3. How the service runs

3. How the service runs

3.1 Clinics

The clinics are run in a segregation format (see section 4.7). There are 2 clinics per week, Monday and Friday – appointments are in 2 waves - 1.45pm and 3.15pm, with a 4.15pm urgent slot. In addition, new referrals of older patients are occasionally seen for the first time in a general respiratory clinic on a Tuesday am or Wednesday pm.

Children with *Burkholderia* species and MRSA do not attend the routine CF clinics. These patients will attend clinic on the 2nd Friday of the 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.

Patients with non-tuberculous *Mycobacteria* (NTM) complex will come to the 2nd wave of a clinic so will be the last ones in their room. No-one can use the room afterwards for at least 1 hour. Spirometry flow heads need only be changed for *M abscessus* patients.

Patients with multiresistant PsA should come to 2nd wave of clinic.

When can patients re-join the usual CF clinic?

- ***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 – get an induced sputum to be certain. They should then come to the 2nd wave of clinic.

- **MRSA**: when they have had 3 negative swabs (see hospital policy) https://www.rbht.nhs.uk/sites/nhs/files/Trust%20policies/MRSA%20policy%20-%20May%202016.pdf

    - If MRSA on skin swabs only – follow Brompton hospital policy.

- 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.

- ***M abscessus* complex***:* considered 'eradicated' when they have had 4 negative samples over 1 year since their 1st negative sample. Considered 'free of NTM' *i.e.* it has not regrown and can re-join standard clinic 1 year after eradication *i.e.* 2 years after 1st negative sample. See also sections 4.7 and 6.2a 6.VII.

There is a joint CF diabetes clinic on the 1st Monday and 3rd Friday of the month at RBH.

Patients may attend Monday or Friday clinic at their convenience although we encourage continuity where possible. Most children are seen in CF clinic every 2 months, or every 3 months for those recognised to be well with mild disease. Infants diagnosed by newborn screening are seen monthly in the first year and sometimes more frequently in the first months following diagnosis. For some, all clinic visits are at the Royal Brompton Hospital and they must be seen 2 (or sometimes 3 monthly) after 1 year of age. Some are seen on a Network-care basis with a local team in their District General Hospital, and our whole MDT attends these visiting clinics. If the full team see the child -

- 2 / year locally, they must be seen at RBH 2/year (including annual review)
- 3-4 / year locally, they need only be seen at RBH once, for annual review

This means they will be seen by the full RBH MDT at least 4 times each year. Obviously if there are difficult clinical issues then the child can be seen at RBH as much as necessary. We do not encourage children who visit from abroad annually as that is not proper Brompton care.

All out-patient visits are discussed at a weekly multi-disciplinary meeting which the consultants attend. After every clinic visit, a letter is sent to the GP, shared-care consultant and parents, which is countersigned by the patient's named consultant. A list of the named consultants for each patient is maintained by the CF nurses and CF secretary and is available on the paediatric T drive.

The families see the following:

Doctor. This may be a consultant (Mondays – Bush, Davies, Carr, Goldring, Greenaway; and Fridays – Balfour-Lynn, Carr, Pabary, Charlton, Rosenthal), a specialist registrar (usually a national grid respiratory trainee), or a respiratory clinical/research fellow. Parents may request which doctor they wish to see, and this is usually possible although may lead to a longer waiting time. We aim to have patients seen by a consultant alternate visits as a minimum, and a consultant will often speak to the parents in clinic if they have been seen by a trainee.

All patients are allocated a **named consultant** when first seen at our unit**,** although may be seen by any member of the consultant team at various times. The named consultant will take the lead role if there are difficult clinical decisions to be made. They will also co-sign clinic letters and write the annual review reports.

Health Care Assistant. To measure height and weight, oxygen saturation by pulse oximetry.

Respiratory physiologists. To measure lung function.

CF nurse specialist. To see all patients and provide general information and support. Portacaths may be flushed if required. HbAIc measured in CFRD clinic.

Physiotherapist. All the children should be seen by a physiotherapist to review airway clearance techniques, exercise, inhalation therapy, posture and continence; and obtain sputum or cough swab specimens.

Dietitian. All pancreatic insufficient patients and all babies are seen by the dietitian, for review. It may not be necessary for them to be seen every clinic visit. Whilst pancreatic sufficient patients are routinely seen at annual review, they may be seen at other clinic appointments if necessary.

Clinical psychologists. Are available for annual reviews and may see families to commence or continue with their clinical work.

