4. Admission to hospital

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4. Admission to hospital

There are several reasons why a child with cystic fibrosis is admitted to hospital, which include the following:

- Education of the family at time of new diagnosis.
- Specific investigations *e.g.* bronchoscopy, pH study.
- Any deterioration in clinical condition that fails to respond to out-patient measures *e.g.* chest exacerbation, DIOS, CFRD.
- Elective 3 monthly admissions for IV antibiotics (usually 2 weeks).
- Elective 1 monthly admission for IV methylprednisolone (usually 3 nights).
- Elective operations *e.g.* portacath or gastrostomy insertion, ENT or dental operation.
- A complex presentation of a child with CF *i.e.* symptoms and the effect that this has on their daily functioning which would warrant very close observation for a period of time by the CF MDT.

4.1 Admitting the child

Pre-admission

If an admission date is certain (unlikely to be until day before) then it may be possible to pre-order the IV antibiotics using the CIVAS (Centralised Intravenous Additives Service); this is especially useful if the admission is on a weekend.

Occasionally a child and / or their family have very particular needs (*e.g.* the child has autistic spectrum disorder) or have had a very challenging previous experience with an inpatient admission at RBH or another hospital. In these circumstances a plan ('Pre-admission Plan') is constructed which serves to document the needs and/or expectations of the child and their family and of the inpatient CF services at RBH to promote a successful admission.

We also have Pre-admission form to be filled out by the person arranging the admission. This gives guidance to what IV antibiotics should be used, and any special instructions for specific investigations to be carried out (appendix 3).

Clerking

On admission, the reason for hospital attendance must be identified, and documented clearly in the integrated care pathway (ICP), which is available on the intranet and on Rose ward. All subsequent documentation for that admission is entered on continuation sheets as part of the ICP. Medical admission paperwork covers the following information.

- **Allergies** – Any allergies, particularly to drugs should be recorded both in the notes and on the drug chart, the type of reaction experienced should also be included (*e.g.* rash, anaphylaxis). Check it is also written on the front cover of the notes.
- **Reason for admission** (tick box).
- **Current CF complications** (tick box).
- **Past history of ABPA** - (if applicable) should be recorded with most recent total & aspergillus-specific IgE, together with maximum values in the past year for comparison.
- **Current medications** -
  - A full drug history including the types of inhaler used *e.g.* turbohaler, MDI with spacer (with or without a mask) etc., is mandatory. Inhaler technique must always be checked.
  - Write inhaled steroids doses in mcg **not** number of puffs.
  - If a patient is on oral steroids, record the starting date and dose/kg/day.
  - Drug doses are often recorded in the last clinic letter **but** should be checked directly with the patient or their parents before recording and prescribing them.
  - Check whether there have been problems with aminoglycoside levels in the past.
  - **Inhaled antibiotics**
    - **No-one can receive a nebulised drug if it is being given intravenously**.
    - If they are on IV tobramycin they receive nebulised colistin (even if it is the month they would have been due nebulised tobramycin)
    - If on IV colistin they receive nebulised tobramycin rather than nebulised colistin. If they have not had nebulised tobramycin before, then they have no nebuliser whilst in hospital.
    - The same applies to dry powder inhalers.
  - Drug histories are confirmed by a pharmacist or pharmacy technician at the earliest opportunity within pharmacy opening hours.
- **Date of last admission.**
- **Last sputum/cough swab obtained.**
- **Is annual assessment due soon?** If so, investigations should be arranged during admission (see section 3.2).
- **Best FEV_1% and FVC% in last year.** Absolute (litres) as well as % predicted values must be recorded. These can be found from clinic letters/EPR and the lung function trend over time is available on the T drive\Paediatrics\Lung Function Trends.
- **Documented concerns about weight and height.** Electronic longitudinal growth charts can be found on EDM. Growth trend over time is available with the lung function on the T drive\Paediatrics\Lung Function Trends. A paper chart for weight during the admission is kept in the notes.
- **Recent microbiology** – growths and sensitivity/resistance. The most recent positive sputum culture result should be documented with full sensitivities. Certain bacteria like *B. cepacia* complex, MRSA and *M. abscessus* complex require specific action with regards to therapy and isolation from other CF patients.
- **Respiratory system** - cough, wheeze, sputum production (quantity, frequency, colour, consistency), haemoptysis, chest pain/tightness, dyspnoea, exercise tolerance.

- **Gastrointestinal system** - appetite, heartburn, water brash, funny taste in mouth, nausea, vomiting, frequency bowels are opened, quality of stool, abdominal pain, rectal bleeding, weight loss, calorie supplements, gastrostomy/NG tube feeds (amount, type, nights per week).
- **Genito-urinary system** - thirst, urinary frequency, polyuria, nocturia.
- **ENT** - nasal obstruction, epistaxis, rhinitis, sense of smell & taste.
- **Neuromuscular** - headache, paraesthesia, muscle weakness, joint pains, backache.
- **Pain**.
- A full **social history** should be taken paying particular attention to school attendance, housing, pets and active/passive smoking. Also, whether social care has been involved in supporting the family either currently or in the past, and/or whether the family have worked with psychology services in the past and/or currently.

