WellChild
the national charity for sick children

10 Principles For Complex Discharge

Discharge reference guide and tools to support health and care professionals to improve practice for all children and young people requiring a complex discharge from hospital to home and beyond.

Pan Thames Paediatric LTV Programme
North Thames Paediatric Network
Connecting paediatric services
South Thames Paediatric Network

PPLLTV
Paediatric Pan London Long Term Ventilation

Royal College of Nursing
RCNENDORSED

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This resource has been created specifically to assist health professionals planning the discharge of children and young people with complex medical needs. The information in this document and the accompanying toolkit was produced and reviewed by health professionals including nurses, physiotherapists, and occupational therapists. The guidance included adheres to the NMC code of conduct and other relevant governing body guidelines. This resource also adheres to the Charity Commission's public benefit requirement via WellChild's charitable purposes.

Please note this reference guide and accompanying tools are designed to be working documents which will be updated, and new resources will also be created. Please make sure you are using the latest version by checking the version number and date updated at the bottom of the page.

Version	Issue Date	Reason for Issue/changes made	Updated by
1.0	July 2021	New Document	Working Group
2.0	October 2022	Additions to introduction section giving more background on how the resource was developed	Core working group
3.0	May 2024	Updates to appendices	Core working Group

Discharge Reference Guide and Tools

Guidance and toolkit to support health and care professionals to improve practice for all children and young people requiring a complex discharge from hospital to home and beyond.

APPENDIX A

Discharge Planning

1. MDT Member List
2. Template for discharge planning meeting

These documents can be used for any complex child requiring a coordinated Multi-Disciplinary discharge meeting.

APPENDIX B

Discharge Checklists

1. CYP with complex medical needs
2. CYP on TrLTV

These documents can be used for any medically complex child requiring discharge.

APPENDIX C

Home Assessment Form for CYP with complex needs/LTV

This document can be used for any child with complex medical needs including Long Term Ventilation.

APPENDIX D

Parent/Guardian Housing screening form

This document is designed to be used by parents and can be used for any child with complex medical needs including LTV.

APPENDIX E

LTV room layout

This document is designed to be used as an exemplar room layout for a child returning home on LTV.

APPENDIX F

Equipment for your child

This document is designed to give parents an idea of some of the equipment they may need for their child on LTV. This information should be discussed with the family.

APPENDIX G

Useful information for families

A list of useful contact details for services to be given to families on discharge.

APPENDIX H

Respiratory Action Plans

1. Child on TrLTV
2. Child on NIV

These documents provide a consistent format when providing guidance for families and carers around managing respiratory deterioration in the community.

Introduction

Background

WellChild is the national UK children's charity making it possible for children and young people with exceptional health needs to be cared for at home instead of hospital, wherever possible.

WellChild's vision is for these children and young people to have the best chance to thrive – at home, with their families.

The Pan Thames LTV collaborative, a collaboration between the South Thames Paediatric Network, the North Thames Paediatric Network and Paediatric Pan London LTV Group brings together the skills and knowledge of clinicians and commissioners from across London and the South East of England who have extensive experience in working with children with complex needs.

How the resource was developed

Following the success of the 11 Principles for Better Training project the WellChild Nurses, a network of 50 specialist children's nurses from across the UK and Northern Ireland, identified the national need for something similar to be created for the area of complex discharge from hospital to home.

A working group of WellChild Nurses was established (in 2018) with the aim to draft Principles for Complex Discharge. As part of this project it was agreed that family experience should be included to highlight the need for a more consistent approach to discharge nationally. Feedback was gathered via an online survey, the results of which are included below.

At a similar time the Pan Thames LTV Collaborative were looking to create a similar resource to improve provision across their region following feedback on the delayed discharge of children and young people requiring Long Term Ventilation in their area. This included the creation of a toolkit to support best practice and encourage a standardized approach to the care of this cohort.

