

# CYSTIC FIBROSIS AND NON-CF BRONCHIECTASIS: HOSPITAL IN THE HOME MANAGEMENT (HITH) PRACTICE GUIDELINE<sup>®</sup>

## DOCUMENT SUMMARY/KEY POINTS

- Children with Cystic Fibrosis (CF) or Non-CF Bronchiectasis who require intravenous (IV) antibiotic therapy and physiotherapy for a respiratory exacerbation can safely and effectively be treated at home with Hospital in the Home (HITH)
- The following Practice Guideline identifies:
  - Criteria for admission to HITH
  - Exclusion criteria for HITH
  - HITH Models of Care
  - HITH Treatment Plan
    - Nursing
    - Physiotherapy
    - Dietetic and Social Work

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.

<b>Approved by:</b>	SCHN Policy Procedure and Guideline Committee	
<b>Date Effective:</b>	1 <sup>st</sup> October 2019	<b>Review Period:</b> 3 years
<b>Team Leader:</b>	Clinical Nurse Specialist & Physiotherapist	<b>Area/Dept:</b> Hospital in the Home (HiTH)

## CHANGE SUMMARY

- New Models of Care added
- Eligibility criteria updated
- Infection control added

## READ ACKNOWLEDGEMENT

- HITH staff, Respiratory multidisciplinary team and Patient Flow should read and acknowledge they understand the contents of this document.

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## 1 Introduction

The Hospital in the Home (HITH) Service provides acute hospital substitution or hospital avoidance for children who are known to the SCHN.

Children with Cystic Fibrosis or Non-CF Bronchiectasis who require intravenous (IV) antibiotic therapy and physiotherapy for an exacerbation of their lung disease can safely and effectively be treated at home with the HITH service.

## 2 HITH Admission Criteria

### 2.1 Admission criteria for HITH

- Patient is clinically stable to leave hospital but still requiring acute or post-acute care
- Admitting Medical Officer's (AMO) approval for admission/transfer to HITH
- Consent received from parents/carers for admission to HITH
- Presence of a carer 18 years or over during home visits
- Carer competency to manage the child's condition
- Phone access to parents
- Mutual recognition of identified goals of care (parents and clinical team)
- Medicare eligibility or a reciprocal agreement (HITH currently does not have an agreement with Private Health Funds therefore all HITH patients must be categorised as Medicare unless Executive approval is given for non-Medicare eligible patients)
- Family have access to transport
- No issues identified that can compromise staff safety during home visits
- Patient lives (or can be seen somewhere appropriate) within an approximate 30-35 kilometre radius from SCH or CHW. Care by Parent or Ronald McDonald House can be used as alternatives therefore location is not solely an exclusion.

All patients with CF or Non-CF bronchiectasis who meet the above HITH admission criteria are eligible for HITH management following consultation with the respiratory team unless they meet the exclusion criteria outlined below.

### 2.2 Exclusion Criteria for HITH

- Significant social issues or risk of non-compliance with treatment plan i.e. high risk for not attending mid/end of admission reviews, poor adherence with independent physio sessions or other treatments.
- TDS physio required
- Medically unstable / requiring oxygen, daytime NIV or hospital only equipment i.e. Metaneb
- Requiring significant input from other members of MDT that can't be provided through HITH

- Requiring overnight NG feeds and family does not have capacity to manage / monitor appropriately
- Does not meet criteria of Home Risk Assessment (HRA)

### 3 HITH Admission Process

- Referrals are to be discussed with the Ambulatory CNS2 and are to be completed electronically via powerchart (HITH referral for transfer)
- Medications that are required to be given by HITH nurses are to be ordered on the MAR
- Antibiotics to be administered via an infuser need to be ordered 48hrs prior to transfer home
- HITH team will meet with the family in the ward to discuss planned treatment, complete consent and HRA. If after hours, the HITH team will liaise with the family over the phone.

### 4 Models of Care

A patient may be admitted to HITH via the following models:

#### 4.1 Direct admission to HITH

- If medically stable as determined by the consultant / treating team, children can be directly referred to HITH for their entire treatment plan as a complete hospital avoidance
- Referral made via powerchart (HITH referral for transfer) stating treatment required, IV access, duration of treatment and follow up arrangements.
- Patients are referred to HITH by the consultant or delegate, CF CNC or Physio.
- The patient presents to the hospital for either access of existing CVAD/Port or insertion of an access line, review with the team, Pulmonary Function Test and any other required tests as determined by the treating team
- Direct admission to HITH will occur after the above is undertaken

#### 4.2 Transfer following inpatient stay

- Patients who are admitted to an inpatient ward and meet the above criteria are eligible for transfer to HITH to complete the rest of their planned treatment
- Patient transferred from inpatient ward to HITH ward on inpatient Patient Management System.
- Patients requiring overnight NG feeds can be transferred to HITH once the CF Dietitian / respiratory team have agreed the family is able to manage feeds at home appropriately. This can be from day 3 of admission as per dietetic reviews.