Play specialist. Is available to help children to manage invasive procedures (usually blood tests) on request.

Paediatric Pharmacists. The team can be contacted via bleep for medication related enquiries, and those related to the homecare delivery of medicines.
Others. The social worker or Welfare Rights Officer can also meet parents and often help guide them on how to obtain appropriate benefits to which they are entitled.

Clinic procedures

- Children aged 5 years or less are always weighed in underwear, those older than 5 in light clothing. All children have their height measured on a stadiometer without shoes. Head circumference should be measured in children less than 1 year of age.
- Children over 4-5 years have lung function measured on a standard spirometer in a sitting position. All children have oxygen saturation measured on a pulse oximeter.
- Urine is tested for glucose if the child has lost weight or if they are receiving oral steroids, in which case blood pressure is also measured.
- Sputum or cough swabs are always collected for microbiology. Occasionally families may carry out a cough swab at home, BUT this is not routine practice and should only be done after proper training. Only sputum is sent for culturing non-tuberculous mycobacteria (NTM) as cough swabs are always negative for this. Culture for MTM is not carried out in every clinic but is sent at annual review, if there is clinical concern, or if the child has cultured it previously (also on all BAL and induced sputa).

Research
Consideration is always made by clinicians as to whether the child might be suitable for one of the many research projects undertaken at RBH. Participation will in the first instance be discussed with each patient and /or their parents. Expressions of interest to participate in research studies are always welcome.

Shared care clinics
We conduct joint clinics with many of our shared care hospitals. We aim to take the full Brompton MDT with us to the clinics to work alongside the local consultant and their MDT.

The clinic should follow the same format as our own clinics, including the emphasis on patient segregation.

3.2 Annual review

All patients are seen annually for a full clinical review of progress over the last year and for surveillance investigations; we intend to move this away from birthday time as we are aware some children associate their birthday negatively with having a blood test. This usually takes place in the normal CF clinic, with the patient attending radiology (+/- nuclear medicine) and the lung function lab beforehand. The family will then come back to clinic 4-6 weeks later (or be seen in a shared care clinic) by their named consultant, who will have all the results available, and will agree a plan and write the report.

If a patient is admitted around the time of the annual review, all investigations take place as part of the admission (usually bloods on day 2 with aminoglycoside levels, and other measures *e.g.* chest x-ray & formal lung function on day 9-10). When the child is next seen in clinic the AR proform (for data entry to the CF registry database) is completed and letter summarising the review and all results is sent. For patients having regular admissions, bloods will always be taken for AR so that they do not need repeating in clinic.

The children will be seen for the following:

- Discussion with the nurse specialist following the CF Registry proform. This will include the number of IV and oral antibiotic courses, usual symptoms and microbiology. Some of these data are filled in prior to the appointment.
- Dietary assessment - including written evaluation of nutritional intake by the dietitian. Height & weight, growth velocity and BMI charts will be filled in.
- Physiotherapy review of airway clearance techniques, exercise and inhaled medication regimens. Posture and urinary (or faecal) stress incontinence will be reviewed when appropriate. Home air compressors for nebulisation should be brought in for yearly service. Parents must email NebPhysioEquipment@rbht.nhs.uk when they have the date for their annual review to get it booked in. Exercise testing is not routinely carried out.
- All patients are offered the opportunity to meet with a Clinical Psychologist as part of their annual assessment**.** This will hopefully explore how the child with CF and their family are managing. As per CF Trust and British Thoracic Society guidelines, both the child with CF (if aged 11years and over) and their parents/carers are invited to complete mood questionnaires. If the families are already meeting with a psychologist, then they will not need to be seen by a psychologist at annual review unless they wish to make an appointment in advance. They will still be invited to complete the questionnaires.

Investigations

- *Full lung function* (including plethysmography) for children over 6 years. Bronchodilator responsiveness will be carried out for specific patients only by request. This is done in the Lung Function Laboratory on the 1st floor Fulham wing and takes 1 hour.

- *Lung clearance Index (LCI).* This test requires only passive co-operation and can potentially be performed at all ages. The child only needs to breathe normally through a mask or mouthpiece. The advantages of the test include (a) it is non-invasive, (b) only passive co-operation is needed, (c) the normal value is essentially the same over the

whole age range, (d) it is more sensitive than spirometry to early disease. It is also frequently used as a research technique. We can measure it in children as young as 4-5 years old.