Both parties made the decision to bring together their regional and national expertise and resources to develop a comprehensive Discharge Guide and Toolkit; endorsed by professionals, with parents and carers voice included.

The role of the working party

This project has involved collaboration across a wide range of health professionals involved in Child Health. The health professionals, teams and centres listed on page 8 played a number of key roles in the creation of the Discharge Guide and Toolkit during the many stages of development. This has included the following:

- Identifying the 10 principles needed when facilitating a complex discharge and drafting the recommendations for these.
- Providing clinical expertise in the development of the supporting documents.
- Submitting documents to be included in the toolkit
- Reviewing and providing feedback on the layout, language and ease of use of draft documents.

- Providing feedback on the implementation of the resources into clinical practice
- Collecting patient experience to inform the development of the resource.
- Ensuring that the resource was up to date with local, regional and national guidance.

Although a smaller working group made up of representatives from WellChild and the Pan Thames LTV Collaboration continue to push this work forward, the wider working party will continue to be consulted as the project develops in the future. This document will be updated every three years.

Learning from families' experience

It is acknowledged that complex discharge is carried out differently depending on where you are in the UK and who or what is available to support the process. To highlight the direct impact this has on families we invited parents and carers to take part in an online survey to share experiences of their children's discharge from hospital. Some key headlines included:

- 64% of respondents were not made aware how long discharge was expected to take.
- Regular updates were only received by 55% of respondents.
- 48% of respondents had the opportunity to attend MDT meetings.
- Respondents were split 50:50 on whether the length of time taken for discharge was generally appropriate.
- Only 11% of respondents commented that their child was involved in the process where possible.
- 23% of respondents rated their discharge planning experience as 1 star: with 28% rating it 5 star.

Respondents were also asked to reflect on their time in hospital and the impact this had on their mental health, family life, personal finances, and career.

- 80% of respondents said that their time in hospital had a negative or very negative impact on their mental health.
- 86% of respondents said it had a negative or very negative impact on family life.
- 89% of respondents said the impact on their personal finances had been negative or very negative.
- 77% of respondents said the impact on their career had been negative or very negative.

The impact extended hospital stays have on these families should not be underestimated. Feedback from parents and carers clearly demonstrates the importance of a smooth and safe discharge to all aspects of family life as well as the detrimental, and often long term, impact a 'bad' experience of discharge can have. The principles for complex discharge and accompanying toolkit aim to support health professionals to improve practice for all children and young people requiring a complex discharge and provide greater support for families on their journey from hospital to home and beyond.

Purpose

The aim of WellChild, Pan Thames LTV collaborative and associates is to ensure that children and young people with complex needs get the right care at the right place and time. In situations where children do spend time in hospital, our purpose is that this framework will be a useful reference framework to give clinicians the information and tools to ensure that there is a consistent, safe, and timely approach to discharge.

The content of this framework is a consensus of nurses and therapists actively leading and supporting children, their families, and other professionals through complex discharge pathways.

The framework does not aim to be prescriptive: it is a tool to support practice and drive change, supporting resource allocation and local service delivery plans.

It sets out recommendations on quality in the discharge journey and provides a means by which teams can measure and improve practice. The associated reference documents can be used by all discharging centres as a consistent framework to support timely and safe discharges. The documents have been designed so that they can be adapted to meet local needs.

What is it?

The project comprises three key elements to support professionals working to discharge children and young people home from hospital.

1. **The 10 Principles for Complex Discharge** – guiding principles for what to consider at each stage of the discharge process.
2. **Discharge guidance and toolkit** – information, templates, forms to be used at each stage of the discharge process.
3. **Useful existing references or resources** – other useful information around discharge to support professionals.

Although available separately all three elements are designed to be used together to aid best practice.

