

STARSHIP LONG-TERM VENTILATION (LTV)

Discharge Planning Process – Northern Region

The Northern Region refers to Waitemata, Auckland and Counties Manukau DHB's. The following processes will often be occurring in parallel, the process outlined below is not sequential.

Discharge Planning Initiation

Members of the multidisciplinary team participate in the assessment regarding decision to proceed with LTV (refer to associated documents Assessment Process for LTV Decision Making and Guiding Principles for Decision Making).

As soon as the decision to proceed with long term ventilation occurs the process of discharge planning should begin. During the assessment process many issues relevant to discharge planning will have been discussed so it is important to pick up and continue the process to ensure time in hospital is minimised.

Parent (primary carer) engagement in discharge planning is critical. Confidence in their ability to manage the care of their child will be a significant driver of the time to discharge. Graduated distancing from the environs of PICU should be encouraged as the parent's confidence increases and training proceeds i.e mobilising with the child within PICU / ward, then accompanied outside PICU but within the building, within the grounds and eventually visits to the home and within the community.

A transition period in an environment other than PICU is desirable before discharge home. It is preferable that the child transition to a paediatric medical ward following PICU. This may be within Starship or the child's local DHB as appropriate.

Care Coordination

Care of a child with LTV involves a large and diverse group of people working across Starship, the local DHB and community to ensure initial discharge and on-going care for the child & family in the community. The need for a dedicated Clinical Nurse Specialist (CNS) to support the care of children with LTV has been supported by the Starship Foundation with the recent appointment of a CNS LTV Care Coordinator.

The CNS LTV Care Coordinator will work closely with the CNS PICU Long Term Care Coordinator and various other team members to ensure a coordinated approach to the planning for discharge.

Multidisciplinary Team involvement

Members of the Starship multidisciplinary team (MDT) that will be involved in the child's care are identified; Dietician, Medical Specialists (Intensivist, Respiratory), Nursing (Primary Nurse, Clinical Charge Nurse, CNS – PICU Long Term Care Coordinator), Occupational Therapist, Pharmacist, Physiotherapist (Respiratory and Developmental), Play Specialists, Social Worker, Speech Language Therapist

Early identification and engagement with the community based MDT eg Family Options, General Practitioner, Nursing, Occupational Therapist, Developmental Paediatrician, is critical. A community base care coordinator should be identified, usually the Occupational Therapist due to the housing and equipment issues but could be another member of the team. The community care coordinator will liaise closely with the CNS LTV Care Coordinator through the process of discharge planning and post discharge support.

Inclusion of community support services and Non-Government Organisations (NGO's) should be considered.

Initiate fortnightly MDT Discharge Planning meetings coordinated by CNS LTV Care Coordinator or the CNS PICU Long Term Care Coordinator. Attendance by teleconference is an option. Meeting minutes circulated. Family attendance requested as appropriate.

Needs Assessment and Service Coordination

(NASC) initiated via referral to Family Options – refer to specific process

Child's Personal Care Plan

Prior to discharge a suite of documents will need to be completed that collectively detail a plan for ensuring the care needs of the child are understood by the family and carers. Completion of the documents should include the family carers and members of the MDT. Some documents will be completed during Education and Training for family (refer to the LTV Education & Training programme).

Documentation will include:

*"Child's Health Passport" (including members of the child's MDT, GP, local DHB team, Starship Specialist Team)

*"Health Check" (includes a medical emergency plan)

*"Being prepared for non-medical emergency once your child is home"

Calendar of scheduled and annual reviews

Daily Care Plan

Nursing care Plan

Therapies / Community Care Plan

Nutrition Care Plan

*Denotes documents within the LTV Education and Training Programme

Housing assessment

Referral for Housing Assessment should be initiated as soon as the decision is made to proceed with LTV via referral to Community Occupational Therapist (NZROT). The Occupational Therapist holds the role of an Equipment and Modification Service (EMS) Assessor accredited to complete Complex Housing Modifications.

The EMS Process can be lengthy due to the number of steps which must occur prior to any modification being completed, in some circumstances a transitional plan may need to be considered.

