

DISCHARGE HOME PLANNING FOR CHILDREN WITH CARDIAC CONDITIONS PRACTICE GUIDELINE[®]

DOCUMENT SUMMARY/KEY POINTS

- Planning for discharge home should commence as early as possible
- Post-discharge care should be individualised and facilitated as close to home as possible.
- Discharge planning should be the same regardless of the discharging unit at SCHN.
- The focus of discharge planning is on safety and care once the child is home.
- Discharge planning requires a holistic and multidisciplinary coordinated approach that is transparent and family-centred.
- Communication is paramount, and all planning should be clearly documented identifying staff who are care providers, education needs as they are met and escalation processes for care on discharge.
- Some patients are at higher risk of deterioration, re-presentation to hospital, insufficient support or being lost to follow up. These risks must be taken into account when discharge planning and their local emergency department should be made aware, with any discharge summaries and other relevant care plans included in correspondence with them.
- Transfer to SCHN Hospital In The Home (HITH) may be appropriate for ongoing care and management of high risk groups, or those who can have their care needs delivered in the home rather than hospital

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

Approved by:	SCHN Policy, Procedure and Guideline Committee	
Date Effective:	1 st May 2023	Review Period: 3 years
Team Leader:	Nurse Manager	Area/Dept: Cardiology CHW

CHANGE SUMMARY

- New Document

READ ACKNOWLEDGEMENT

- Read Acknowledge Only – clinicians responsible for the care and coordination of cardiac patients.

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Principles

- Planning for discharge home should commence as early as possible (prior to admission if appropriate) to ensure adequate preparation of family and multidisciplinary teams.
- The focus of discharge planning is on safety and care once the child is home, not just what is needed for them to be well enough to leave the inpatient setting.
- Care post-discharge should be facilitated as close to home as possible, regardless of where the child lives. This is individualised to support the safety of the child and the needs of the parents/carers and their local teams.
- Discharge planning requires a holistic and coordinated approach that is transparent and family-centred, working alongside other specialty teams and parents/carers to ensure comprehensive preparation.
- Communication is paramount, and all planning should be clearly documented identifying staff who are care providers, education needs as they are met and escalation processes for care on discharge.
- Consistency in planning and accountability of the discharge process is required to ensure streamlined and comprehensive care. The discharge planning should be the same regardless of the discharging unit.

Early preparation

EDD documentation

Estimated date of discharge (EDD) should be documented on the patient flow portal on admission (or within 48hrs if the admission is unplanned) and adjusted during the length of stay depending on clinical condition. This should be attended by clerical staff in consultation with the NUM/admitting team on duty. The reason for admission can be used as an initial guide for expected inpatient time frame (e.g. patients admitted for electrophysiology studies will likely have EDD documented as the day following admission). For further information see [Care Coordination: Planning from admission to transfer of care](#) policy

Criteria for discharge home

To be safe for discharge the following must be completed:

- Cardiovascular stability for the child, with observations within expected ranges
- Stable feeding regimen and appropriate weight gain, or documented plan for surveillance of same. This should be determined in collaboration with a nominated dietician or speech pathologist
- Appropriate discharge location identified
- All equipment and medications acquired must be sourced (or a clear plan for sourcing these negotiated with the family and the local team)

- Parent/caregiver is competent in caring for the child and attending to their health needs. This includes an understanding of appropriate developmental care and safe handling/positioning
- All follow up plans (including medical, nursing or allied health) have been arranged and the family/caregivers are aware of same
- Appropriate referrals to appropriate outpatient services (medical, nursing or allied health) are made
- Medical discharge summary completed and distributed to relevant teams/individuals

Children being discharged with a palliative care plan (not necessarily having had a palliative surgical procedure) will not always fulfil the above criteria, and appropriateness for discharge should be determined on a case-by-case basis in consultation with the family and their treating teams (cardiology as well as any additional teams involved in their care, e.g. general paediatrics or allied health teams).

Identification of increased risk patient groups

The following groups of patients should be identified early as they may be at a higher risk of deterioration, re-presentation to hospital, insufficient support or being lost to follow up. ¹

Cardiac	Added complexities	Hospitalisation	Location	Social
- High risk patients on watch list * - Transplant/advanced heart failure	- Prematurity - Complex comorbidities - Respiratory support - Feeding or nutrition support - Vascular access - Wound care - Complex medication regimes - Palliative	- First time home - Prolonged length of stay	- Regional or remote - Transport limitations - Limited local services (regardless of location)	- Non-English Speaking Families - Aboriginal and Torres Strait Islander families - Socially vulnerable (limited supports) - Financial hardship - Mental health challenges - Department of Communities and Justice involvement/ Out of Home Care

* See later section *Considerations for certain patient cohorts: High risk children on watch list* for definitions

Risk may vary over time, impacting the EDD and organisation of discharge planning. Identification of risk on the discharge checklist can ensure it is highlighted and incorporated into planning. These risks should be discussed and communicated with the teams involved in the patients' care so that appropriate strategies can be put into place to address them effectively.