### 4.3 Care by Parent

- Depending on the child's clinical status as determined by the consultant / treating team they may be directly admitted to HITH through "Care by Parent" (CBP). This model is a good option to consider for patients who live out of geographical area. The child and accompanying parent/carer reside in CBP and receive daily or BD treatment as provided by HITH nurses and physiotherapists.
- Patients requiring overnight NG feeds for the first time can start their feeds after education with dietitian and HITH nurses on day of admission and day two, with the plan to start overnight feeds on night two. Some patients may be able to start night one if appropriate education has been provided on day of admission.

## 5 Treatment Plan

### 5.1 Aim of treatment

The aim of antibiotic therapy and physiotherapy for an acute exacerbation in a patient with CF or Non-CF Bronchiectasis is to decrease the bacteria, inflammation and mucus present in the airways.

Length of treatment is determined by improved Pulmonary Function Test's (PFT's) and a return to the patient's baseline pulmonary status.

Another aim of treatment is to ensure patients have adequate nutrition and calories to achieve optimal growth. The need for further review of nutrition and intervention throughout the HITH admission is determined by the CF dietitian and consultant.

### 5.2 HITH Treatment Plan – Nursing

- Patients are visited daily or twice daily (BD) at home or at school for a treatment time as determined by the treating team
- Nursing care can include but is not limited to:
  - Documentation of observations as per SPO chart
  - Weekly weight
  - Daily or BD administration of intravenous antibiotics
  - Care of CVAD or IVAD
  - Documentation and communication with CF team regarding any change in condition or new symptoms, including gastrointestinal symptoms (e.g. abdominal pain, change in bowel habits or loss of appetite)
  - Discuss and record oral intake including any nutritional supplements
  - Support and guidance with nasogastric or gastrostomy feeds and use of feeding pumps if required.

- Ensure family is monitoring BSL and forwarding information to the relevant medical team (if required)
- Management of IV antibiotics
  - IV antibiotics are managed in accordance with the HITH IV antibiotic guideline
  - Patients will require blood level assessments for Tobramycin in line with CHW and SCH protocols

### 5.3 HITH Treatment Plan - Physiotherapy

Physiotherapy plays a key part in the overall management of CF and Non CF-Bronchiectasis. Airway clearance therapy, exercise and inhalation therapy are the cornerstones of treatment and are associated with improved long term outcomes. Physiotherapists are also involved in musculoskeletal management, care of complex patients, infection control, education of patients and their families, promotion of self-management, transition to adult care, pre- and post- transplant care and end-of-life care.

#### ***Physiotherapy Models of care***

- In combination with IV antibiotics and nursing care
- Physiotherapy-only after IV antibiotic course has ceased to optimise physio management in the home environment
- Physiotherapy hospital avoidance through early intervention
- Care by Parent model

HITH physiotherapy is offered in three models of care depending on the patient's requirements and staff capacity:

1. Twice daily face to face sessions for airway clearance / exercise
2. Once daily face to face session– with the patient undertaking the second airway clearance / exercise session under supervision of family
3. Once daily face to face session and once daily telehealth session
4. Once or twice daily telehealth sessions for patients living out of area

#### ***Airway Clearance and Exercise***

Airway clearance techniques (ACT's) vary between patients. The most effective and appropriate method is determined by the treating therapist in conjunction with the referring physiotherapist and with the patient. In some cases (e.g. post sinus surgery, pneumothorax, haemoptysis) guidance from the medical team is sought in regards to the commencement and cessation of therapies. Exercise is also an important component of physiotherapy and is incorporated into the HITH physiotherapy model.

Airway clearance is often timed with inhaled therapies to optimise the effectiveness of clearance and of the inhaled agents.

Information on the different airway clearance techniques, inhaled therapies and exercise used in this population can be found in the [useful resources](#) section below.

## **Communication and Continuity of Care**

The HITH physiotherapists will receive handover from the treating ward physiotherapist / CF physiotherapist. There is regular communication between the HITH and CF physiotherapists, and when able a HITH physio will attend the CF meetings. Urgent matters or acute changes to the patient's condition will be directly communicated to the CF medical team.

## **Useful Resources**

SCHN Randwick HITH staff: see hospital specific guidelines in the CF manual. Appendix 1

SCHN Westmead HITH staff: see physiotherapy section of CF manual, Appendix 1.