Consent for use of IV aminoglycosides.
See section 6.2a 6 IIIe. All parents/children who will be receiving IV aminoglycoside antibiotics should be given time to read the dedicated **written consent form** (see appendix 4) before discussing the issues with the medical team. Should they consent, this should be signed in the presence of the medical team and filed in the patient notes. Should the parent/child not consent, a decision on an alternative antibiotic regimen should be made by the SpR or consultant for the ward. Consent must be taken at the start of admission before any IV antibiotics are given. Do not forget to start N-acetylcysteine (NAC) when prescribing IV aminoglycosides (see section 6.2a 6 IIIe).

Examination

Examination findings should be recorded in the standard way according to systems. Do not forget the ENT system, particularly nasal polyps. Blood pressure is mandatory on all patients, with particular attention paid to those on oral steroids. Check presence of glycosuria in all patients.

All children should have the following observations recorded:

- Weight (kg & centiles) in underwear when aged 5 or under, and light clothing aged over 5. If the child has been weighed fully clothed, they must be weighed again. Growth chart should be in notes and on EDM.
- Height (cms & centiles).
- Head circumference in <1 year olds.
- Temperature, heart rate, respiratory rate.
- Oxygen saturation in air or oxygen (include O_2 requirement).

4.2 Investigations

All children old enough will have **pulmonary function tests** (spirometry) performed following admission. If the child has been admitted from clinic, these will already have been performed and do not need repeating**. This must be performed within 24 hours of admission, INCLUDING at weekends** (use the ward spirometer).

Admission bloods. These are generally performed at the same time as the first aminoglycoside level (pre-2nd dose) unless they are needed immediately – this is to minimise exposure to needles. For blood sampling, try to use veins on the back of the hand so that antecubital fossae veins can be reserved for long lines. For all infants and children, we use anaesthetic cream (EMLA) applied under an occlusive dressing for 60 minutes (will last up to 5 hours). Avoid Ametop due to the high frequency of allergic reactions, especially in atopic children (it may be tried if there has been a previous reaction to EMLA). You can also use Cryogesic spray (ethyl chloride) which is used immediately before the procedure but is only suitable for very short procedures (some children prefer this). Please always check with the child and family if coping with bloods and/or needles has been challenging in the past – if so there is likely to be an existing support plan for coping with blood tests on the patient's Electronic Record. If there is no existing plan or additional support to the plan is required, please discuss this with a play specialist or a clinical psychologist in advance for help and support, and if necessary, defer testing unless it is absolutely urgent.

If the child is due annual review (usually within 3 months after birthday) within 3 months, make sure all annual review bloods are taken (add immunoglobulins, serum vitamins, clotting) on day 2 when aminoglycoside levels are taken - see list in section 3.2. Remember to arrange other tests if required - chest x-ray, liver ultrasound or DEXA scan, and arrange formal lung function and lung clearance index for the final week of the admission.

The list of blood tests (with the appropriate bottles) required on admission is given below:

• **Full blood count (FBC)**	**EDTA (pink) 1ml**	***Haematology***
• **Urea & electrolytes**	**serum (brown)**	
• **Liver function tests**	**serum (brown)**	***Biochemistry***
• **Calcium, magnesium, phosphate**	**serum (brown)**	**3 ml minimum**
• **Glucose**	**serum (brown)**	**(alternatively**
• **HbA_{1c}**	**serum (brown)**	**lab will accept**
• **Total IgE**	**serum (brown)**	**clotted blood)**
• **Aspergillus specific IgE**	**serum (brown)**	
• **CRP**	**serum (brown)**	
• **Aspergillus IgG**	**serum (brown) - 1ml**	***Virology/Immunology***

A **chest x-ray** is only performed if clinically indicated *e.g*. to exclude pneumothorax or for annual assessment. They are **not** performed to check long line position.
Sputum/cough swab must be sent to microbiology within 24 hours of admission.
Nasopharyngeal aspirate for viral detection is sometimes indicated (usually <1 year old).
Urinalysis must be performed on admission especially if the child is on oral steroids or if recent history of weight loss.

Further investigations during admission:
- Twice weekly sputum/cough swab, and at point of discharge.
- Daily SpO_2 unless initial one >95%.
- Twice weekly spirometry (Monday, Thursday).
- Twice weekly weight (Tues, Fri): aged 5 or less in their underwear, those older than 5 in light clothing.
- Daily BP and urinalysis if on oral steroids.

- Overnight SpO_2 study (Masimo) early in admission, especially if FEV_1<50% or resting SpO_2 <92% (see section 6.16).

Drug monitoring – MUST NOT BE TAKEN FROM LINES/PORT

Aminoglycosides (Tobramycin, Amikacin)

- Pre-dose levels 23 hours after 1st dose (*i.e.* before 2nd IV dose). These are sent in a serum (brown) bottle to biochemistry. If in desired range, repeat 1 week later; and 1 week after that if having 3 weeks antibiotics. See section 6.2a, part 6.IIIg.
- Drug level timings should be prescribed on electronic drug chart at admission.

IV Polymyxins (Colistin)

- Once weekly U + Es.

Chloramphenicol

- 3-weekly WBC, so not routinely required unless having >2 week course.

Linezolid

- Weekly FBC (mandatory – see BNFc).