Hospital in the Home (HITH)

Prior to discharge, transfer to SCHN HITH may be appropriate for ongoing care and management of high risk groups (for transition to home support), or those who can have their care needs delivered in the home rather than hospital (for example long term IV antibiotics). Regardless of the reason, suitability for discharge and all discharge planning (including discharge summary and parental education) must be completed prior to transfer to the HITH bed board.

For information regarding inclusion criteria and services offered, see [Admission to Hospital in the Home](#) (HITH) procedure or contact the HITH team via email SCHN-HITH@health.nsw.gov.au or phone via switch at CHW 9845 000 or SCH 9382 1111.

Common reasons for re-presentation after discharge

For children at high risk of representation and deterioration, their local emergency department should be made aware, with any discharge summaries (inclusive of escalation plans) and other relevant care plans included in correspondence with them.

In the event of representation to ED within 30 days of cardiac surgery, specific procedures must be followed, as outlined in the [Cardiac Patients Post Surgery Presenting to ED – CHW Practice Guideline](#).

Parents should be advised to always carry copies of the child's most recent discharge summary outlining surgical dates and details.

Re-presentations to hospital may be due to issues such as postoperative infections or pericardial/pleural effusions². Often however, they may be multifactorial and unrelated to the cardiac diagnosis³, such as viral infections, poor weight gain or feeding issues (particularly if the child is nasogastric tube fed, or has had previous speech pathology involvement for oral aversions or dysphasia) or gastrointestinal concerns.

Combined with the increased risk patient groups mentioned, these possibilities should be outlined to the parents/carers as teaching points prior to discharge (see below).

Parental education and preparedness

Parental preparation and preparedness for home should be an ongoing process throughout admission. The lived experience of returning home following a cardiac procedure should not be underestimated, with themes of uncertainty, fatigue and control known to dominate⁴.

Each child and family will have different needs, with education and preparation encompassing any number of the following:

- Diagnosis (and any procedures that have been performed)
- Escalation plans – what to look out for (cardiac and non-cardiac related), actions to take and who to inform

- Feeding regime (including specialist formula scripts, and oral feeding strategies as required)
- Medication administration and management – see [Gate Pass, Discharge and Outpatient Medications Management](#) Practice Guideline
- Wound care
- Post-operative positioning and handling considerations as required
- Care of vascular access devices – see [Central Venous Access Devices \(CVAD\)](#) Practice Guideline
- Equipment and ongoing supplies
- Procedures – for example nasogastric tube insertion, see [Insertion and Care of a Feeding Tube at Home](#) Homecare Guideline
- Transport (logistics of how they will get home in case extra planning is required)

If the child has never been home before, the following routine care considerations may be necessary:

- Car seat – present and installed correctly. Review of car seat position by an Occupational therapist can be attended as required.
- Crib – present and appropriate
- Safe sleeping – information regarding SUDI and SIDS guidelines and preparing the bedspace at home which may be different than during the inpatient stay – see the [Safe Sleeping Practices for Babies](#) Policy
- Formula demonstration – by an Allied Health Assistant in the formula room if the family are unfamiliar with the process or the formula recipe differs from standard
- Baby cares – routine baby cares such as bathing, umbilical stump care

In the preparation for discharge, accountability for each action needs to be addressed, with documentation in the patient's medical record to reflect the current status of the discharge planning process. The earlier the education is provided the better as it increases confidence and experience, particularly with troubleshooting. The discharge planning checklist can be used to support this documentation.

If it is appropriate for some elements of education to be continued in the outpatient setting (for example, nasogastric insertion education) the plan must be documented and include who is responsible for same following allocation of responsibilities.

Collaborating with local teams

The following principles should be taken into account when collaborating with local teams to plan for care post an inpatient stay at SCHN:

- *Early identification of relevant healthcare providers* – the more complex the circumstances, the sooner local health care teams need to be involved in care planning. Paediatric nursing specialists (e.g. care coordinators and/or CNCs) can assist in identifying the relevant healthcare services and providers in an area. **Occupational Therapy and/or Physiotherapy can assist in community referrals for developmental**

therapy and linkages with ECEI/NDIS (Early Childhood Early Intervention/National Disability Insurance Scheme) where appropriate.

