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Appendix B2: Discharge Checklist: child/young person on Tracheostomy Long Term Ventilation (TrLTV)

*Discharge planning starts well before the child is medically stable, ideally on admission.
All members of the MDT have a shared responsibility to complete the discharge pathway/checklist*

This is a working document. Please make sure you are using the latest version by checking the version number and date updated below. The latest version of the document is available here <https://www.wellchild.org.uk/10-principles-for-complex-discharge/>

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Document developed by Pan London LTV Collaborative in partnership with WellChild.



Patient Name:

Hospital Number:

User guide – Appendix B2: Discharge Checklist: CYP on TrLTV

Who is this checklist designed for?

- Any CYP that is identified as potentially requiring TrLTV

When should this checklist be commenced?

- Discharge planning starts well before the CYP is medically stable, ideally on admission
- For some CYP requiring TrLTV it is possible to commence discharge planning prior to admission
- Commence discharge checklist at the point at which it is identified that CYP may require TrLTV

How to use this checklist:

- This checklist should be used in conjunction with the WellChild 10 Principles for Complex Discharge (wellchild.org.uk/for-professionals/research-resources/10-principles-for-complex-discharge/)
- A key professional managing the discharge should be identified. This may be a discharge coordinator or another key professional/s e.g. link nurses on ward
- This/these individual/s should take responsibility for completing the form and ensuring that actions have a designated responsible individual to complete them. Ideally this would be updated at regular MDT meetings, DPM
- All members of the MDT have a shared responsibility to complete the tasks within the discharge checklist and regularly feedback to the key professional/s
- Including the date that tasks are applicable from as well as completed allows the discharge processes to be kept on track and audited. For those tasks that are not required for the CYP ensure that the N/A column is ticked
- This document is meant as a guide and will need to be adapted according to the setting, workforce and local policy
- Each CYP and discharge will be unique and patient specific, therefore time frames within the document must be used as rough guides and will likely require patient specific adaption
- Individual sections within this document may well need to be revisited multiple times during a patient's admission depending on CYP length of stay

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Identification that child/young person may require TrLTV	Responsible Individual	Date task applicable from	Date task completed	N/A
Name of CYP.....DOB..... NHS No..... Lead Hospital.....				
MDT Tasks				
Who has parental responsibility of CYP? Document clearly on EPR				
Who is the lead for discharge planning? E.g. link nurse, discharge coordinator				
Who is the named consultant for CYP?				
What, if any, are the safeguarding issues that the MDT should know about?				
Complete necessary diagnostics e.g. sleep study, MLB, tertiary review				
Who are the key members of the MDT? Hospital and Community				
MDT meeting to discuss if TrLTV is appropriate decision for CYP and parents/carers, including local DGH if well known (Pan London LTV ethical pathway)				
Meeting with parents/carers to discuss if TrLTV is appropriate decision for CYP and family (Pan London LTV ethical pathway)				
Tracheostomies and life with a tracheostomy discussed with parents/carers (and CYP if appropriate)				
Parents/carers offered psychology support (if available and consent given)				
Has parallel planning and palliative care input been discussed (this should be ongoing throughout admission)				
Are parents/carers clear in their role and responsibilities during CYP's admission?				
Nursing/Key Worker Tasks				
Who is CYP's GP? (If not registered, register CYP with a GP as a priority)				
All local teams that CYP is known to, to be informed of admission e.g. CCNT, HV, School Nurse, community therapies				

Within 48hrs following decision for TrLTV	Responsible Individual	Date task applicable from	Date task completed	N/A
MDT Tasks				
All relevant members of MDT informed of decision for TrLTV				
Will CYP require long term access e.g. Port, Hickman Line	Review Date:			
Parents/carers and CYP informed and understand planned treatment/interventions				
Parents/carers and CYP informed and understand expected discharge pathway				
Team of staff e.g. nurses, nursing associates, CSW's identified to promote continuity of care				
Tracheostomy training commenced prior to insertion of tracheostomy				
Nursing/Key Worker Tasks				
Which parents/carers will be trained (2 or 3 individuals), identify if there are any additional training needs? E.g. language barriers/literacy of parents/carers Name: Name: Name:				
Is CYP eligible for a continuing care package? Discuss with local Continuing Care Team if unsure				
With parental consent, complete referral to CYP's local continuing care team & social services (Children with Disabilities team)				
CYP referred to RBH Central LTV team who will facilitate NHSE LTV data collection				
Two portable ventilators are available/ordered e.g. trial to buy				
Request made for CCNT to complete a home oxygen assessment and review home setting (if unclear that property is suitable for oxygen/continuing care package)				