Intended Benefits

Intended benefits of this framework are:

- To provide a comprehensive resource for nurses, therapists, and other health professionals to access guidance and support when encountering a complex discharge. This is particularly relevant for those who may not be familiar with or have an awareness of the process or the documentation to support discharge.
- To define a level of quality for the delivery of planning and care when supporting a child and family through their discharge journey.
- To improve the transition from hospital to home for children, young people, and their families.
- To provide a measure against which teams and organisations can benchmark and audit their current discharge practices.
- To provide a tool to guide service development and improvement.
- To improve equity and reduce variation, ensuring complex discharges follow the same processes and pathways no matter where they happen.
- To clarify roles and help manage expectations for all involved in the discharge process.
- To support professionals to keep children and their families informed of what lies ahead and their achievements as they progress.

Scope

This framework is aimed primarily at providing guidance for health and care professionals working in a variety of environments in the delivery of a safe discharge for children and young people with complex health needs.

The framework is a supportive tool for health and care professionals who are unfamiliar with complex discharge and aims to aid the understanding of the discharge process. The additional reference documents can be used by clinicians to promote consistency in approach to discharge.

Structure

The framework consists of 10 principles, which subdivide into relevant guiding principles. The principles can be viewed together or in part as applicable to the discharge process. Common themes run through each of the principles, when collating the principles, the working party felt these themes are important enough to be repetitive. Each of the reference documents contains a short explanation to guide its use as well as the logos and details of each partner involved in the collaboration. All documents are freely available and accessible via the WellChild website here (wellchild.org.uk/for-professionals/research-resources/10-principles-for-complex-discharge/). For appendices H1 and H2, contact Pan Thames Paediatric LTV Programme here. The forms should not be changed but can be downloaded and adapted to include locality specific information or trust logo's. Please acknowledge WellChild and Pan Thames LTV Collaborative as the source.

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PRINCIPLE 1 | Preparation for discharge: Planning and managing expectations.

The expectations of all involved in co-ordinating discharge should be proactively and formally managed prior to embarking on the discharge journey. When preparing to commence the discharge process, the following principles should be considered:

- Prior to commencement of discharge, a lead professional should be identified and an initial meeting(s) should be held between the identified discharge lead/coordinator and the family to develop a shared understanding of their relationship and the discharge journey.
- The initial meeting/meetings should be scheduled at an appropriate time during the child's admission to hospital. It should be a mapping meeting to introduce the discharge process and explain expectations of both the family and professional's involved.
- The purpose of discharge planning should be clarified at the start of the journey and outcomes need to be measured throughout and reassessed at each discharge meeting.
- The process and structure of the discharge journey should be explained with timelines, actions and responsibilities delegated to the appropriate professionals and explained at each stage.
- A timeline should include details of planned training, meetings, shared consent, dates, reviews, home leave and referrals for the onward journey after discharge.
- The discharge meetings should be an opportunity for the family to ask questions about the process and openly discuss any assumptions and concerns.
- During the discharge journey the discharge lead should review expectations of both the family and MDT periodically to ensure they match and have clarity.
- All of the above should be documented in the appropriate notes and shared with the MDT so expectations are managed and reassessed throughout the discharge process.

Reference document:

- Appendix A2 - Discharge Planning Meeting Template.

PRINCIPLE 2 | Governance

Members of the MDT who support discharge have an obligation to maintain their confidence and capability in the skills they will require to enable discharge and consistently evaluate the quality of their service delivery. In order to achieve this, consideration should be given to the following:

- Discharge leads should maintain accurate records of discharge for every family. Ideally using a database with audits and evaluations.
- The discharge lead will need to be clear who holds parental responsibility for the child or young person.
- Consent will need to be obtained to match local guidelines and policies ensuring safe information sharing.
- Throughout the process risk assessments will need to take place. The designated person to complete this will need to have an understanding of local policies and be deemed competent.
- The MDT should engage in regular review of local processes related to discharge and applicability.
- Professional teams need to be aware that it is acceptable to raise concerns when an unsafe discharge is occurring. This should be done via escalation and in line with local safeguarding policies.