- *Identification of local capacity* – early discussion with local teams allows identification of any potential issues with providing care locally or foreseeable challenges with keeping the child safe and well.
- *Education and equipment* –if the local teams require any education and training to be able to safely care for the child closer to home, this should be identified early, as well as the access to equipment or consumables. It should not be assumed that a local team can or cannot provide care locally without a discussion and/or the facilitating of support as required.
- *Information sharing* – opportunities for discussion of clinical and social patient information should be identified as required and attended in the manner requested by the local teams, rather than simply a handover or the provision of information late in the child's stay. Multidisciplinary team meetings may not always be necessary, but detailed discussions with local medical, nursing, and allied health staff is essential to ensuring the smooth transfer of information and two-way communication between all relevant teams. Parents are often relied upon to relay information about their child⁵ but this should not be the primary source of information handover. Use of the My Health Memory App may assist with up to date information being readily available.
- *Transparency* – communication between local and SCHN teams should be transparent with the family and carers of the child. This promotes trust in the local service providers and helps foster ongoing relationships that may have otherwise been difficult for the family to establish.

Plans for home

Discharge documentation

Contact details of the child, family and relevant care providers (such as the GP) need to be confirmed and updated in the medical record prior to discharge.

The planning of discharge (including multidisciplinary meetings and long term patient meetings) should be documented in the child's medical record.

Use of the discharge planning checklist on eMR ensures completeness and accountability for planning and education prior to discharge from SCHN.

Discharge documentation

- Medical discharge summary – must be completed prior to the child leaving SCHN with senior medical sign off to approve the final version of the document. Distribution of the document to relevant local staff and an explanation of the content of the summary to the family must be completed by SCHN medical staff
- Care/escalation plans (such as those for the high risk on watch list or transplant patients) – should be completed, provided to the family (and other relevant staff) and explained by the senior nurse overseeing the child's care (eg. CNC, CNS2)

- Scripts, imaging forms, ongoing referral pathways and any other paperwork required for outpatient management – if required, they should be explained and provided by medical staff
- Medication management plans/timetables – if required, this should be completed, provided to the family, and explained by a pharmacist
- Formula recipes, feeding plans and feeding strategies – if required, this should be completed, provided to the family, and explained by a dietitian or speech pathologist as applicable.
- Nursing discharge instructions – should be completed by the bedside nurse (or delegate) on the day of discharge and explained to the family
- Blue book – if relevant, any new information must be added to the Blue Book prior to discharge by the junior medical officer, bedside nurse and/or delegate
- Education resources such as fact sheets and discharge home booklets – families should receive these prior to the day of discharge. These can be provided by any staff members

Escalation plans: linking with local services for support

The following services may be highlighted to families as sources of support following discharge as determined by the treating team:

- SCHN Cardiac Nursing Team – can provide assistance and support for families and local staff, with their contact details given to each patients care providers
- Local nursing/ambulatory care – may provide cardiac surveillance or support unrelated to the child's cardiac condition. Services offered vary between hospitals and local staff.
- Local Emergency Department – for urgent care
- Kids GPS – SCHN Kids Guided Personalised Service (GPS) is a care coordination service assisting families of children with complex healthcare needs to navigate the health system and improve the integration of care delivery across multiple sectors LHDs. This may include appointment coordination and ED avoidance strategies. Eligibility criteria can be found on [Kids Guided Personalised Services \(Kids GPS\) Care Coordination](#) Practice guideline or for questions contact Kids GPS on schn-kidsGPS@health.nsw.gov.au
- Child and Family Health – local child and family health centres facility primary healthcare engagement and may be a source of support for families, especially if they have missed routine follow up due to hospitalisation following birth. A list of available services may be found on the NSW Health website [NSW Health Child and family health services](#)
- Local allied health or multidisciplinary services.

If referred to these services, or the child is likely to present for assistance, the service should be included in the communication with SCHN about discharge planning and receive documentation about the child's health status, with updates forwarded as required.