Within 48hrs following decision for TrLTV	Responsible Individual	Date task applicable from	Date task completed	N/A
Play Specialist/Education Tasks				
Does CYP have regular input from hospital play team (throughout admission as appropriate)				
Does CYP require input from hospital school?				
Dietetics Tasks				
Initial assessment of nutritional status completed				
TrLTV's impact on child's nutritional status and source of nutrition considered				
Liaison with community team completed as appropriate				
Occupational Therapy Tasks				
Home environment discussed with parents/carer and local OT (if CYP known to them)				
Home assessment arranged and liaison with local social care OT team underway (if it is considered CYP's home is likely to require adaptations/not be suitable)				
Housing assessment request to CYP's local housing team sent if required				

Within 1 week of tracheostomy insertion	Responsible Individual	Date task applicable from	Date task completed	N/A
Nursing/Key Worker Tasks				
Weekly FFD data submitted to RBH Central LTV team for NHSE data collection (ongoing)				
Once first tracheostomy change completed (day 5-7 post tracheostomy) relevant competencies from PPLTV competency documents commenced				
CYP referred to local CCNT (if not already known), with EDD (if possible)				
Local CCNT updated (if already known), with EDD (if possible)				
HV/School nurse contacted and informed of TrTLV				
Welfare support discussed e.g. Housing, DLA, Carers Allowance, blue badge				
Multi Therapy Tasks				
Baseline functional, developmental, neurological, respiratory, mobility assessments and treatment plans completed as appropriate (OT/PT/SLT)				
Local community therapy teams contacted to see if patient known to them (OT/PT/SLT)				
Therapy plan and programme completed, and training needs have been identified (OT/PT/SLT)				
Assessed for appropriateness of cuff deflation (SLT/PT)				
Occupational Therapy Tasks				
Assessment completed and provision of equipment required to support the CYP in the hospital environment e.g. seating, toileting and positioning equipment				
Respiratory Physiotherapy Tasks				
Need for airway clearance techniques or respiratory adjuncts (e.g. MI:E) discussed with MDT and assessed				
Assessment and review of need for mucolytic therapies completed				

From 1 to 8 weeks post tracheostomy insertion	Responsible Individual	Date task applicable from	Date task completed	N/A
MDT Tasks				
Has a regular MDT meeting with hospital and community team been set up to discuss: <ul style="list-style-type: none"> - Care/management plans - Discharge goals - Criteria for discharge - Potential barriers to discharge - Tentative discharge date 				
Are parents/carers engaged with care, visiting regularly and taking a lead in cares				
Parallel planning and palliative care input e.g. ACP				
Nursing/Key Worker Tasks				
Continuing care assessment completed and date set for panel				
Equipment list agreed by MDT and sent to local continuing care team/CCNT including list of any consumables				
CYP on portable ventilators				
Dry circuit time established as able (aiming to safely facilitate time off ward and discharge home)				
Regular sleep studies as clinically indicated, results communicated to MDT, CYP and family				
CCNT/parents/carer has contacted local fire brigade for a home safety check for oxygen				
Relevant competencies commenced e.g. NGT, tracheostomy, feed pump (specific to locality)				
Local CCNT contacted to request CYP requires oxygen saturation monitor, suctioning or nebuliser machine				
Referral made to Children's Services under Section 85 of the Children's Act, 1989 (if child has remained in hospital continuously for over 90days)				