PRINCIPLE 3 | Assessment and identification

Discharge planning should be started as soon as possible following admission. The person who will lead on the child's discharge planning should be identified. A continual assessment of need should be commenced at this time and reassessed throughout the discharge process.

At this stage it is recommended that the following should be considered:

- A child or young person requiring complex discharge planning, should be identified at the earliest opportunity.
- The MDT required to support the child, including identification of the lead professional for coordination of discharge.
- The child's local area MDT should be involved as early as possible if the child is in a tertiary centre.
- Any training needs for those involved in caring for the child or young person should be identified.
- Care plans should be in place prior to discharge.
- The criteria for discharge should be agreed, time scales established and regular MDT meetings arranged. The timescales set should suit the child's clinical situation.
- Any necessary risk assessments should be completed.
- A list of equipment and supplies that will be required should be identified and compiled.

Reference documents:

- Appendix B 1 & 2 - Discharge Checklists.
- Appendix A1 - MDT Member List.
- Appendix H1 & 2 – Respiratory Action Plans

PRINCIPLE 4 | Environment

Throughout a child or young person's hospital journey towards discharge they will be cared for in a variety of clinical areas and settings. Changes in environment may impact on feelings, risk factors and responsibilities. This should be managed with a safe and timely approach taking into consideration the following:

- Consideration should be given to the type of environment in which the child will receive their care e.g. home, hospice, DGH, placement, school etc.
- An environmental risk assessment should be undertaken by an appropriate hospital or local professional.
- This assessment may be undertaken by either a hospital, community or local authority, OT, Nurse or relevant Allied Health Professional. It is essential that this is completed early in the timescale.
- For very early identification of housing needs a parent screen form can be used to collate information to inform the need for an early, timely home assessment by professionals.
- The expectations of the family in relation to housing need to be explored and managed.
- When assessments are completed and a plan is formulated the results should be discussed with the family and referrals need to be made to appropriate partners. This should be done with estimated timescales of action completion with a designated person assigned to task and finish.
- As part of assessment consideration needs to be given to transport, car seats and mobilising aids that might be needed. These assessments need to be undertaken by appropriate experienced professionals and before any home leave takes place.
- Risk assessments need to be undertaken for each environment and should be co-ordinated by the discharge lead.
- Families should be taught to manage risk to enable them to take part in daily life.
- If housing is not suitable this needs to be highlighted and families signposted to the relevant housing officer, companies or council etc who can provide assistance. For housing and hospital discharge early planning document click here ».
- Once discharged, housing and other environments need to be reassessed as the child and young person matures, it should be clear on discharge who is responsible for this.

Reference documents:

- Appendix C - Home Assessment Form for Children / Young People (CYP) with complex needs/ on Long Term Ventilation (LTV).
- Appendix D - Parent/ Guardian Housing screening form.
- Appendix E - LTV Room Layout.

PRINCIPLE 5 | Communication

Communication needs to be effective and meaningful between all parties in order to achieve a safe and timely discharge. During this process of complex discharge planning the following principles need to be considered:

- Clear expectations of roles and responsibilities should be set from the start.
- Any conversations must be open and honest and cover all outcomes both positive and negative.
- All information being shared must be at a level that everyone can understand and all reasonable adjustments should be put into place to enable this.
- Any barriers to communication i.e., learning disability, language, literacy should be considered and addressed.
- A variety of ways to share information e.g., audio recording, easy text should be offered.
- The family's preferred method of communication i.e., email, verbal, text, letter in line with local Information Governance and data protection policies should be discussed and identified.
- Other resources that facilitate communication should be utilised - advocacy, peer support, charities, third party sectors.
- If appropriate, parallel planning using Advanced Care Pathway or alternative should be initiated.
- It is recommended that patient health care passports should be used to share information on individual patient needs.
- A comprehensive contact list of who needs to be involved in each area should be produced.
- Documentation should be in an accessible and appropriate place and share as per local policy.
- Consent from family and patient must be gained ahead of information sharing in line with local policy.
- Be aware of professional barriers to communication e.g., email security, IT system, phone calls.