We carry this out routinely **only in children with FEV_1 ≥80%** as it is more time-consuming to perform in those with poor lung function and we find we do not get any extra clinically-useful information. Subject to the above, LCI should be a routine part of the annual assessment and is undertaken in all children aged 5 years and above. Additionally, the test can be useful in children who supposedly have 'poor technique' with spirometry leading to lower than expected lung function; if the LCI is abnormal this would indicate the low lung function is genuine and not due to technique. LCI should be booked through Sam Irving (ext. 88233, email s.irving@rbht.nhs.uk) and is carried out in Fulham Wing 1st floor.

The higher the LCI, the worse is the distal gas mixing. Normal ranges for LCI are device-specific so it is important that the device used is recorded alongside the result, and the same device (where possible) is used when a patient has a subsequent LCI.
In general, a value > 8.0 is above the normal range and >10.0 is significantly abnormal (we do not often have values >12).

- *Ventilation scan* is carried out in children too young to perform formal lung function. This is done in Nuclear Medicine Department, Level 3 Chelsea Wing and takes 1 hour. Ext 88666.

  What to do with an abnormal ventilation scan
  Our internal audit has shown that children with just one abnormal ventilation scan in the first 5 years of life will have a slightly lower lung function at 6 years than those that have normal pre-school scans. We therefore treat all abnormal scans even in well children. All will receive a minimum of three months of a muco-active agent, either RhDNase or hypertonic saline. If unwell at the time of the scan, antibiotics should have been given already. A repeat scan at 3-4 months will be arranged, if normal a decision on continuation of muco-active agent will be made in clinic. Always consider whether a bronchoscopy is required. If still abnormal, more aggressive IV antibiotic treatment will be considered as well as long term muco-active agent. We do not take into account the % distribution between the two lungs.

- *Chest x-ray* is not scored but we record changes and differences from the last year.

- *Ultrasound liver and spleen*. Liver ultrasound is performed as screening at the Brompton Hospital (or at the local hospital) on all children aged 5 years and above every other year (*e.g.* age 5, 7, 9, 11, 13, 15 yrs). It should be performed in anyone else with a palpable liver/spleen or significantly abnormal liver function test (2x upper limit of normal). If the ultrasound is abnormal or there are other liver abnormalities (hepatosplenomegaly, blood results) it will be repeated annually. It will be done without the child fasting for convenience. The only downside of that is that is the gall-bladder will not be visualised well. This will not matter unless the child is having abdominal pain in which case it is important to look for biliary stones.

- *Bone densitometry (DEXA scan)* is measured as screening at **10 and 15 years** of age. We no longer start at 8 years and carry out every other year. If abnormal, we consult with Dr

Bridges or Dr Alexander and decide when to repeat (usually 2 years later). DxA dept no. is 88965.

- *Continuous glucose monitoring System (CGMS)* is carried out in all **10 and 14 years** of age patients as a screening procedure for CF-related diabetes, in addition to those considered to be at increased risk or where there is clinical concern of CFRD (see section 8.1).

- *Sputum or cough swab* for microbiology, and sputum only for NTM.

- *Blood* is taken by the phlebotomist (or doctor). The default is for blood to be taken at RBH as when taken in the local hospitals, we often find some tests were not carried out, and, we do not have an instant record on EPR of previous bloods that can be compared on a trend plot. Bloods can be taken locally when the child has a significant problem with needles if that helps them. We take15 ml is taken for the following:
    - Full blood count (with WBC differential)
    - Clotting studies
    - Electrolytes and creatinine
    - C-reactive protein
    - Calcium, magnesium and phosphate
    - Liver function tests (AST, ALT, ALP, γGT)
    - Random glucose and glycosylated Hb
    - Vitamins A, D & E
    - Serum ferritin
    - IgG, IgA, IgM
    - Total IgE
    - Aspergillus specific IgE
    - Aspergillus IgG (ICAP)
    - Varicella antibodies at 6th birthday [DO NOT FORGET THIS]

Blood bottles: 2 (red) EDTA bottles, 4 (brown) SERUM bottles (6 in older children), 1 (green) COAGULATION bottle. Bottles must be full. Use larger bottles in older children.

- *Urine* – dipstix for glucose for all with CFRD and anyone on oral corticosteroids.

- *Blood pressure* when old enough to do lung function. Also if on Orkambi/Symkevi.

Annual Review Letter

A normal clinic letter should be dictated by the doctor who sees the patient, with available investigation results **including blood results.** Results of lung function should always be reported in litres in addition to %predicted values. A report of the AR including all investigation results will be compiled by the patient's lead consultant when the results are available. Blood results will be checked within 1 week.