Follow up appointments (planned)

Planned follow up appointments:

- Should be arranged prior to discharge
- Should be timely, and if challenges with appropriate scheduling occur, the individual physicians should be made aware and alternative arrangements must be made
- Must have the importance of attendance, any required costs and associated tests (such as chest x-rays) explained to the family, and alternative arrangements made if concerns such as financial or transport challenges are flagged
- May include (as deemed relevant by the treating team, and be attended locally if appropriate):
 - Cardiologist
 - Watchlist surveillance (medical or nursing)
 - Cardiothoracic surgeon
 - GP
 - Aboriginal Health Service
 - Paediatrician
 - Other specialists
 - Allied health teams
 - Grace Centre for Newborn Care Acute Review Clinic
 - Routine post discharge phone calls

Considerations for certain patient cohorts

High risk children eligible for the watch list

Children with conditions that require high level surveillance in the community as identified by their treating cardiologist are added to a database to track progress by senior cardiac nursing staff.

These may include children with:

- single ventricle anatomy
- shunts (Blalock-Taussig or Sano)
- stents
- pulmonary artery bands

Oversight of the database is allocated to senior cardiac nursing staff and any concerns post-discharge are to be escalated to cardiology medical staff as required. Depending on the child's condition and location, monitoring may be undertaken in person at HCfC or by a local nominated proxy. This should be confirmed by the treating cardiologist and factored in early

into the discharge planning process to facilitate parental and local staff education (if required).

Prior to discharge, the family require specific education about their child's cardiac condition and how to identify if their child requires review. This will be attended by the senior cardiac nurse overseeing the child's care and they will require completion of Appendix A - Discharge Information for parents/carers of infants with shunt dependent circulations, with copies provided to the parents.

If a local service has agreed to complete reviews, or may be where the child presents if unwell, they require Appendix B - Outpatient surveillance of neonate/infants with shunt dependent circulations – staff information, along with the most recent discharge summary and any other care or escalation plans.

Monitoring Schedule

The child's initial review must occur within 72 hours of discharge. Ongoing review timeframes to be determined as per plan of care. As a general guideline these reviews will occur weekly or fortnightly with HCFC CNC/S, local paediatric ambulatory or child and family health teams, paediatrician or their GP.

Each review must include:

- Oxygen saturation monitoring
- Weight assessment
- Feeding & nutrition review
- General physical assessment (including wound if relevant)
- Escalation of care and medical review (only if required)
- Documentation of visit in child's medical record (SCHN eMR and relevant local documentation processes if attended close to home)
- An update for the surgeon/cardiologist prior to next follow up, or when required

If the review is attended by staff not affiliated with the HCFC, the results must be relayed to the cardiac nursing team at the time of, or following the review, for transcription into the SCHN eMR. Any concerns must be relayed to the cardiac nursing team (in the first instance), or the cardiologist in the event escalation of management is required.

Children post heart transplant

As well as routine discharge planning, extra consideration needs to be given to patients and their families following heart transplant. This includes information on immunosuppression and regular surveillance. For details see [Heart Transplantation at CHW](#) Practice Guideline

Regional/remote considerations

- Consideration should be given to remaining close to SCHN in the initial discharge period (eg. at RMH) if advised by the cardiology team
- Medical staff review should be within 2 weeks of discharge if the child is regionally based

- Service capacity for primary health care follow-up (e.g. GP, Paediatrician) due to availability and access needs must be determined prior to discharge in the event that alternative arrangements need to be made
- Additional planning is required for the likelihood of deterioration because presenting straight to SCHN may not be a viable option for all of this patient cohort
- Care and follow-up closer to home should be considered when possible. If not appropriate or if it is deemed unsafe, the plan must be communicated clearly to the family to ensure compliance with follow-up

Immunisation considerations

Children with cardiac conditions may have a number of indications for changes to the routine immunisation schedule. These may include:

- Prematurity
- Low birth weight
- Risk of respiratory infections
- Being Aboriginal and/or Torres Strait Islander
- Receipt of blood products
- Critical illness or surgery
- Immunosuppressed

[The Australian Immunisation Handbook](#) outlines authorised schedule changes and catch up plans⁶.

All children should have their vaccination status checked prior to their discharge. Any anticipated alterations (such as delaying until cardiothoracic surgeon follow-up appointment) or extra doses required must be identified prior to discharge, clearly documented and parents and relevant teams informed. If clinically appropriate, catch-up immunisations may be given before going home. Alert cards highlighting the earliest date next immunisations can be given may be provided as a prompt for families.