Itraconazole

- Monthly LFTs + drug level if indicated (*e.g.* an interacting drug is commenced, efficacy is not observed, or toxicity is suspected). See section 6.3a.

Posaconazole

- Monthly LFTs + drug level to be taken after at least 1 week of commencing therapy or dose changed, if an interacting drug is commenced efficacy is not observed, or toxicity is suspected. Take sample just before the next oral dose. See section 6.3.

Voriconazole

- Weekly LFTs for the first month then monthly thereafter + monthly U&Es + drug levels should be measured at least 3 days after commencing therapy or dose changes, if an interacting drug is commenced, efficacy is not observed, or toxicity is suspected. Take sample just before the next oral dose. See section 6.9.

4.3 Venous access & PICC/long line insertion

All children will require venous access for administration of IV antibiotics. If they have a portacath in-situ, the nursing staff will access the portacath with a gripper needle on the child's admission. Otherwise peripherally inserted central catheters (PICC) are our preferred method of access. There are occasions when a short cannula or peripherally inserted long line will be necessary. Long lines are usually inserted by the SpR but may be inserted by the SHO once they have been seen to have achieved competency under the supervision of an SpR.

PICC lines are inserted by the radiology department and doctor or nurse specialist arranging admission should sort this in advance of the admission.

- Fill in details on ICE (or access requests via EPR)
- Phone radiology 82326
- Email usually Bruce Barton (b.barton@rbht.nhs.uk) or Nelly Samchkuashvili (n.samchkuashvili@rbht.nhs.uk).

These lines are generally inserted under ultrasound guidance in the radiology department, assisted by the play team if necessary, but only Monday to Fridays 9-5. We try to avoid them being inserted under general anaesthesia. They do not need chest X-ray to confirm placement

unless specifically requested by the inserting professional. These PICC lines can often be safely used for blood taking during the admission (but NOT for drug levels when the drug is delivered through the line).

Whatever grade of doctor, **no more than three attempts of line insertion** should be tried before asking for additional support from colleagues. We understand from research and talking with our patients that the line insertion can often be the most challenging part of their admission. We also appreciate that if this feels challenging for the child/family this can often set the tone for a difficult admission, and future problems. As such, if children have reported that venous access may be difficult for them then please identify whether there is a support plan already in place on the child's electronic patient record or ask a play specialist and/or clinical psychologist for support (see below). Similarly, should 'therapeutic safe holding' (restraint) be deemed necessary for the insertion of a line for any child older than a toddler please ensure that a play specialist is informed and that strategies are employed to prevent and / or mitigate the necessity for this.

Some children will require sedation prior to PICC or long line insertion. In suitable children, **Entonox** (50% nitrous oxide / 50% oxygen) should be the first choice. Relevant contraindications are pneumothorax and intestinal obstruction. Please note that the patient should have an empty stomach prior to the procedure to reduce the likelihood of nausea and vomiting, they must be **nil by mouth for 1 hour** (we do not require 6 hour fasting) - see separate guideline for its use available on our intranet in Clinical Guidelines section. Entonox is not used by adult service due to risk and therefore any child or young person who uses it will need to learn to manage without by transition to adult CF service.

If **oral sedation** is required, it can be achieved after 30 minutes following administration of oral midazolam (0.5mg/kg, max 20mg) or after 15 minutes following **sublingual** midazolam (<10 yrs - 0.2 to 0.3 mg/kg, max 5 mg; 10 yrs or over is 6-7 mg dose). In accordance with the trust's sedation policy, all children having oral sedation need written consent and must be kept nil by mouth as follows -

- Bottle milk, solids - 6 hours
- Breast milk - 4 hours
- Clear fluids - 2 hours

Vein selection is made taking the needs/request of the patient (*e.g.* to try to access right arm if they are left handed) into account. Local topical anaesthesia should be offered (EMLA).

For long line insertion, we currently use Vygon Nutrilines which are 30 cms in length and available in 2 French (24 gauge inner lumen, 0.6mm external diameter) or 3 French (20 gauge inner lumen, 1 mm external diameter) sizes. As a general guide 2 French lines are suitable for infants and 3 French lines for those > 1 year old. Veins in the antecubital fossa are the preferred sites of insertion (preferably the side the child does not use for writing). Prior to insertion, measure the distance externally from the vein to where you wish the tip to lie (the medial end of the clavicle is the usual position for lines inserted in the antecubital fossa). We do not routinely x-ray these lines, but should the child have an x-ray for another reason (*e.g.* chest x-ray done to check position of pH probe), don't forget to check the position of the line.

The equipment required is:

- Long line (Vygon). Each pack contains: catheter x 1, splitting needle introducer x 1, 10 ml syringe x1, filter needle x1, fenestrated drape x 1

- Surgical gown
- Sterile gloves
- Disposable tourniquet
- Chlorhexidine (ChloraPrep) swab stick x 2
- Non-toothed forceps
- Sterile scissors
- Sterile gauze & Steristrips
- Clear sterile dressing (IV 10000 or Tegaderm depending on the child's allergy status)
- 10ml 0.9% saline
- 10mls heparin saline (10 units heparin/ml)
- 10ml syringe
- Green needle
- Bionector
- Bandage
- Biopatch

Position the patient in a comfortable position with the arm extended. Remove the anaesthetic cream and use a tourniquet. Wash hands and put on sterile gloves and gown. Flush the catheter with 0.9% saline to ensure that line is intact. This is a sterile technique so clean the skin with a chlorhexidine swab stick and then place a sterile drape around the arm/leg to create a sterile field. Veins in the antecubital fossa are the preferred sites of insertion (preferably the side the child does not use for writing). An assistant should tighten the tourniquet.