UK CF registry

All data is entered on to the UK CF national registry, for which the parents will have given written informed consent. Data entry is critical as it determines patient banding and payment to the hospital via the PbR system (see section 3.8, and appendix 17). If parents decline

consent to CF Registry, we calculate annual review banding for that child and it is sent to RBH commissioning dept.to be passed onto NHSE. Website – https://cfregistry.org.uk/pages/home. User name for staff to access our data can be obtained from our Database Team, Hannah Wright or Abdul-Wakil Odeye.

3.3 Transition from paediatric to adult care

Transition from paediatric to adult care is discussed with all patients and their families from diagnosis and at every annual review. A more detailed discussion takes place from 14 years and a letter is sent to both parents and the young adult. We aim for transition to take place at the age of 16 after GCSE exams. The transition process has been divided into two parts: pre-transition and transition. Invitations to attend a pre-transition clinic are sent to all young adults and their families at 14 and 15 year of age, so they now have 2 pre-transition visits. This is an opportunity to meet the adult CF team and ask any questions before attending the transition clinic. We will provide information about growing up with CF, the similarities and differences of adult care and an overview of the adult CF service. The Adult CF Clinic at the Brompton Hospital may not be the Centre of choice for some patients – advice is given on how to access other services with contact details for each centre. Either way we will make the necessary referrals.

Most patients will transfer at some stage after their 16th birthday, depending on the individual and family circumstances. However, we plan to transition all young adults by their 17th birthday at the latest. The Transition Integrated Care Pathway (TICP) is commenced at this time (Appendix 1). The document detailing family, social and clinical history is completed by each patient, their family, clinical nurse specialist and the rest of the MDT. The adult team can access this document prior to the transition clinic (Appendix 1). There is a section entitled 'all about me' which we like the young adult to fill in as a way of introducing themselves to the adult team. **The original laboratory report of the genotype must be attached to the ICP.**

Transition clinics are held on Monday and Friday afternoons in the usual paediatric clinic area. There are about 4-6 clinics per year. The adult CF Team (consultant, nurse specialist, physiotherapist, dietitian, and clinical psychologist) attend each transition clinic to give patients and families an opportunity to meet and ask questions about the move to adult care. The patients remain under the care of the paediatric team until they are seen for the first time in the adult clinic, we aim for this to be 8 -12 weeks post this clinic.

It is problematic if a young person keeps missing their transition appointment. If that happens they will be sent an adult clinic appointment, as moving to the adult service cannot be delayed unnecessarily.

Following each transition clinic an adult CF clinical nurse specialist will arrange each patient's first adult clinic appointment on days that the same doctor, nurse specialist, physiotherapist and dietitian are in clinic to ensure continuity. The TICP is continued until after the first adult clinic appointment. A regular paediatric/adult transition meeting is held where CF team members from both services meet to discuss all patients attending the following transition clinic and to discuss issues arising from patients who have recently made the transition to the RBH adult CF service. After making the transition to the adult CF service, adolescents are initially followed up closely by the Named Transition Nurse (based

in the adult unit) - the 'Named worker' as per NICE guidelines - to ensure that the change of CF team to make sure the young person and their family are well supported as they transition into the adult service.

If or when patients need admission to Foulis ward (the adult ward) the named transition nurse will visit them on alternate days to support the patient and their family throughout their first admission. There is also some support available from the hospital school particularly for those who are in continuing education or need careers advice. Young adults are supported if it is necessary for them to take exams whilst an inpatient.

At admission every patient (regardless of age) is asked to sign a 'contract of care', which sets out activities expected from patients during admission (including adhering to cross infection policies). Part of the contract also includes a list of what patients can expect from the CF team.

3.4 Homecare & Outreach Service

The role of the Homecare Service is to provide a specialist nursing/physiotherapy input at home, and to facilitate the continuity of care between the Royal Brompton Hospital, local services and the family. The team currently comprises 4 children's CF nurse specialists; and 2 physiotherapists specialising in providing homecare for children with CF and their families. In addition, one of our dietitians and clinical psychologists will occasionally do home visits. Criteria for referral are that RBH is the child's specialist centre assuming distance is not prohibitive.

The Nursing service core hours are Monday to Friday 9am to 5 pm.
The Physiotherapy service operates Tuesday to Friday 9am to 5pm.

Contact for families and professionals is via mobile telephone (with answerphone); messages left within the hours of 9am to 4pm will be answered the same day (weekdays) where possible.