Reference documents

- Appendix G - Useful information for families

PRINCIPLE 6 | Family

All members of the child's family will need time and support to adjust and understand the child's diagnosis, condition and prognosis. Health care professionals should have an understanding of family life and work in partnership with the family to provide support in the now as well as preparing for the future. In order to do this the following should be considered:

- Family dynamics and existing support networks should be explored.
- The person/persons who hold parental responsibility need to be identified.
- The impact on family life should be appreciated and taken into consideration throughout the discharge process.
- Local support available across relevant sectors should be reviewed and relevant referrals made when appropriate.
- Identify who will support the family and what services are available.
- Parental/family/carers capacity to care for child's needs should be identified.
- The child and family should be involved at all stages of discharge planning.
- The family's expectations should be explored and the use of engagement contracts to strengthen partnerships considered.
- A financial assessment should be arranged for the family and signposting for appropriate funding where relevant.
- Families should be given notice of and opportunity to attend MDT meetings and where appropriate minutes shared.
- Families should be aware who is leading the discharge process. They need to receive regular progress updates and have an opportunity to ask questions.
- Families should have an opportunity to be introduced to ongoing care providers before discharge.
- Families should be provided with a contact list of key professionals and services prior to discharge.
- Families should be empowered to ask questions and encouraged to participate in decision making where appropriate.

PRINCIPLE 7 | Training

Training is a key part of discharge planning and essential for getting a child home safely. The expectations of anyone providing care should be proactively and formally managed prior to embarking on their training journey. To achieve this we need to consider:

- Identifying training needs for the child or young person by completing a training needs analysis.
- Identifying who needs to be trained within the child or young person's support network for discharge. Acknowledge that not all family members will wish to undertake training in medical care. This should be documented.
- It needs to be recognised that different levels of training will need to be delivered to each child or young person's support network in the community from expert to situational awareness.
- Training expectations should be discussed and documented by both family and professionals and revisited during the discharge process.
- Identifying a lead/key worker for training (this does not need to be the discharge lead) during the discharge process and beyond.
- It is good practise to recognise different levels of training required for different placements the child will attend.
- Training is a linear process and needs to take place alongside and during the discharge journey.
- Follow WellChild's 11 Principles for Better Training. (wellchild.org.uk/supporting-you/trainingprinciples)
- The key worker/training lead should schedule and undertake review of training goals and feed into MDT.
- It needs to be recognised that due to complexities for some cases deviation from local training procedures may need to take place. This needs to be risk assessed and documented.
- If families are transferred from the hospitals/trusts out of area the documentation and handover needs to be shared and documented.

PRINCIPLE 8 | Assessment of capability

The correct equipment needs to be identified and purchased as soon as possible in preparation for discharge. When purchasing this equipment the following needs to be taken into consideration:

- Producing an equipment list with details of all items needed including quantity, size product code etc where relevant.
- This equipment list should be discussed as an MDT in the first meeting.
- For each piece of equipment who will provide training and update training should be identified, assigned to the appropriate team and documented it in the discharge plan.
- Risk assessments should be undertaken for equipment, for example can they survive a night without equipment.
- The equipment prescriber should liaise with the fund holder as soon as possible to ensure there are no delays in equipment ordering.
- If there is a gap in provision/funding, this should be escalated to senior management in line with local policies and procedures.
- It should be confirmed that those caring for the child can competently use the equipment before discharge. Detailed records must be kept with clear identifiers of when updates and servicing are due, which teams are responsible for the ongoing management and maintenance of the equipment.
- Ensuring a service contract has been drawn up for any equipment.
- If equipment breaks families should be made aware of the pathway /who to contact to get the equipment fixed or replaced.
- Providing families with user guides, servicing schedules, emergency contacts and troubleshooting tips for each piece of equipment where relevant.
- Liaison with MDT is key to ensure all appropriate equipment has been purchased and family are ready and competent to use it.