Cannulate the vein and observe for a backflow of blood. Hold the needle stationary and advance the sheath. Release the tourniquet and remove the needle. Thread the line using sterile toothless plastic forceps. If obstruction is encountered try: a) pull back a few millimetres then re-advance b) stroking the arm along the line of the vein, c) moving the arm from the shoulder, d) flushing whilst advancing the line. If any sign of swelling or pain occurs, then stop. Once inserted to the desired length, flush with sterile heparinised saline to confirm patency. Pull back the introducer sheath and split to remove from line. Apply gentle pressure to the exit site to stop bleeding. Secure the line in place initially with Steristrips over the insertion site. Cut a small piece of gauze on which to place the bevel of the long line prior to securing with a sterile clear dressing. Flush the Bionector and connect to the line before adding a biopatch to the insertion site and covering the whole dressing with a bandage.

If inserted without ultrasound control, do a CXR to check position (i.e. not gone too far - into the heart or up the neck). No need to do CXR when ultrasound confirmed position.

If insertion of a longline is unsuccessful, consider a short cannula while alternate means of access are considered so as not to delay the start of treatment. Anaesthetic teams can be very helpful particularly if central access is required. If IV access is becoming an issue for a patient, the discussion around portacath insertion should start.

Thrombophlebitis - there is some anecdotal evidence for the use of hydrocortisone in long lines complicated by thrombophlebitis. It is **NOT** suitable for blocked lines. It appears to be safe and can be repeated as necessary. The steroid dose is minimal so there should not be any steroid adverse effects. If it is going to work, it will usually do so after 24 hours.

1. Give IV antibiotics in the usual way.
2. Use 3 mg hydrocortisone made up to 3 mls (with 0.9% normal saline) into PICC line.
3. Leave in line until next dose of IV antibiotic.
4. Aspirate and flush line in the usual way prior to IV antibiotic.
5. Concurrently use 0.5% or 1 % hydrocortisone cream topically on arm (over erythematous area).

Taking bloods from portacaths has been associated with an increased risk of thrombosis, so generally we would try to avoid doing so. However, this must be carefully weighed against the potential benefits, particularly for needle phobic/aversive children. Regardless of this, blood aminoglycoside levels must NEVER be taken from portacaths or longlines.

Consider use of alteplase or urokinase if long line or portacath are blocked (see section 6.2d).

4.4 Procedural distress

Preparation and planning with the child and family is essential to understand how the CF team can best help them to cope with any invasive procedure. A play specialist is routinely offered to support all children. The following are some suggestions for managing an invasive procedure in all cases, and especially when you know that the child or adolescent is feeling very anxious:

- Ask what has helped previously if/when the child had a good experience.
- Talk to the parent/carer accompanying them about their role; *i.e*., do they themselves have any fears or anxieties about the procedure; who they want to come in to the room (often as few people as possible is most useful), who will hold the child, positioning the child, soothing the child and above all modelling calm themselves. In all preparatory conversations with the family, normalise any anxiety they express, and be empathic (*i.e*. "It's understandable you feel worried/scared/etc.", etc.).
- Encourage child to occupy themselves beforehand (gentle exercise, attend hospital school *i.e*. not to sit feeling anxious for an hour before).
- Encourage child to keep warm (not become chilly).
- Encourage child to drink a lot of fluids (to not become dehydrated) – unless nil by mouth.
- Give the child some choice *e.g*. which arm, who they want in the room, what they want to talk about, what distraction has worked in the past etc.
- Make an agreement with the child about how many attempts you will have and do not exceed it. This may mean that you have to take a break and try again later.
- Consider the timing of procedures, as far as possible keep to the agreed time and do not leave the child waiting beyond this.
- If at all possible do invasive procedures in a dedicated treatment room (not the child's cubicle/play room etc.).
- Make sure all equipment is ready before you get the child into the treatment room.
- Make sure that the child has been to the toilet and removed Tagaderm and EMLA prior to entering the treatment room to avoid delaying tactics.
- At annual assessment try to do bloods at the time that the child/family have indicated would be best for them - many children prefer to get the blood test done first.

- Consider who should carry out the procedure. If a child is already known to be highly distressed, they would benefit from an experienced and confident clinician undertaking the procedure.
- Discuss what reward the child will receive once the procedure is completed.
- Focus on (even small) signs of coping by the child, and praise accordingly.
- Set a time limit, a distressed child is unlikely to change their mind and agree to a procedure that they have been refusing for half an hour. Take a break, re-plan and try again if necessary.
- At the end of the attempt, (successful or not), praise even small signs of coping/trying that have been observed.
- Use of supportive holding (previously been known as restraint) warrants planning and agreement with the MDT and family unless the procedure is deemed urgent.

Reference - Good Practice Guidelines: Evidence-based guidelines for the management of invasive and/or distressing procedures with children. British Psychological Society March 2010.