Nurse specialists	
Laura Seddon	07973 173969
Karen Henney	07971 224068
Katie Dick	07773 964573
Caroline Devon	07483 338160

Physiotherapists	
Emma Dixon	07970 269452
Nicky Murray	07791 584749

Purpose of visits

- Monitoring and assessment including measurement of SpO_2, lung function and collection of specimen *e.g.* sputum, cough swabs
    - between routine appointments
    - following a course of oral antibiotics

    - before or during course of IV antibiotics
    - at the discretion of the MDT
- Flush portacaths / change portacath needles (nurses only)
- Education, reinforcement and encouragement following:
    - diagnosis
    - diagnosis of new complication
    - commencement of new treatments
    - preparation for transition
    - support with adherence to treatments
    - school/nursery education
- Newborn Screening
    - The screening labs inform the CF nurses of babies who have been screened as 'CF SUSPECTED'.
    - The homecare nurses with support from local health visitors, visit the families at home to inform them of the suspected result.
    - The homecare nurses are able to answer parent's questions with specialist, up to date knowledge.
    - Parents are given an appointment for their baby to attend the Royal Brompton Hospital the next day for a sweat test where they will meet with the Consultant and a formal diagnosis made.
    - A physiotherapy homecare review will be offered within 4-6 weeks
- Training of local teams
- Physiotherapy service offers:
    - assessment and review of airway clearance techniques
    - advice on exercise, posture correction and stress urinary incontinence
    - education on inhaled medication use and regimens
    - infant massage.

Home visits are strongly encouraged and offer families the undivided attention of a health professional away from a busy ward or clinic in the security and privacy of their own home. We aim for visits to be no longer than one hour whenever possible. This provides the opportunity for less hurried discussions about anything the family wish to talk about. In particular, practical issues can be dealt with and it gives us an opportunity to explore how the family is coping with the situation of living with a child with CF. Home visits can be an ideal opportunity to involve both parents, the child, siblings and extended family members. In order to maximise the effectiveness of visits, appointments are made with the family responding to their individual needs regarding frequency and content. The team will endeavour to make appointments at a time convenient to the family and school aged children can be seen before or after school. Additional contact, support, and follow up are also maintained by telephone on a two-way basis; however repeated refusals of home visits will be discussed further within the team, and in some circumstances may be escalated to the safeguarding team. Home visits should not be allowed to be a substitute for regular clinic attendance. The clinical psychology team and dieticians are also able to offer occasional community visits depending on the needs of each individual family.

Liaison

The team aims to establish links with local services as appropriate to each individual child to promote continuity of care. The Homecare service is not a replacement for local services but aims to complement them in providing a specialist resource.

Liaison and joint working occurs when necessary with Community Children's Nurses; Health visitors; School nurses & teachers; GPs; Practice Nurses; Social workers; Community physiotherapists; Community dietitians; local psychological well-being /mental health services (*e.g.* school counsellors, local child and adolescent mental health services - CAMHS).

- The nursing team are available to visit GP surgeries if required when children are newly diagnosed or new to their Practice.
- They liaise regularly regarding medication requirements, linking also with local pharmacists.
- The team visits schools to educate school staff regarding CF and the particular needs relating to the child during their school day. The homecare team will also train teaching staff for school residential trips to ensure the child can attend without missing vital treatments. If requested by the child, class talks can be given allowing greater understanding of CF by their peers.
- The team attends shared care clinics and acts as a resource for shared care teams
- Parent Support Groups are offered where possible which are facilitated by the homecare team
- The homecare team work closely with the hospital-based team, attending MDT meetings, clinics and ward rounds where necessary. They have direct access to medical advice at RBH at all times and will consult with medical staff from the home as appropriate.
- The safety of the child is paramount, and the homecare team have regular meetings with the safeguarding team.

3.5 Clinical Psychology

Paediatric clinical psychologists have specialist knowledge in child development and emotional and behavioural difficulties in children. They have expertise in working with children and families who are having to adjust to difficult situations such as physical illness. The psychologists are part of the CF team, and can accept referrals from anybody. They offer a service to children with CF their parents and/or carers, their siblings, and other family members. The psychologists provide a service to both inpatients and outpatients (and offer occasional community visits, depending on the requirements of the family. They are available during CF clinics if required (it is always advisable to contact the psychologist directly prior to the clinic appointment to ensure that they have enough time available). They also offer a consultation service to other members of the CF team both at RBH and at shared care centres, and to colleagues from other statutory and voluntary agencies (with consent from the patient or their parents). The clinical psychologists attend ward rounds and other multidisciplinary meetings. A clinical psychologist currently attends two of the shared care clinics with other members of the RBH CF team.