From 1 to 8 weeks post tracheostomy insertion	Responsible Individual	Date task applicable from	Date task completed	N/A
Dietetics Tasks				
Ongoing monitoring of nutritional status				
Will CYP require long term feeding support e.g. gastrostomy Review Date:				
To work closely with SLT regarding swallow assessments, progression with oral nutrition and optimal timing for enteral nutritional support				
Organisation of training for parents/carer if new route of feeding introduced				
Multi Therapy Tasks				
Individualised developmental/therapy programme established, reviewed and regularly updated (OT/PT/SLT)				
Ongoing therapy with goals and outcome measures if appropriate (OT/PT/SLT)				
Liaison with community therapists, schools and other outside agencies with regards to ongoing care needs post discharge (OT/PT/SLT)				
Buggy/wheelchair requirements identified with MDT and parents/carer (PT/OT)				
Complete referral to wheelchair services (PT/OT)				
Manual handling requirements e.g. hoist and slings identified with MDT and parents/carer (PT/OT)				
Necessary manual handling equipment ordered/liaison with appropriate service (PT/OT)				
Cuff deflation programme identified as appropriate by MDT and understood by parents/carer (PT/SLT)				
Ongoing weaning plan identified as appropriate by MDT and understood by parents/carer (PT/SLT)				

From 1 to 8 weeks post tracheostomy insertion	Responsible Individual	Date task applicable from	Date task completed	N/A
Occupational Therapy Tasks				
Cot/bed requirements identified with MDT and parents/carer				
Necessary cot/bed ordered following local policy				
Home environment advice leaflet shared and parents/carer plans for home set up discussed				
Liaison to ensure home modification needs identified are on schedule				
Respiratory Physiotherapy Tasks				
Individualised respiratory physiotherapy programme established, reviewed and regularly updated				
Ongoing assessment and review of mucolytic therapies				
If indicated, liaise with CCG/ICS regarding procurement of respiratory adjuncts for home use (e.g. MI:E) and commence process for provision of these				
Airway clearance competencies started including respiratory adjuncts (e.g. MI:E), with responsible adults if long-term chest physiotherapy input indicated				
Speech and Language Therapy Tasks				
Swallow assessment completed				
Safe oral feeding plan if appropriate +/- enteral feeding support established				
Developmental/acquired communication assessment completed				
Communication plan +/- AAC in place				
Mouth care advice/support given (if non oral)				

No later than 8 weeks prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
MDT Tasks				
Discharge planning meeting including inpatient and community teams held, minutes sent and EDD set				
Local hospital contacted and patient discussed (potential step down also discussed if applicable)				
MDT training needs for local DGH explored e.g. medical, nursing, AHP				
Immunisations up to date? Does CYP require palivizumab/flu vaccination?				
Named local general paediatrician allocated				
Referral to community paediatrician completed				
Nursing/Key Worker				
Contact GP and update				
All necessary equipment/consumables ordered by continuing care team and community nurses				
CCG/ICS funding approved and care package hours agreed				
PPLOG bundle (including consent form and home risk assessment)/local oxygen discharge paperwork completed and documents uploaded to electronic records				
Referral to local hospice for respite completed				
Multi Therapy Tasks				
Individualised developmental/therapy programme, reviewed and regularly updated (OT/PT/SLT)				
Car seat discussed with parents/carer and onward recommendations made (PT/OT)				
Ongoing collaborative work with the MDT with regards to cuff deflation and tracheostomy weaning (PT/SLT)				
Ongoing consideration of one-way valve trial if patient satisfies relevant criteria (PT/SLT)				
Ongoing liaison with community therapists, wheelchair services, school and other outside agencies with regards to ensuring equipment is in place for discharge and ongoing care needs post discharge (OT/PT/SLT)				

No later than 8 weeks prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
Respiratory Physiotherapy				
Individualised respiratory physiotherapy programme reviewed and updated				
Ongoing assessment and review of mucolytic therapy				
Ongoing respiratory physiotherapy training with parents/carer				
Confirm provision and funding of respiratory adjuncts e.g. MI:E for home				
Ongoing liaison with community professionals/MDT regarding respiratory care plan for home				
Speech and Language Therapy Tasks				
Access to appropriate AAC				
Current feeding plan reviewed and updated				
Education re safe feeding plan, oral development and mouth care given				
No later than 6 weeks prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
MDT Tasks				
Trial any specific equipment e.g. Aerogen if required				
Care provider (in house or private agency) allocated by CCG/ICS				
Relevant paperwork in place to facilitate care agency attending ward (liaise with HR and care provider)				

