NURSING OPERATIONAL MANAGEMENT

17.1 LADY LAWLEY COTTAGE – OPERATIONAL PROTOCOLS FOR TRANSFER OF PATIENTS TO THE HIGH NEEDS UNIT

The Lady Lawley Cottage High Needs Unit (LLC HNU) was established in December 2002 as a joint initiative between the Child and Adolescent Health Service (CAHS) and the Australian Red Cross. The Unit is funded by the Department of Health to provide specialised nursing care for children with high medical support needs whose health status is stable and for whom transition to home planning is required.

BACKGROUND

A growing number of children are surviving extremely premature birth, severe neurological incidents and other medical disorders which result in significant long-term disability and require a high level of support to return to the local community.

The children are eventually medically stable but dependent on medical technology to sustain their daily needs. Many of the children have minimal or no family support and for those whose families are involved, the high level of ongoing care is not possible without support from both government and community services.

As a result the children remain in an acute care facility at Princess Margaret Hospital (PMH) for many months while the necessary supports are identified and secured. The long-term developmental needs of the children are not necessarily well met as the resources at PMH are not structured for this purpose.

The LLC HNU is designed to provide an interim service for up to six children at a time that allows the necessary discharge planning and carer/family training to occur in an environment that supports the child and their family/carers.

Experienced staff will be available to provide training for families and carers in the ongoing care required once the child is discharged from the Unit.

OUTCOMES

The following describes the intended outcomes of the service:

- Interim accommodation for children who are dependent on medical technology and/or require a high level of care while they prepare for discharge home;
- Children receive care in the environment that most appropriately meets their needs, including the provision of programs to enhance development;
- Contribution to successful transition from hospital to home that involves families and relevant health staff;
- Families and carers trained and supported in the safe and effective care of their child at home;
- Local support networks established; and
- Efficient use of acute tertiary hospital resources.

ACCESS

Children referred to the Unit will typically meet some or all of the following criteria:

- Dependence long term on mechanical support to maintain respiratory function;
- Chronic illness that may lead to permanent disability or developmental delay
- Unable to be discharged directly to the care of their family or carer due to further training requirements, care and protection issues or the need to establish additional support systems.

Other children who do not meet the above criteria may be considered for the Unit if resources are available. This decision rests with the Executive Director Nursing and Patient Support Services, Child and Adolescent Health Service (CAHS).

The CATCH Program is a separate service providing community based support to children with disabilities who require mechanical support to maintain respiratory function. These children may be discharged to the Unit or they may go directly home from hospital. For further information about the Program please contact the CATCH Program Coordinator on 9286 5267.

REFERRAL/TRANSFER PROCESS

Responsibility for identifying children suitable for discharge to LLC rests with the Clinical Nurse Managers (CNMs) of the wards at PMH. Early identification is optimal to enable adequate planning and preparation including referral to the CATCH Program if appropriate.

Where possible, parents should be included in the decision making process, while the child's Consultant will ultimately determine when the child is medically ready for discharge to LLC. It may be appropriate for the family to visit the Unit at this stage to assist in discharge planning. This would be organised by the CNMs at both PMH and LLC.

The Nursing Director, Paediatric Medicine Clinical Care Unit will be advised of the decision to discharge by the relevant PMH CNM. The PMH CNM will liaise with the CNM at LLC regarding administrative details including discharge dates. The CNM - Orthopaedics will continue to liaise directly with LLC with regards to children referred to LLC for post-operative orthopaedic care.

If there are issues related to lack of parental involvement, the child should be referred to the Department of Child Protection (DCP) prior to transferring the child to LLC.

Once a child has been identified for discharge to LLC, the PMH CNM and Social Worker will coordinate a meeting with some or all of the following stakeholders:

- Family or foster carers;
- PMH CNM, Allied Health, Clinical Nurse Consultant (CNC) for Technology Dependent Children, Ambulatory Care Co-ordinators, Hospital School and Medical staff;
- LLC Nurse Manager;
- Disability Services Commission (DSC) Local Area Coordinator and/or Manager Individual and Family Support (Metropolitan) or Country Manager (Rural); and
- Department for Child Protection (DCP) Case Manager.

Other people considered relevant to the discussions may be invited to attend.

The purpose of this initial planning meeting is to:

- Clarify the role of the family/guardian in the care management and future planning;
- Identify care resources and equipment requirements;
- Identify specific education or training requirements for LLC staff;
- Determine a discharge date and expected length of stay at LLC;
- Clarify the role of each individual in transition planning;
- Identify a facilitator to progress transition planning and implement discharge at LLC.

Other issues may need to be addressed at this meeting, dependent on the needs of the child and their family. Further meetings may be held to monitor progress.