Clinical psychologists recognise that CF can affect a child and/or their family in a variety of ways. They offer the opportunity to discuss things which can arise when a child and family are living with CF (or anything else - it need not be related to CF). As well as talking and listening, clinical psychologists can offer suggestions for change and practical ways for

coping with difficult situations such as managing invasive procedures (*e.g.* blood tests). Any assessments and interventions carried out would be made sensitive to the needs and wishes of the child and their family. Confidentiality is respected and discussed with each person seen as it can often be helpful to share some information with other members of the CF team. Depending on the age of the child, permission from the person identified as having parental responsibility would be sought prior to a clinical psychologist working with the child unless there were very exceptional circumstances.

Sometimes the psychologists will liaise with local counselling/mental health services because long term follow up is often better carried out nearer to the family's home or the degree of concerns about the child with CF and /or their family member (*e.g.* severe clinical depression) is such that more specialist assessment and/or intervention is warranted. This would not be done without the permission of the patient and/or their family.

Some reasons for referral or consultation include:

- Meeting the family during the new patient education visit at the hospital, usually following newborn screening. This meeting is to introduce the psychology service, as we are aware that a new diagnosis of CF or change of hospital can present as a challenge to any family.
- Thinking with the patient or a family member about talking with family, friends and people who work with a child with CF (*e.g.* teachers) about CF and managing their reactions to this.
- Helping a child to manage medical treatments *e.g.* to swallow tablets whole.
- Checking and informing (often with a medical or nursing colleague) the understanding the child has about their CF.
- Consideration of future treatments that may be offered along with the implications.
- Managing invasive procedures - including fear of needles.
- Challenges which may occur with the CF patient's feeding behaviour/nutrition.
- Life changes related to CF care *e.g.* transfer to adult CF services, change in treatments, consideration of possible transplantation.
- Life circumstances related to the young person or family such as new sibling, new house, stressors affecting family relationships.
- Thinking about school *e.g.* returning to school after long periods of absence; changes of school placement such as transfer to secondary school; and other school related challenges such as difficulties with peer relationships or helping to identify learning difficulties.
- Problems which may or may not have something to do with CF *e.g.* toileting problems.
- Mood/behaviour problems which may or may not have something to do with CF. As previously documented at all CF annual assessments we aim to monitor the young person's (4 years and above) and their main carers' mood and behaviour in order to identify and offer support for any challenges identified.
- Any other challenges which may or may not be attributable to CF.
- Support for parents and other family members (as above).

Please note that this is not an exhaustive list. If you think psychology support might be helpful, please do not hesitate to contact directly one of the psychology team at Royal Brompton Hospital to discuss this further.

3.6 Safeguarding Children Team

The Safeguarding Children Team based at RBH, deliver advice and training to all staff, as well as support to families across the Trust to ensure the safety and welfare of children and young people. They are members of the multidisciplinary team and will support staff to make appropriate referrals to Children's Social Care (CSC) within the child's local authority if concerns are identified or further support is required. Examples are:

a) when a child is seen as being a 'child in need' as a result of his/her disability, or because his/her health and development is likely to be significantly impaired, or further impaired, without the provision of services (Section 17, Children Act 1989).
b) when a child is suffering or is likely to suffer significant harm (Section 47, Children Act 1989).
c) where emerging problems and potential unmet needs have been identified for individual children and their families, 'Early Help' interventions are offered through multi-agency referrals (Working Together to Safeguard Children, HM 2015).

All NHS providers are expected to comply with legislation and statutory guidance, this includes:

- Children's Act 1989, 2004.
- Compliant with statutory guidance *i.e.* Working Together to Safeguard Children (2015) and Section 11 of the Children Act 2004.
- Meeting Care Quality Commission (CQC) Essential Standard for Quality and Safety – Outcome 7.
- Safeguarding Children & Young People: Roles and Competencies for Health Care Staff (RCPCH Intercollegiate Document 2014).