4.5 Self-administration of Medicines

The Self Administration of Medicines (SAM) scheme is a means of preparing patients and their parents/carers for continuing care and discharge by ensuring that they have sufficient knowledge about their medicines and the practical skills to comply with their therapy. The SAM scheme encourages patients/parents/carers to take more responsibility for their own medicines whilst they are still inpatients. Another useful aspect of the SAM scheme is that it may alert healthcare staff to any problems the patient/parent/carer may have in adhering to the medicine regimen. It also helps to identify patients/parents/carers who may require additional support or other strategies to ensure adequate pharmaceutical care in the home. The SAM scheme is only intended to operate in the in-patient ward setting.

Full details are available on the intranet in the Clinical Guidelines section. Look up **'Medicines management policy for the self-administration of medicines in children'**, dated Nov 2018.

The SAM policy

All CF patients/parents/carers responsible for administering their own medicines at home are considered. The decision to is discussed with the CF multi-disciplinary team on the daily ward round and they are given the information sheets (intranet policy appendices 1 & 2). Signed consent is obtained (intranet policy appendix 4).

Exclusion criteria

- Patients <12 years or those not deemed capable following assessment may not administer drugs themselves. However, they may be included in the scheme if their parents/carers are assessed as competent and are resident with their child at all times.
- Parents who would benefit from further observation and/or education in use of the medications.
- Patients with unstable medication requirements.
- Patients/parents/carers who are unwilling to agree to participate.

- Patients/parents/carers who are clinically confused or who are expressing suicidal/self-harm tendencies. Those with a past history of drug or alcohol abuse may only be included with extra supervision.

Medications included in the scheme

- Medicines suitable for the SAM scheme are those the child was taking prior to admission, and those that will be continued on discharge.
- Intravenous medications are only self-administered when the patients/parents/carers are being trained to administer home intravenous antibiotics.
- Routine oral medications included pancreatic enzyme replacement, vitamins, antacids, long term antibiotics, ursodeoxycholic acid, laxatives.
- Routine inhaled medications included bronchodilators and corticosteroids, nebulised antibiotics, hypertonic saline and pulmozyme.
- We do not include intravenous antibiotics, controlled drugs nor post-operative pain infusions.

Assessment

The assessment of suitability to participate is carried out on admission by the child's nurse using the self-administration tool (intranet policy appendix 5). The patient is assigned to a SAM level (see below). The decision can be made later on in their stay if appropriate, and the initial assessment may also be obtained at an MDT pre-admission meeting.

Throughout the admission, the SAM level is reassessed by the nurse at the start of each shift (intranet policy appendix 6), as the patient's condition and level of supervision required may change. The pharmacist also checks the SAM level when checking the drug chart on their clinical round. If a parent/carer administering medicines is to be away from the hospital for a period of time, then the level of SAM is revised for that period.

Categories of drug administration responsibilities in the SAM scheme.

Level	Medicine administration	Medicine storage	Documenting on Medchart®
0	2 nurses	Nurse	2 nurses sign they have administered drug
1	Supervising nurse comes to patient & gives with patient/parent/carer	Nurse	Nurse signs patient on Level 1
2	Patient/parent/carer prompts nurse and give together	Nurse	Nurse signs patient on Level 2
3	Patient/parent/carer	Patient/parent/carer has access to drug locker	Nurse checks given by patient/parent/carer and signs 'patient on Level 3'