Subsequent to this initial planning meeting, the CNMs will liaise to:

- Organise the specific nursing and equipment requirements utilising the PMH Complex Care Nursing Transfer/Discharge Summary.;
- Arrange a visit to LLC for the child, their family and relevant PMH staff to view the facility and meet staff;
- Organise appropriate training opportunities for LLC staff at PMH while the child is still an inpatient;
- Arrange change of TOPAS details to reflect LLC as the place of residence. This will ensure correspondence is directed appropriately;
- Ensure a PMH Medical Discharge Summary accompanies the child to LLC;
- Organise enrolment in the Ambulatory Care Coordination (ACC) program. (Refer to transfer checklist, Appendix one)

Once the child is at LLC, Ambulatory Care Coordination (ACC) at PMH will be the key PMH contact and is available twenty four hours a day, seven days a week to offer advice out of hours, notify the emergency department of impending visits and will navigate across the different departments and individuals from the hospital on behalf of LLC.

At LLC, the CNM will be the key person in which all information is relayed from PMH and to PMH.

CASE REVIEW

Throughout the period of stay at LLC, regular meetings will be organised with the family or foster carers and agencies involved in the child's care to plan progression towards discharge. These meetings will review progress towards discharging the child to a home care setting and include:

- Review of care plan and implementation of developmental programs;
- Updates from each agency on progress towards discharge from LLC, including funding applications for necessary home supports;
- Plans for ongoing family/carer/foster involvement; and
- Plans for community-based social and educational opportunities while at LLC.

MEDICAL MANAGEMENT

At all times the medical management of the child remains the responsibility of the PMH Consultant. The PMH Rehabilitation Registrar will medically review the children in the High Needs Unit monthly, including renewing medication charts. The team approach will also include the Clinical Nurse Specialist from Rehabilitation, the CNC for Technology Dependent Children and a representative from ACC. A local GP will be used for non urgent medical matters. PMH Emergency Department is used for urgent medical matters where the Consultant is aware and informed of arrival via ACC.

If the children require review in between these monthly reviews, LLC will organise with ACC to have them assessed/treated in the Ambulatory Care Day Facility (ACDF) at PMH.

EMERGENCY TRANSFER TO PMH

- In the event of a medical emergency, the LLC Procedure for Medical Emergency and Transfer of Client to an Acute Care Facility is to be implemented.
- If a child in the High Needs Unit requires emergency medical treatment, the Duty RN at LLC will undertake the following:
  - Liaise with ACC to arrange transfer for medical review, if the child requires emergency management, ACC will liaise with the Emergency Department Consultant. An up to date Integrated Health Care Plan (IHCP) will be available in the triage area of ED for utilisation by ED staff.
  - Contact St John Ambulance Australia and arrange transport. Inform the Ambulance Communication Centre that the child has been previously registered through PMH and whether or not a staff member from LLC is available to escort the child;
  - Notify ACC to alert the emergency department of the impending arrival once the child has left LLC.
  - Equipment from LLC will be transferred if required on admission. This avoids the unnecessary transport of equipment in the event that the child is not admitted. LLC staff will bring an equipment checklist that should be sighted and initialled by the PMH nurse in the event that the LLC staff member returns to LLC.
  - LLC Allied Health staff should notify PMH Allied Health staff if ongoing intervention is required, or liaise with PMH medical staff to request a referral for assessment.

HOSPITAL IN THE HOME (HITH)

HiTH is an acute substitution model which can be utilised as an alternative to hospital inpatient stay. PMH HiTH nursing staff provide up to three visits per day and 24 hour contact. The hospital consultant retains clinical responsibility. This service can be accessed where appropriate for children in the High Needs Unit at LLC.

ATTENDANCE AT OUTPATIENT APPOINTMENTS

Attendance at outpatient appointments is an important part of the child's ongoing care and the CNM at LLC will arrange for the child to attend with a parent or carer as required.

EQUIPMENT

Children will be discharged from PMH with the necessary equipment in working order. This equipment will remain with the child as long as required.

An equipment maintenance schedule is included in the Nursing Transfer/Discharge Summary. Planned maintenance for medical equipment will be completed by the Medical Technology Management Unit at PMH, as arranged by the LLC CNM.

In the event of equipment malfunction, appropriate first aid should be undertaken to maintain a patent airway whilst arrangements are made for the immediate transfer to PMH ED Department.

For assistance with technical problems that do not represent a medical emergency, contact the number listed for the specific specialty in the child's IHCP or contact ACC.

MEDICAL CONSUMABLES

Princess Margaret Hospital will purchase and provide LLC with those consumables normally provided to families on discharge. These include:

- Tracheostomy tubes
- Suction catheters
- Gastrostomy tubes
- Speaking valves

PMH will inform LLC of the child's requirements in time for ongoing consumable requirements to be obtained by LLC. Children will be discharged to LLC with a reasonable supply of consumables.