References

1. Crowe, S., et al. (2016). "Death and Emergency Readmission of Infants Discharged After Interventions for Congenital Heart Disease: A National Study of 7643 Infants to Inform Service Improvement." Journal of the American Heart Association 5(5): 20.
2. Carlson, L., et al. (2022). "Digital solution for follow-up in congenital cardiac surgery." Cardiology in the Young 32(7): 1032-1040.
3. Berry, A. E., et al. (2021). "Variables Prevalent Among Early Unplanned Readmissions in Infants Following Congenital Heart Surgery." Pediatric Cardiology 42(6): 1449-1456.
4. Simeone, S., et al. (2018). "The lived experience of parents whose children discharged to home after cardiac surgery for congenital heart disease." Acta Bio-Medica de l'Ateneo Parmense 89(4-S): 71-77.
5. Gaskin, K. L., et al. (2016). "Parents' preparedness for their infants' discharge following first-stage cardiac surgery: development of a parental early warning tool." Cardiology in the Young 26(7): 1414-1424.
6. Australian Technical Advisory Group on Immunisation (ATAGI). Australian Immunisation Handbook, Australian Government Department of Health and Aged Care, Canberra, 2022, <https://immunisationhandbook.health.gov.au/>

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Appendices

Appendix A: Discharge Information for parents/carers of infants with shunt dependent circulations

As you are aware your baby has _____ . This condition means that your baby will need further heart operations and regular follow up by both your cardiologist and local healthcare team.

In preparation for going home the following information will assist you in identifying is your baby is becoming unwell and what action to take.

If your child displays any of the following signs:

- Significant changes in feeding pattern/poor appetite
- Increased sleeping/ tiredness
- Increased sweating and/or cool clammy skin
- Puffy eyelids
- Working harder to breathe/effort and new cough
- Change in skin colour, especially around the mouth and nose lasting more than a few minutes
- Not as many wet nappies as usual
- Diarrhoea and/or vomiting
- Temperature above 38 degrees C
- Baby doesn't settle as well (irritable/constant crying)
- Changes in scar: redness, oozing, swelling or opening

Between 8 am and 4pm Monday to Friday (except public holidays) please phone
- The Cardiac Nursing Team on 98453246

If they are not available or it is out of hours please present to your closest Emergency Department.

If your child displays any of the following signs:

- Persistent grunting, noisy breathing and/or struggling to breathe
- Floppy and unresponsive baby. Unable to wake baby up
- Prolonged changes in your baby's skin colour – more blue/grey than usual, cool to touch, waxy/pale looking
- If your baby is choking

Please phone 000

Remember to take this document and your discharge letter with you every time you see your local health care team or go to the Emergency Department.

Important contact numbers	
The Children's Hospital at Westmead Switchboard	9845 0000
Cardiac Nursing Team (Mon-Fri 0800-1600)	9845 3246
Local emergency contact	
Important contact names	
Paediatric Cardiologist	
Paediatrician	
GP	

Appendix B: Outpatient surveillance of neonate/infants with shunt dependant circulations – staff information

Important Information for your GP/Doctors/Nurse at your local hospital

_____ has _____ and has had xx at The Children's Hospital at Westmead on _____.

_____ will need further operations over the coming months. Occasionally, between the first and second stages of surgery the circulation can become unstable and for this reason we would like to be kept informed of any contact they have with health care professionals.

The family is aware to seek assistance for the following:

- Significant changes in feeding pattern/poor appetite
- Increased sleeping/ tiredness
- Increased sweating and/or cool clammy skin
- Puffy eyelids
- Working harder to breathe/effort and new cough
- Change in skin colour, especially around the mouth and nose lasting more than a few minutes
- Not as many wet nappies as usual
- Diarrhoea and/or vomiting
- Temperature above 38 degrees C
- Baby doesn't settle as well (irritable/constant crying)
- Changes in scar: redness, oozing, swelling or opening

If you have been asked to perform regular surveillance monitoring of this child it should include the following:

- Oxygen saturation monitoring
- Weight assessment
- Feeding review
- General physical assessment (including wound if relevant)
- Escalation of care if required

Important contact numbers	
The Children's Hospital at Westmead Switchboard	9845 0000
Cardiac Nursing Team (Mon-Fri 0800-1600) (including cardiothoracic nurse practitioner)	9845 3246 Schn-cardiacnc@health.nsw.gov.au
On call paediatric cardiology fellow (24/7)	Via switch 9845 0000
On call paediatric cardiothoracic fellow (24/7)	Via switch 9845 0000
Important contact names	
Paediatric Cardiologist	
Paediatrician	
GP	

Please send though the results to the Cardiac Nursing Team at the time of, or following review, for review by the cardiac team and transcription into the SCHN eMR.

- For general questions please contact the cardiac nursing team.
- For urgent medical concerns or escalation of care please contact the on call cardiology fellow/cardiologist and follow local escalation management.
- For concerns about a wound please contact the cardiothoracic fellow or nurse practitioner.