All SCHN HITH staff:

- Physiotherapy for Cystic Fibrosis in Australia and New Zealand: Practice Guideline (2016): [https://www.thoracic.org.au/journal-publishing/command/download\\_file/id/32/filename/TSANZ-Physio-Guidelines-2016-web.pdf](https://www.thoracic.org.au/journal-publishing/command/download_file/id/32/filename/TSANZ-Physio-Guidelines-2016-web.pdf)
- Physiotherapy for Cystic Fibrosis in Australia: A Consensus statement: [https://www.thoracic.org.au/journal-publishing/command/download\\_file/id/19/filename/Physiotherapy\\_for\\_Cystic\\_Fibrosis\\_in\\_Australia\\_A\\_Consensus\\_Statement.pdf](https://www.thoracic.org.au/journal-publishing/command/download_file/id/19/filename/Physiotherapy_for_Cystic_Fibrosis_in_Australia_A_Consensus_Statement.pdf)

## **5.4 Dietetics and Social Work**

The HITH service has both Dietetic and Social Work input available

### **Social work**

To support continuity of psychosocial care of children, young people and their families, the Social Worker assigned to Cystic Fibrosis will continue to manage patients within HITH wherever possible.

The CF social worker will liaise with the social worker in HITH as required regarding children and young people with CF referred to HITH, considering a home visit where appropriate.

### **Dietetics**

To support continuity of nutritional care for children, young people and their families, the Dietician assigned to Cystic Fibrosis will continue to manage patients within HITH wherever possible.

The CF Dietician will liaise with the HITH Dietician as required regarding workforce capacity to ensure optimal nutritional management for children and young people with CF referred to HITH, considering a home visit where appropriate.

Optimising growth and nutrition for children with CF has been shown to have a positive influence on lung function and survival.

- A BMI of >50th centile has been associated with a lower risk of morbidity and mortality.
- A correlation exists between the BMI centile and lung function in patients with CF.

Nutrition also plays an important role in the prevention and/or management of a number of CF comorbidities including CF related diabetes (CFRD), bone health, CF liver disease



(CFLD) and other gastrointestinal manifestations i.e. constipation, Distal Intestinal Obstruction Syndrome (DIOS) and gastro esophageal reflux.

CF dietary recommendations differ from the dietary guidelines for the general population. The main differences are that the CF diet should be high in:

- Energy - 110-200% of the recommended dietary intake (RDI) for energy compared to the healthy population.
- Fat – the most energy dense macronutrient providing more energy per gram than the other macronutrients
- Salt – specific dosing recommendations are lacking but in practice, 500-1000mg sodium per day is recommended during infancy and this increases with age to 6000mg per day for adolescents and adults.

### Useful Resources

More information regarding the nutrition management for people with CF is available in the Nutrition Guidelines for Cystic Fibrosis in Australia & New Zealand (2017).

- Available for download: <https://www.thoracic.org.au/documents/item/1045>

## 6 Infection Control

The below tier system has been developed for infection control for the CF population and should be followed by all HITH staff:

Tier One	Tier Two	Tier Three
No pathogens identified Sensitive Staph Sensitive pseudomonas Haemophilus Influenzae Any micro-organism not identified in tier 2 or 3	MRSA NTM mycobacteria (except Abscesses) ESBL VRE Acinetobacter baumannii Other emerging pathogens demonstrating high levels of resistance	Burkholderia cepacia M Abscessus Multi resistant pseudomonas (as identified by microbiology on an individual patient basis) Pandora Other emerging pathogens demonstrating high levels of antibiotic resistance and virulence, clonal strains as determined by ID and microbiology)
Staff involved in procedures promoting cough / collection of mucous to wear gown and gloves (mask / goggles at user discretion)	<b>All HITH staff to wear gown, gloves and mask Goggles at user discretion</b>	<b>All HITH staff to wear gown, gloves and mask Goggles at user discretion</b>

As well as wearing the appropriate PPE, staff must ensure they are limiting the equipment taken into homes and are cleaning all equipment appropriately, including bags, laptops, stethoscopes, saturation monitors, thermometers etc.

Planning of patient visits should take into consideration infection status ie. Tier 3 patients last if possible.

## 7 Parent Education

Education begins at admission and continues throughout duration of treatment. Negotiation of care is necessary to provide family centred care. Nurses and Physiotherapists will provide ongoing education throughout the HITH admission, liaising with the MDT as required.

## 8 Discharge

- Patient attends hospital for medical review and end of treatment lung function at the discretion of the team. Phone consult and or telehealth session may also be utilised in place of a formal consult.
- Ongoing Physiotherapy / Treatment Plan is discussed with patient and family
- Remove CVAD or hep-lock IVAD as per hospital policy
- Complete documentation
- Discharge from HITH

## Appendix 1: SCHN Randwick and Westmead useful resources

### SCHN Westmead

- CF Manual - CHW: <http://webapps.schn.health.nsw.gov.au/epolicy/policy/3180>

### SCHN Randwick

- CF Management Guidelines: SCH:  
<http://webapps.schn.health.nsw.gov.au/epolicy/policy/3657>

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