LLC is funded to provide all other consumables and medication including nappies and cotton buds etc.

DAILY LIVING COSTS

LLC is funded by DoH to meet the basic living costs of the child while they are in the Unit. The child's guardian (parents or DCP) are responsible for costs associated with social activities, education, non-medical transport and clothing.

ROLE OF DISABILITY SERVICES COMMISSION

The DSC provides a range of services, based on eligibility and relative need, to children with disabilities and their families, including foster carers. This includes:

- Local Area Coordinators who work with families to assist them to plan, select and receive services and to develop informal networks that support and strengthen the family capacity to care for a child with a disability
- Respite and family support can also be obtained through various agencies, including Flexible Family Support and Intensive Family Support via priority-based application processes
- Respite and family support through provided and funded services including LLC, which is funded for 14.5 respite beds.
- Professional services are available through DSC and other funded non-government organisations
- Aids, equipment and modifications funded through a range of organisations.
- Funding via priority-based application processes for accommodation options for people with disabilities who can not be supported at home by their family.

ROLE OF THE DEPARTMENT FOR CHILD PROTECTION

The department provides a case management service for children when their families are unable to care for them or where the family retains guardianship but requires either ongoing or intermittent support. The case management service is coordinated by a case manager and may include the provision of:

- financial support including a subsidy to meet day to day living costs; school uniforms, books and fees; clothing allowance; pocket money; and planned expenditure associated with the out-of-home placement of a child;
- assessment and planning functions considering the day to day care arrangements for children and their ongoing development;
- family supports to strengthen the family to care for the child including access to social work services, counseling, advocacy and facilitating family meetings; and
- referral to other services for both the child and extended family members.

Children with disabilities may also be eligible for additional funding from the Department to assist with the provision of specialised equipment, consumables, medication, contributions towards home modifications and specialised vehicles etc.

ROLE OF PRINCESS MARGARET HOSPITAL ALLIED HEALTH STAFF

A PMH physiotherapist will continue to provide therapy for these children while other allied health staff at PMH will handover to LLC, DSC and/or DCP staff to enable continuation of allied health services required by the child on discharge from hospital.

TRANSITION FROM LLC

The organisation of transitioning a child from LLC to their home in the community will ultimately rest with the CNM/DON at LLC.

Prior to discharge home, the following will be in place:
Detailed care plan provided to the family or foster carers;
Procedure for recruitment, training and supervision of paid carers if applicable;
Access to respite or in-home support;
Access to allied health services;
Access to community nursing services;
Arrangements for ongoing contact with the family or foster carers; and
Notify relevant medical team at PMH

KEY CONTACTS

Ambulatory Care Coordination (ACC) PMH
9340 7656 24/7
9340 7913 office

PMH/LLC Speed Dial
Phone: 6012

Director of Nursing, Lady Lawley Cottage
Phone: 9384 2466

Nursing Director, PMCCU, Princess Margaret Hospital
Phone: 9340 8750
Pager: 8751

Country Manager, Disability Services Commission
Phone: 9426 9733

Manager Metropolitan Services Coordination (Individual and Family Support), Disability Services Commission
Phone: 9426 9371

Clinical Nurse Consultant for Technology Dependent Children, Princess Margaret Hospital
Phone: 9340 7676
Mobile: 0406 998 759

Manager Department of Community Development
Phone: 9222 2856

CATCH Program Coordinator
Phone: 9286 5267

APPENDIX ONE

Transfer Checklist

ACTION	PERSON RESPONSIBLE	OUTCOME
- Patient identified for transfer - Nursing Director PMCCU informed	PMH CNM discuss with DON, LLC	- Child deemed medically fit for transfer
- Family offered visit to LLC, introduce to LLC staff	PMH CNM/Social worker and CNM LLC	- Family involved in transfer and orientated to LLC
- Planning meeting arranged	PMH CNM/Social worker	- Roles clarified - Discharge Coordinator identified - Discharge date and length of stay at LLC determined
- Nursing care/ education organised - PMH Complex Care Nursing Transfer/Discharge summary completed and forwarded to LLC prior to transfer - Across site allocation of nursing where appropriate	CNMs from both sites	- Facilitation of nursing care education for LLC staff - LLC staff competent to care for child - Continuity of care optimised
- Equipment and consumables arranged	PMH CNM/ discharge Coordinator	- Child safely transferred with required equipment and consumables
- OPD appointments to be arranged	PMH CNM/ ACC	- Carer and/or family are able to attend all outpatient appointments with child
- TOPAS change of address to LLC	PMN CNM/ discharge Coordinator	- All correspondence will be forwarded accordingly to ensure ongoing care
- ACC enrolment	PMH CNM	
- Send medical discharge summary, nursing transfer/discharge summary and necessary equipment with child on transfer to LLC with nurse escort	PMH CNM	- Safe transfer to LLC