Overall remit of the Safeguarding Children Team:

- To be the point of contact for all safeguarding children concerns throughout the Trust. See appendix 14 for pathway & contacts.
- Assess and analyse family strengths and difficulties in complex cases in conjunction with staff, children and their families, particularly regarding family history and family functioning, using risk assessment tools.
- Supporting staff in the collation of evidence of concerns and in developing safeguarding chronologies and in supporting staff with report writing.
- Supporting staff to make referrals to CSC for safeguarding concerns.
- Offer training and guidance, as well as regular team or one to one safeguarding supervision to all paediatric staff.
- Identifying children and young people subject to Child Protection Plans (CPP), Child in Need Plans (CIN) or who are Looked After Children (LAC), with early liaison with the relevant multi-agency team.
- Ensure that RBH is adequately represented at appropriate strategic, core groups, conferences and professionals' meetings as well as Team Around the Child/Family meetings. This may include the Safeguarding Team attending with staff to offer support where required.
- Supporting families with no recourse to public funds or who are homeless, by liaison with appropriate CSC or local services to ensure that the safety and welfare of the child remains of paramount importance.

- Attend regular child related meetings within RBH, where necessary to offer support and advice.

The Paediatric Social Worker (PSW)
The RBH Paediatric Social Worker (PSW) is a non-statutory role within the Safeguarding Children Team. The PSW works collaboratively with the CF multidisciplinary team to assess and analyse family strengths and difficulties in managing the child's diagnosis and long term treatment and needs, particularly regarding family history, functioning and environment. Signposting or referrals to appropriate services are made where required, whilst the child is an inpatient and/or prior to discharge into the community in conjunction with the MDT and partner agencies.

Specific PSW's role includes:

- Joint working with child, family and multi-agency professionals to ensure clear information sharing and continuity of care and services. This will include attendance at pre-admission planning and discharge planning meetings, for children and families with known social or safeguarding concerns.
- The PSW will refer the child and/or family to local CSC departments with the recommendation of further assessment of needs of provision or services, where required.
- Eligibility criteria and the availability of services vary in different local authorities. The responsibility to provide services lies with the child's local authority and they undertake their own assessment of needs once the child is discharged from hospital.
- Working jointly with the Family Liaison Team and Welfare Rights Officer to recognise unmet needs and signpost to appropriate additional social security benefits or charitable support within their local area for families, prior to discharge.

3.7 Family Liaison Team & Welfare Rights Adviser

The family liaison team support parents and carers during their child's hospital stay, particularly in relation to non-medical issues. They are able to help families if problems arise either in hospital or at home. They can also liaise with other members of the multi-disciplinary team on behalf of the families. Being far from home can be stressful, particularly if other children and partners are still at home, and also may cause extra financial burdens. Their aim is to try to alleviate that stress. If they cannot help, they usually know someone who can!

The Welfare Rights Adviser provides welfare advice to paediatric patients and their families on the following issues
- financial concerns.
- benefit advice and assistance with applications.
- housing issues.

3.8 Payment by Results – the mandatory tariff.

Since April 2013 there has been a mandatory tariff paid via the Specialist Commissioners to the CF centres, based on a year of care tariff that is dependent on the severity of the child's CF disease. This is determined by the complexity adjusted yearly banding system (see below)

produced from data at annual review. This is entered on to the CF national registry who informs the centres and local commissioners of the banding. It is critical data is entered for every patient without exception, assuming consent obtained, usually by January 31st each year with the previous year's data.

This is to cover CF related care only (*e.g*. not A&E visits or admissions for trauma or non-CF illness). It also specifically excludes charges for high cost CF drugs – DNase, nebulised antibiotics (colistin, tobramycin, aztreonam), mannitol and ivacaftor. High cost antifungals *i.e*. voriconazole, posaconazole, liposomal amphotericin and caspofungin are also excluded from the tariff.

Part of the tariff is paid to our shared care Network Centres. Each centre must comply with the NHSE National Service Specification - https://www.england.nhs.uk/wp-content/uploads/2018/07/a01Sb-spec-cystic-fibrosis-child.pdf; the CF Trust Standards of Care (2011); and the Service Level Agreement signed with the Brompton each year. The paediatric tariff does not take into account the extra costs incurred by shared care arrangements nor costs of local community services.

The following explanation is taken from the '2019/20 National Tariff Payment System – A consultation notice: Annex DtB' jointly from NHS England and NHS Improvement. https://improvement.nhs.uk/documents/488/Annex_DtB_Currencies_with_national_prices.pdf. See appendix 17.

Cystic fibrosis pathway payment

- The cystic fibrosis (CF) pathway currency is a complexity-adjusted yearly banding system with seven bands of increasing patient complexity. There is no distinction between adults and children.