Other rules

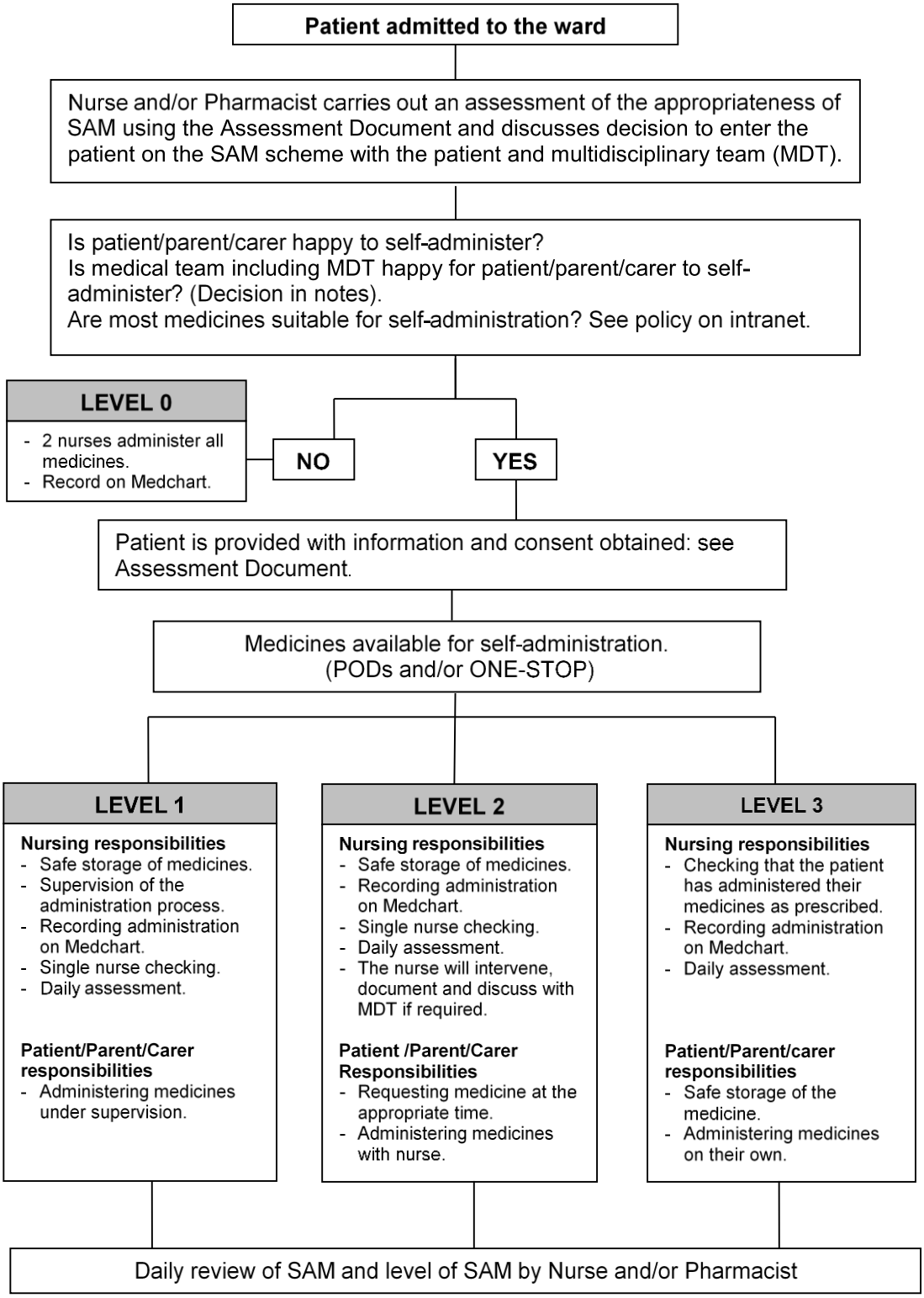
- Education / information is provided by the ward pharmacy team, but outside of normal working hours the nurse provides this information.
- All medicines to be self-administered must be prescribed on the in-patient medication chart. The chart is checked by the bedside nurse at regular intervals.
- The doctor should always discuss changes to the patient's medication therapy with the patient/parent/career and inform the nursing staff of prescription alterations; this must be documented.
- Patients/parents/carers are strongly encouraged to bring their current medication supplies from home.
- Medicines are stored in the Patient's Own Drug (POD) locker which has a 4-digit programmable security code that is changed for each admission. Some drugs are stored in the ward fridges (nebulised tobramycin, Pulmozyme).
- PODs should be checked/assessed by the paediatric pharmacy team prior to use.

Amendments to the original policy

The policy has been updated as a result of feedback and particularly when problems were highlighted in the Datix reporting (see below).

- The drug chart was initially a standard paper chart but later became part of electronic prescribing using Medchart®.
- Parents of patients on Level 3 document drug administration on their own paper chart (intranet policy appendix 7) which is also checked by the nurse. Nurse then documents this on Medchart®.
- Children can not start the admission on Level 3 but have to be on Level 2 for 24-48 hours before going on to Level 3.
- Level 3 cannot be started on a weekend.
- No PODs can be used until checked by pharmacy for condition and expiry date.

SAM pathway


Patient admitted to the ward
Nurse and/or Pharmacist carries out an assessment of the appropriateness of SAM using the Assessment Document and discusses decision to enter the patient on the SAM scheme with the patient and multidisciplinary team (MDT).
Is patient/parent/carer happy to self-administer?
Is medical team including MDT happy for patient/parent/carer to self-administer? (Decision in notes).
Are most medicines suitable for self-administration? See policy on intranet.
LEVEL 0
- 2 nurses administer all medicines.
- Record on Medchart.
NO
YES
Patient is provided with information and consent obtained: see Assessment Document.
Medicines available for self-administration.
(PODs and/or ONE-STOP)
LEVEL 1
Nursing responsibilities
- Safe storage of medicines.
- Supervision of the administration process.
- Recording administration on Medchart.
- Single nurse checking.
- Daily assessment.
Patient/Parent/Carer responsibilities
- Administering medicines under supervision.
LEVEL 2
Nursing responsibilities
- Safe storage of medicines.
- Recording administration on Medchart.
- Single nurse checking.
- Daily assessment.
- The nurse will intervene, document and discuss with MDT if required.
Patient /Parent/Carer Responsibilities
- Requesting medicine at the appropriate time.
- Administering medicines with nurse.
LEVEL 3
Nursing responsibilities
- Checking that the patient has administered their medicines as prescribed.
- Recording administration on Medchart.
- Daily assessment.
Patient/Parent/carer responsibilities
- Safe storage of the medicine.
- Administering medicines on their own.
Daily review of SAM and level of SAM by Nurse and/or Pharmacist

4.6 Discharge

All children should have a discharge letter done on Infoflex before discharge. There is a specific CF summary, which includes:

- The indication(s) and general conclusions about the admission, including which IV/oral antibiotics were administered.
- Weight on admission & discharge.
- Spirometry results (absolute and % predicted FEV_1 & FVC) on admission & discharge.
- All drugs on discharge – medications prescribed during the admission can be converted into discharge medications on Medchart®. The discharge prescription will then be sent through to Infoflex automatically.
- Ensure you fill in the section on Infoflex 'changes to medications and reasons for those changes'.
- Plan for review - when / where (this should usually by 4-6 weeks in CF clinic).
- Relevant results including positive microbiology.
- Pending results.
- Plan for tests necessary at home (*e.g*. WBC after 3 weeks if still on chloramphenicol)
- Date of next admission if elective (3 monthly IVABs, monthly IV methylprednisolone).
- Whether any extra plan needs to be made for further admissions to promote success (*e.g*. how successful invasive procedures were managed.

