is nursed in a way that fully complies with the current cot death guidelines unless otherwise indicated for specific medical reasons. Ensure the message is reinforced that this is how a baby should be nursed at home, following discharge. As per local policy indicate that the baby is on a ‘Home regime’ meaning.

   - Baby nursed supine, feet at foot of cot.
   - Cot mattress flat if no reflux issues.
   - Baby not to be swaddled - if not in constant sight of staff or parents.
   - No toys or positioning aids in cot.
   - No hat on baby - should be able to regulate temperature inside without a hat.
   - No cot canopy - expose to ‘normal’ daylight conditions.

3. Ensure baby has stopped physiological monitoring, other than temperature, pulse and respiration observation, which will occur according to hospital policy. (Unless there is a plan for the baby to go home with physiological monitoring in place.)

4. Ensure parents/carers have all relevant leaflets and information and that it is documented. Such as Bliss ‘Going Home’ booklet, cot death prevention information and information on developmental milestones. Ensure parents have details of sources of advice, information and support for after discharge.

5. Baby and parent(s) can ‘room in’, at this stage with their baby to gain confidence and experience prior to discharge. It can be, but does not have to be the night(s) before discharge.

6. If a baby is going home on medication ensure the TTO’s have been ordered. Once TTO’s are on the ward parents can practice with supervision giving these medications to their baby, with the actual packets and marked syringes they will be using at home. Preferable ‘Safely Administering Medicines to your Baby’ will have been completed by parents.

7. Ensure mothers who are breastfeeding their baby or still expressing breast milk have been given information about managing their feeding/expressing after discharge. Ensure they have details about sources of advice, information and support after discharge.

8. Parents should be encouraged to bring in their car seat (if they have a car) and check they know how to fit it into the car and fit the baby securely and safely into it. Staff cannot take responsibility for fitting a car seat, or for guaranteeing that a baby is correctly and safely secured within a seat. However they can offer their opinion and advice. A physiotherapist or more experienced colleague will often be good sources of information for the less experienced staff member.

9. It is normal for a baby to have its hearing screening test, in the days just before discharge. Arrange for this to occur.

10. If the baby fits the criteria for BCG immunisation, gain consent from the parents and then arrange for this to occur.

11. Is Newborn Blood Spot Screening (Guthrie) testing up to date? Will further testing be required after discharge? If so, document clearly when it is due and decide which community team will be asked to take on the responsibility of completing this testing schedule (either community midwife, health visitor community neonatal nurse). Contact the relevant community team and pass on this responsibility. Communicate this to parents.

12. Is ROP screening still ongoing? Contact ophthalmology team to clarify when and where this follow up will occur after discharge. Document this and communicate this to parents and the community midwife/ health visitor or neonatal nurse as appropriate. Ensure any appointments recorded in SEND/BadgerNet.
13. Remind those authorised to complete SEND/BadgerNet discharge that the baby’s discharge is imminent, so that updating can be done in preparation for discharge.

14. The baby should have a medical examination within 72 hours of discharge (including discharge OFC), but this does not need to be on the actual day the baby goes home. Remind the doctor or ANNP that this examination is required.

15. Where the baby will be going to a confidential foster placement, ensure the BadgerNet/SEND discharge letter does not reveal any confidential information.

16. Remind parents a loaned breast pump will need to be returned on the day of discharge (including expressing kit).

3.6 Day of Discharge

3.6.1 Actions to be taken:

1. Weigh baby and document discharge weight.
2. Ensure, if needed that a ‘Newborn and Infant Physical Examination’, discharge examination has been completed and documented.
3. SEND/BadgerNet discharge summary- final details to be completed. Copy to:
   - Parents
   - In baby's notes
   - To GP
   - To Health Visitor
   - To Community neonatal nurses (if following up)
4. Complete Red Health Record Book and give to parents.
5. Sign in returned breast pump and expressing kit, if loaned, return deposit.
6. Give parents explanation of and written record of any follow up appointments e.g.
   - Neonatal outpatient appointment
   - Ophthalmology follow up
   - Hearing screening follow up
   - Hip screening
   - BCG
7. Give parents TTO’s.
8. Give parents any milk for their baby from the fridge/ freezer.
10. Inform Social Worker, if involved, of discharge.
11. Community nurse referral documentation completed if appropriate, and community nurse informed of discharge.
12. Community midwife to be informed, if baby less than 10 days old.
13. Complete any outstanding documentation.

Version Control:

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<td>New</td>
<td>KR/Team</td>
<td>Neonatal Network Board approved</td>
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<td>2</td>
<td>December 2015</td>
<td>Revised with agreed amendments</td>
<td>KR/Team</td>
<td>TV&amp;W Neonatal Governance Group approved 20.01.16</td>
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Review Date: December 2015
### Appendix 1

**Example of form used for Collating Visitation Monitoring Information.**  
*Document supplied by Carmen Hayes, Neonatal Discharge Planning Co-ordinator on the Oxford Newborn Care Unit.*

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**Neonatal Unit Parenting Assessment:**

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### Feeding: Breast/Bottle/Tube

- Offers feeds at appropriate times
- At night wakes to give feed if required
- Provides own bottles
  - Able to make up bottle feed appropriately
- Interaction with baby during feed.
  - Observation of safety

### Hygiene:

- Carries out personal care for baby.
- Washing/bathing as required
| **Changes nappy when appropriate.**  
| **Attention paid to need for skin care if nappy rash present**  |
| **Provides nappies and clean clothing clean**  
| **Changed clothes & nappy appropriately**  |

**Visiting:**

| **Is visiting regular and planned?**  
| **Any unusual visiting times? Eg. Late @ night**  |

| **Duration of the Visit.**  
| **Do they tell staff if they are unable to visit?**  |

**Interaction:**

| **Response to baby’s needs/involvement in care**  
| **e.g. response when cries, eye contact, play, rest, appropriate stimulation**  |

| **Parent’s interaction with Nursing/Medical staff and seeking information about their baby’s condition**  
| **Behaviour with other parents/carers?**  |

| **Do parents work together to provide care?**  |

**Safety:**

<p>| <strong>Handling of the baby e.g. rough/gentle</strong>  |</p>
<table>
<thead>
<tr>
<th>Positioning of baby</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Incubator or cot sides secure</td>
<td></td>
</tr>
<tr>
<td>Cot space appropriately tidy</td>
<td></td>
</tr>
<tr>
<td>Choice of equipment, toys age/developmentally appropriate</td>
<td></td>
</tr>
</tbody>
</table>

**Further relevant observations:**

- It is important to comment on any positive or negative or inadequate responses affecting the care of the baby
- Please comment on the parent’s ability and willingness to learn as well as their adaptability to their baby’s changing needs
- Please comment where possible on the degree of support from extended family.