- Bandings are derived from clinical information including cystic fibrosis complications and drug requirements. The bands range from Band 1, for the patients with the mildest care requirements (involving outpatient treatment two to three times a year and oral medication) to Band 5, for patients at the end stage of their illness (requiring intravenous antibiotics in excess of 113 days a year with optimum home or hospital support).

- Patients are allocated to a band by the Cystic Fibrosis Trust using data from its national database, the UK CF Registry.

- The pathway payments cover all treatment **directly related to cystic fibrosis** for a patient during the financial year. This includes:

    a. admitted patient care and outpatient attendances (whether delivered in a specialist centre or under shared network care arrangements)
    b. home care support, including home intravenous antibiotics supervised by the CF service, home visits by the multidisciplinary team to monitor a patient's condition, *e.g*. management of totally implantable venous access devices (TIVADs), collection of mid-course aminoglycoside blood levels and general support for patient and carers
    c. intravenous antibiotics provided during inpatient spells
    d. annual review investigations

- For any patient admission or outpatient contact in relation to cystic fibrosis, the HRG is included in the year-of-care payment regardless of whether it is one of the CF-specific diagnosis-driven HRGs or not. All outpatient CF activity must be recorded against TFC 264 and TFC 343.

- Some elements of services included in the CF pathway payments may be provided by community services and not the specialist CF centre: for example, home care support, including home intravenous antibiotics supervised by the cystic fibrosis service, home visits by the multidisciplinary team to monitor a patient's condition (*e.g.* management of TIVADs) and collection of mid-course aminoglycoside blood levels. In such cases the relevant parties will need to agree on payment from the prices paid to the specialist CF centre.

- There some specified services that require local negotiation on price:

  a. high cost CF-specific inhaled/nebulised drugs: colistimethate sodium, tobramycin, dornase alfa, aztreonam lysine, ivacaftor and mannitol.

  b. insertion of gastrostomy devices (percutaneous endoscopic gastrostomy –PEG) and insertion of TIVADs are not included in the annual banded prices. These surgical procedures will be reimbursed via the relevant HRG price.

  c. Neonates admitted with meconium ileus who are subsequently found to have cystic fibrosis will not be subject to the cystic fibrosis pathway payment until they have been discharged after their initial surgical procedure. This surgical procedure will be reimbursed via the relevant HRG price. Once discharged after their initial surgical procedure, subsequent cystic fibrosis treatment will be covered by the cystic fibrosis pathway payment. Annual banding will not include the period they spent as an admitted patient receiving their initial surgical management.

- Network care is a recognised model for paediatric care. This model must provide care that is of equal quality and access to full specialist centre care.

Banding definitions & costs –

In appendix 17, we have enclosed the section on CF from the Payment by Results Guidance for 2019/20 published by NHSE.

Band	Base Tariff excluding MFF (£)	Tariff including MFF applicable to RBH* (£)
1	5,226.00	6,446.63
1A	7,732.00	9,537.95
2	7,732.00	9,537.95
2A	12,498.00	15,417.13
3	19,129.00	23,596.92
4	34,498.00	42,555.63
5	41,590.00	51,304.09

2019/2020 NHSE Tariff**.**
* Market Forces Factor is 23.4% at Brompton.

Banding definitions		Band						
		1	1A	2	2A	3	4	5
Therapies	Maximum number of total days of IV antibiotics	0	14	28	56	84	112	≥113
	Nebulised antibiotics (*Pseudomonas* infection)		Yes					
	Long-term (>3 months) nebulised antibiotics or DNase			Yes				
	Long-term (>3 months) nebulised antibiotics and DNase				Yes			
Hospitalisations	Maximum numbers of days in hospital	0	7	14	14	57	112	≥113
Supplemental feeding	Nasogastric feeds				Yes			
	Gastrostomy					Yes		
Complications	CF Related Diabetes or ABPA w/o other complications				Yes			
	CF Related Diabetes and ABPA					Yes & (FEV_1 ≥60%)	Yes & (FEV_1 <60%)	
	Massive Haemoptysis or Pneumothorax					Yes & (FEV_1 ≥60%)	Yes & (FEV_1 <60%)	
	CF Related Diabetes and Gastrostomy					Yes & (FEV_1 ≥60%)	Yes & (FEV_1 <60%)	
	Non-Tuberculous mycobacterium treated or difficult to treat infections (*e.g.* MRSA or Cepacia) requiring other nebulised antibiotics *e.g*. Meropenem, Cayston, Vancomycin.					Yes		