A copy of the discharge should be given to the parents/young person before discharge. A copy should be filed in the patient's notes by the ward clerical staff and published onto EPR.

4.7 Infection control

There are concerns about cross-infection between children with CF and these dictate that certain precautions need to be adhered to for all CF children. Segregation is in place in clinic and for in-patients, including in the school rooms etc. to minimise contact between CF patients. There are international guidelines and many families are anxious about cross-infection and we adhere to these views. Although our ward staff will support and reinforce these measures, we also strongly request that parents/carers help us to ensure that the children stick to the rules.

Generally, personal hygiene is emphasised, and children are encouraged to cover their mouths when coughing, then to wash their hands (front and back, and all spaces between). Hands should be washed regularly, and they must be taught not to share (with other children with chronic respiratory conditions) cups, cutlery and so forth.

The formal rules are summarised below:

1. Ward
    - Each patient will either be in a cubicle or in a bay with no other CF patient. No other CF patient or family member is permitted to be in another child's area at any time. **Children with CF should not enter any other CF child's room.**
    - We also separate children with CF from those with non-CF bronchiectasis/Primary Ciliary Dyskinesia.

- We discourage waiting around in corridors on the ward.
- No sitting or waiting around the nurses' station, including during the evenings.
- Disinfectant hand rub dispensers are inside each cubicle and each bay for use by staff, all children, families and visitors. USE THEM!
- Doctors **must** clean stethoscopes between patients. Ideally each CF patient will have a stethoscope that remains with them for the admission.
- Oxygen saturation finger probes are only used for a single patient.
- We have 7 cubicles with their own ensuite shower/toilet and a further one with its own toilet. Children may sometimes be in a bay in which case they use the shared ward bathroom/toilets. There will be medicated wipes available for parents to use if they wish before their child uses the bathroom.
- Physiotherapy is carried out in the children's own rooms only. When coughing up sputum, sputum pots with covers should be used, but if tissues are preferred, these should be disposed of immediately in a yellow bin bag.
- **Children infected with MRSA *Burkholderia cepacia* and *M abscessus* complex will stay inside their cubicles for the whole admission, although may spend time off the ward. Those with other forms of NTM (not abscessus) are treated the same as all CF patients.**
- When can patients be considered free of their organisms?
    - *B cepacia:* when they have **been free of the organism for 2 years, with at least 3 negative sputum or cough swabs or BAL samples per year.** Caution though if the original isolation was on sputum or BAL, and subsequent samples are cough swabs only.
    - MRSA: when they have had **3 negative swabs**. If MRSA on skin swabs only – follow Brompton hospital policy - see hospital policy on intranet (http://www.rbht.nhs.uk/about/policy-and-performance/mrsa-screening/ updated April 2016). If MRSA on sputum/cough swab/BAL – 3 negative respiratory samples, each one taken at least 1 week apart. Caution again as for *B.cepacia* re type of respiratory sample obtained.
    - *Non-tuberculous mycobacteria:* considered eradicated when they have had **4 negative BAL or sputum samples over 1 year since their 1st negative sample**. These samples must NOT be cough swabs. They are then considered free of the infection one year later i.e. 2 years after first negative swab. See also sections 3.1 and 6.2a part 6.VII.
- All patients will have a pre-op wash with specified detergent on the morning of any surgical intervention as per paediatric department practice to reduce post-operative infections.

2. Daily Plan
    - The daily plan is an integrated plan to be used by the patient, their family and the multidisciplinary team to timetable in appointments, investigations, treatments and school 'time slots'. This will help the children know what is planned for each day. The plan is kept by the beds.

3. School Room
    - We actively encourage attendance at our hospital school during inpatient stays for **all** patients. This not only serves to help the children to keep up with their studies but also helps them to feel as ordinary as possible during their time on Rose Ward. The hospital teaching staff are also able to look at each child's academic progress and,

with the permission of the child and/or their parents to share with the wider CF team any concerns about their learning. Teaching staff attend weekly ward rounds. If permission is given from child/parent, a record of engagement with hospital school is forwarded to the child's community school on discharge.

- The school room has 5 separated areas, 2 primary classrooms and 3 secondary classrooms.
- There will be one CF child in each area only at any time. CF pupils will have access to the schoolroom according to their daily plan.
- They will also be provided with school work from the teachers that they can continue with by their bed space.
- The relevant area is cleaned between patients.