Reference Document:

- Appendix F - Equipment for your child.

PRINCIPLE 9 | Partnership working

Successful complex discharge planning requires the engagement of the family and various members of the MDT within the hospital, community and local authority to enable the child or young person to have a safe and robust discharge. Partnership working is key to preparing the family for the transition from hospital to home.

To ensure successful partnership working the following principles need to be considered:

- The specific needs of the child or young person will influence the team that needs to be around the child and family.
- The child or young person's short, medium and long term needs should be identified and reassessed regularly.
- Clarification of the services that are required such as local/regional/statutory and others that are supportive and optional such as charity, hospice should sought.
- The child's entitlement for service provision e.g. overseas patient entitlement to CHC funding, should be considered.
- Ideally there should be an identified key worker to facilitate partnership working.
- Clear time scales and expectations for discharge should be established at the start of the process.
- Roles and responsibilities of all those involved should be identified and documented to mitigate risk.
- Using a family contract to strengthen the partnerships between professionals and families should be considered.

PRINCIPLE 10 | Preparation for final discharge and the onward journey

The journey for the child and family will continue following discharge from hospital. This is an essential part of planning to ensure a safe and appropriate follow up is in place.

Before final discharge takes place the following should be considered:

- Complex children will have had regular MDTs throughout their admission. Ensure that the final discharge meeting isn't on the day of discharge. Ideally this should be held no later than one week prior to discharge.
- Everyone should be aware of the expected date of discharge in order to plan logistics e.g. travel, work time off, TTO's, consumables, home adaptations, equipment, deliveries, package of care, discharge letter/summary etc. Consideration should be given to ensure the availability of services to meet the child's needs during weekends and bank holidays.
- The relevant community leads should be identified and notified of the expected discharge date prior to discharge.
- Family and professionals should be made aware who is continuing their care after discharge.
- The discharge lead should have protected time to complete action plan and ongoing referrals.
- Ensure contact details are documented and shared with the family.
- Consideration should be made about the child and family's wellbeing when moving from hospital to home (this should not be underestimated).
- Discharge planning should include a staggered discharge i.e. ideally day leave or other home leave should be arranged during this discharge journey.
- An estimated date for discharge should be set to keep the discharge on track. However, it should be explained that all agreed criteria must be met before discharge date. If this is not met or the date needs to be moved this should be communicated.
- Clarity of expectations of the family should be discussed and revisited throughout the process and agreed.
- Follow up should be planned to match an appropriate time for the family. The family should be informed of the details of the immediate follow up arrangements.
- Ensure clarity of ongoing roles and responsibilities of all involved including parents.
- A discharge summary, community management plan or Advanced Care Plan should be in place before discharge. It is good practise to test this on a period of home leave before discharge takes place to prevent breakdown of discharge and readmission.

Reference documents:

- Appendix H1 & 2 – Respiratory Action Plans

Summary

The 10 Principles for Complex Discharge provide an overview of the steps needed to help facilitate a safe and timely discharge from hospital when working with children and young people with complex needs. The accompanying discharge pack provides the tools for health and care professionals to deliver these principles and help guide service development and improvement. The documents are freely available and have been designed so that they can be adapted to meet local needs. All documents currently in the toolkit are available for download via the WellChild website here ».

Useful existing reference resources

These documents are up to date at the time of publishing.

- Paediatric Pan London Oxygen Group Documents
  - Home Oxygen information Leaflet.
  - Discharge bundle – 7 separate documents to aid the safe and timely discharge of a child requiring home oxygen across Greater London.
- Compiled by the Occupational Therapy department in collaboration with the Child and Family Information Group Moving home when your child is on long term ventilation with a tracheostomy: information for families.

  Ref: 2017F2078 April 2021 © Great Ormond Street Hospital for Children NHS Foundation Trust
- Housing and Hospital Discharge (ltv.services)
- Occupational therapy long-term ventilation (LTV) information pack.

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