Funding Information

- In general, maximum amount available for funding of access modifications is \$15,334 (inc GST). If the total proposed modifications agreed in principle by the Professional Advisor quoted amount is over \$25,000 this will be required to be referred by Accessable to the EMS Advisory Panel in Wellington for consideration.
- There are specific guidelines and options for funding available for housing which differs according to the individual circumstances and identified needs. These include the family completing the works and having an agreed amount contributed by Accessable or Part Payment where Accessable completes the works and the client contributes part of this cost. Income and asset testing may be applicable for children over 16 yrs.

Home Environment Indicators For Suitability to Modify

- Flat/gently sloping section with drive on access (to enable wheelchair access and safe unloading of mobility vehicle off the road/driveway) if the child is in a wheelchair
- Appropriate area outside the home for mobility vehicle/ambulance parking and turning (must be at least 7 metres flat parking area to enable wheelchair lift to function) if the child is in a wheelchair
- Maximum of 3 – 4 steps with less than 1 metre rise into the home to provide potential to modify with space for ramp or low rise lift if the child is in a wheelchair
- Main rooms (bedroom, bathroom and main living areas) on ground level if the child is in a wheelchair and sufficient circulation space throughout the home.

- Bedroom (or convertible living room) large enough for hospital bed, hoist transfers, commode, LTV equipment (ventilator, oxygen concentrator, oximeter, suction, feed pump), other medical equipment, 2 x caregivers to work with child. Space beside bed for overnight caregiver to sit/do activities during shift. Specific details for power source/running of respiratory equipment will be considered within the housing assessment.
- Level access wet area shower. (Or potential to modify existing bathroom/toilet e.g. combining areas to create large enough space)
- Wide enough hallways to provide circulation space and for turns into doorways. Potential to widen essential doorways (bedroom, bathroom, main living area) to 810mm, 860mm or 910mm.
- Adequate power, phone, and heating – social worker to be involved if there are issues with meeting these needs.

For further information please refer to the following documents:

[Accessible Housing Modifications Process Information Sheets](#)

[Accessible Complex Housing Modifications Process Flowchart](#)

If the current family home is deemed unsuitable develop a plan with the family for alternative accommodation, alternative family home, rental etc.

If necessary involve Housing NZ early in the process to arrange possible access to alternative housing & potentially housing that has already been adapted for people with disability.

If appropriate refer family to agencies aimed at ensuring healthy homes for children

- Kainga Ora Healthy Homes Initiative – Auckland and Waitemata Regions
- Awhi – National Hauora Coalition – Counties Manukau region

Equipment Needs

Referral to community based therapy team and coordination with the Respiratory team is required to ensure appropriate equipment is available for the parent (primary carer) and carer training

Transportation

Members of the multidisciplinary team will work with the family to determine family access to transport. This will include assessment of the medical equipment requirements and need for fixing points (O2 cylinders and ventilator, car seat, wheelchair etc).

Ensure the family has information regarding assistance available:

Mobility taxis

Modified vehicle alterations

Lotto Assistance to purchase

National Travel Assistance

Consumable Supplies

A detailed list of consumable requirements must be collated and submitted to the community nursing service 4 weeks prior to discharge.

The family will be discharged with a 4 week supply of consumables and arrangements in place for re-stocking the agreed consumable supply

Medications

Transition to community pharmacy needs to occur 4 weeks prior to discharge, ensure the family is discharged with 1 month supply of current medications

Family Education and Training

Education and Training is initiated early for the Family – refer to LTV Education and Training programme. Training to be initiated once child is medically stable and early in the process

Educational resources will be available on the Starship website.

Paid Carer Training & Education

PICU and/or Paediatric medical ward based Education and Training for paid carers commences 6- 8 weeks prior to discharge – refer to LTV Education and Training programme.

Refer to the Needs Assessment & Service Coordination Process regarding identification of paid carer requirements and arrangements for supply of paid carers through either a contracted provider or via individualised funding arrangement.

Paid carer training should be proficiency certified and periodically re-certified for on-going competency. Formal processes around the training and proficiency certification of practice are still under development, Current obligations are contained in the contract of service agreed to with a contracted provider.

Financial and Community Supports

Ensure the family receives information related to financial and community supports available to them. This information is usually available via the Social Worker associated with the MDT.

- Child Disability Allowance (WINZ)
- Disability Allowance (WINZ)
- Carer Support payments (MoH)
- Secure electricity supply form
- St John ambulance membership
- Information re appropriate community support groups
- Work and income NZ