No later than 4 weeks prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
MDT Tasks				
Discharge planning meeting including inpatient and community teams held, minutes sent and EDD set				
All outstanding investigations completed e.g. ENT review				
Medical discharge summary up to date				
Nursing/Key Worker				
Ensure all necessary home equipment is at the hospital e.g. suction machine, saturation monitor, nebuliser machine				
Parents/carers competent to use home equipment				
Relevant competency documents completed for parents/carers e.g. tracheostomy, BLS, ventilation, gastrostomy, feed pump				
CYP room at home ready for staged discharge				
Meet and greets with staff from care package completed				
What are the training needs of carers/nurses from care package? Who will provide training?				
Tracheostomy and ventilator training with carers/nurses completed				

No later than 4 weeks prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
Dietetics Tasks				
If enteral tube in-situ, CYP referred to local hospital dietitian/local home enteral feeding team as appropriate				
CYP on a feed regime that can be facilitated in the community e.g. feed times, number of pumps				
Arrange delivery of feed equipment as required (feed pump, stand, back-pack, giving sets, syringes and feed)				
All training required for discharge completed				
Multi Therapy Tasks				
Individualised developmental/therapy programme, reviewed and updated (OT/PT/SLT)				
Equipment trial of buggy/wheelchair complete (PT/OT)				
Parents/carer training for manual handling equipment and guidelines provided (PT/OT)				
Cuff deflation programme identified as appropriate by MDT and understood by parents/carers (PT/SLT)				
Ongoing weaning plan identified as appropriate by MDT and understood by parents/carers (PT/SLT)				
Ongoing consideration of one-way valve trial if patient satisfies relevant criteria (PT/SLT)				
Referral to ENT/SLT airway clinic for ongoing tracheostomy management completed (PT/SLT)				
Liaison with community therapist, wheelchair services, school and other outside agencies with regard to ensuring equipment is in place for discharge and ongoing care needs post discharge				
Occupational Therapy Tasks				
Liaise with relevant team/s to ensure cot/bed has been delivered to home				
Liaise with relevant team/s to ensure home modifications are complete				

No later than 2 weeks prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
MDT Tasks				
Is CYP FFD/approaching FFD?				
Medications rationalised and medication timings compatible with home routine				
Nursing/Key Worker Tasks				
Medication administration training complete (ensure medications are labelled and patient's own)				
CYP's hospital passport complete				
Agreed amount of supplies (usually 2 weeks' worth) is ready and parents/carers have taken this home				
All necessary medical equipment/supplies in the hospital/home and operational				
Oxygen prescription completed and uploaded to electronic records				
Oxygen installed				
Parents/carers competent to go on outings				
All care/escalation plans and paperwork completed, this must include but is not restricted to an escalation plan in the case of an emergency, trips out equipment list, equipment policy that includes service arrangements and guidance in event of breakdown and a clear plan for follow up				
Does CYP require Coordinate my Care/PSP?				
All teams clear on discharge plan and EDD (ideally early-mid week to ensure sufficient support available)				
Final sleep study prior to discharge (ideally no later than two weeks prior to discharge)				
Ventilator prescription completed				
Ventilator service contract set up and parents/carers have necessary contact numbers for support				

No later than 2 weeks prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
Nursing/Key Worker Tasks				
Open access set up at local hospital				
Local hospital has all relevant documentation e.g. interim discharge summary, escalation care plans, ACP, competency documents (if applicable) ahead of home leave				
Multi Therapy Tasks				
Individualised developmental/therapy programme, reviewed and finalised (OT/PT/SLT)				
Liaison with community therapist, wheelchair services, school and other outside agencies with regard to ensuring equipment is in place for discharge and ongoing care needs post discharge (OT/PT/SLT)				
Respiratory Physiotherapy				
Individualised respiratory physiotherapy programme reviewed and finalised				
Assessment and review of mucolytic therapy				
Completion of respiratory physiotherapy training with parents/carer				
Confirm provision of respiratory adjuncts e.g. MI:E for home				
Ongoing liaison with community professionals/MDT regarding respiratory care plan for home				
Parent/carer Tasks				
UK power network/local electricity distribution company have put household on priority services register				
Utility suppliers contacted and priority confirmed e.g. energy, water, phone				
Parents/carers have roomed in overnight (once competencies are complete). This must be a waking night				
Home leave for the day completed (at least one day)				
Overnight home leave completed if possible (must be a waking night as above)				15