4. Playroom

- The Play Team can support children from 0-16 years.
- Rules for the playroom are similar to rules for the school rooms.
- Two children with CF can now use the area at one time (one in main room, one in smaller playroom protected by glass walls/door). CF children will have access to the playroom according to their daily plan.
- Play sessions will be arranged by the play leaders at the bedside at times when other CF children are having their turn in the playroom.
- Most children with CF are asked (and prefer) to eat in their cubicles/away from the ward. Occasionally when a younger child is alone in their cubicle they will be encouraged to eat with some of the other patients (who do not have suppurative lung conditions) in the playroom.
- The relevant area is cleaned between patients.
- Playroom staff finish at 5pm and the playroom closes after supper.

5. Youth Club and School Holiday Program

- When these take place in the school room, the same rules apply as with standard school time**.**

6. School trips & other outings

- The school is committed to equal opportunities and all children will have access to school trips and outings during their admission, assuming they are well enough. We will have to manage transportation to ensure our guidelines are adhered to (i.e., we do not want several children with CF in one minibus). However more than one child with CF may be at the venue e.g. park, museum etc. at the same time. If parents do not want them to go, this will be respected but parents must enforce this.

Specific organisms

Particular care is necessary for children who are infected with -

- *Burkholderia cepacia* complex
- MRSA
- *Mycobacteria abscessus* complex
- Multi-resistant *Pseudomonas aeruginosa* (*e.g.* Liverpool Epidemic Strain)
- Respiratory viruses *e.g*. RSV or Influenza

Note, the above list does not include –

- *Stenotrophomonas maltophilia.* Patients with *S maltophilia* are no longer put in the same category as regards isolation as those with MRSA or *B cepacia*, as our experience and a number of publications have shown the organism is not a major problem in CF with regards to cross infection.
- Non-tuberculous mycobacteria (NTM) – that is **NOT** abscessus.

The risk of transmission is related to the level of intimacy of contact. The child is put into a room with private washing and toilet facilities. Items including toys and TVs should be kept in the room and washed when taken out before use by another child (this includes a stethoscope). Hands are washed and rubbed with DEB hand sanitiser before entering and leaving the room. Socialising with other children is discouraged and visiting other children in their rooms or being visited by other patients is not allowed. It is important not to stigmatise patients and the reasons for their relative isolation must be carefully explained. It is also important that children with *B cepacia,* and indeed any organism, realise that they do not pose an infection risk for healthy school friends.

Relatives of patients colonised with MRSA may also carry the organism. Nasal swabs will confirm this but are not routinely requested. Bactroban (mupirocin) nasal ointment may eliminate MRSA but recolonisation frequently occurs. In the event of an outbreak, staff with direct patient contact will be screened on the recommendation of the Infection Prevention and Control Team. Such screens will include nose and any skin lesions, particularly those on the hands. Screens will be coordinated by the Occupational Health Department. MRSA positive staff will be given appropriate treatment.

We would suggest though that GPs are asked to 'surface treat' (chlorhexidine skin washes and mupirocin) the child's family (parents & siblings). It is also helpful if the child's clothes and bedding are cleaned in a 60°C. wash during the eradication period.

Children with Burkholderia species and MRSA do not attend the CF clinics and like all our CF patients, do not mix with other CF children in the hospital school and play room. These patients will attend clinic held on the 2nd Friday of every month. Patients with MRSA will be booked into earlier time slots and those with *B cepacia* having later time slots. Due to the adult *B cepacia* clinic being held downstairs, patients will be advised to come in via Fulham Road entrance and go straight up the stairs and through physiotherapy into clinic. The HCA/Nurse will take prescriptions down to pharmacy, so they do not mix with patients waiting downstairs.

Segregation clinics

- Clinic appointment letters give a specific appointment time, and this is now crucial. It is very important that these times are kept to, so that the clinics run smoothly. If patients arrive early, we will have to ask them to leave the clinic area until the allotted time unless a clinic room happens to be available. We will then contact them on a mobile phone if the room becomes free early. If they are late for the appointment, they may have to wait until the end of clinic to be seen. These clinics are very complicated to run hence the need for such a rigid policy.

- Each child is allocated to one room, and all the members of the CF team (physiotherapist, dietitian, doctor, CF nurse, psychologist) come to see him/her in that room.

- All procedures are undertaken there (height & weight measurement, lung function, cough swab/sputum collection, blood testing).

- There will be no sitting in the waiting area as children will only be in their own clinic room; we will encourage children to bring their own toys and books etc with them. At the end the family leaves out-patients immediately.

- Between patients, the room is thoroughly cleaned (desktops, chairs, other surfaces, sinks) before the next patient enters.

- We will continue to have free slots at the end of clinics to see children at short notice who have become unwell and phoned us urgently. Patients must not arrive without telephoning to book a slot however. Of course, all children needing to be seen will be seen.

- It is important appointments are cancelled if the child is not coming, in order not to waste a slot.

- All children with MRSA or *B cepacia* come to clinics reserved for them only on the SECOND FRIDAY of the month with MRSA in the first wave and *Burkholderia* in the second wave. Once back in standard clinic, they should come to the second wave.

- Children with multiresistant PsA should come to 2nd wave.

- All children with any form of NTM come to second wave appointments only, because of the greater time (45 mins) required between patients with NTM for aerosols to disappear.