No later than 1 week prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
MDT Tasks				
Follow up appointments booked in (together on the same day if possible)				
Coordinated programme of follow up with specialist arrangements for vision, hearing, developmental progress and ongoing review in place for NICU patients				
Local hospital contacted and step down confirmed				
Named community paediatrician and named general paediatrician confirmed				
Nursing/Key Worker				
Training documents uploaded to electronic records, in paper notes and sent to MDT e.g. CCNT, continuing care				
GP updated of planned discharge. Home visit requested following discharge if GP has not already met CYP				
Transport plans for discharge/transfer discussed				
Parents/carers given necessary hospital/community contact numbers				
Multi Therapy Tasks				
Referral made to community (SLT/OT/PT) with appropriate reports/therapy programmes sent				
Community therapy teams contacted regarding outstanding equipment required following discharge (PT/OT)				
Guidelines for prescribed equipment completed and handed over to parents/carers (PT/OT)				
Dietetic Tasks				
All necessary equipment delivered to patient's home				
Parents/carers competent in managing and delivering nutritional plan in the community				

No later than 3 days prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
MDT Tasks				
Medical discharge summary complete				
TTO's ordered				
Nursing/Key Worker Tasks				
Nursing and discharge coordinators summary complete (if step down/transfer)				
Transport booked				
Parents/carers have taken as many belongings home as possible to aid with discharge/transfer				
No later than 1 day prior to proposed discharge date	Responsible Individual	Date task applicable from	Date task completed	N/A
MDT Tasks				
Bed confirmed				
Nursing/Key Worker Tasks				
TTO's present on ward and checked				
NGT, tracheostomy, MINI button all recently changed. Parents/carers and CCNT given dates of last changes				
Parents/carers have up to date copied of hospital passport, competencies, discharge letters and follow up appointments				
Sufficient home oxygen cylinders/home equipment on sire e.g. suction, saturation machine for journey home				
Dietetics Tasks				
Ensure parents have most up-to-date copy of feed plan and re-check they have all the necessary feed equipment				

Day of Discharge/Transfer	Responsible Individual	Date task applicable from	Date task completed	N/A
Nursing/Key Worker Tasks				
Bed confirmed				
Transport confirmed				
Receiving area informed prior to leaving e.g. local hospital, hospice or continuing care team, care agency				
Drug chart photocopied				
Medical devices not required on discharge removed e.g. cannula				
All belongings and equipment gathered				
TTO's given to parents/carers as per trust protocol				
Care plans uploaded to electronic records and all relevant parties have copies e.g. care agency, hospice, local hospital, local paediatrician, continuing care team, CCNT				
Members of MDT all aware of discharge and have copy of discharge summary				

Acronyms and Abbreviations	Meaning
AAC	Augmentative and Alternative Communication
BLS	Basic Life Support
Carer/nurse	Staff within care package
CCG	Clinical Commissioning Group
CCNT	Children's Community Nursing Team
Continuing Care	A referral to Continuing Care is required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone
CSW	Clinical Support Worker
CYP	Child/Young Person
DLA	Disability Living Allowance
DPM	Discharge Planning Meeting
EDD	Expected Discharge Date
ENT	Ear Nose and Throat
FFD	Fit for Discharge - will be unique for each CYP and family
HV	Health Visitor
ICS	Integrated Care System
MDT	Multi Disciplinary Team
MI:E	Mechanical Insufflation:Exsufflation
MLB	Microlaryngoscopy and Bronchoscopy
NHSE	National Health Service England
OT	Occupational Therapy
Parents/carers	Parents, guardians, foster parent
PPLTV	Paediatric Pan London Long Term Ventilation
PPLOG bundle	Paediatric Pan London Oxygen Group
PSP	Patient Specific Protocol
PT	Physiotherapy
RBH	Royal Brompton Hospital
SLT	Speech and Language Team