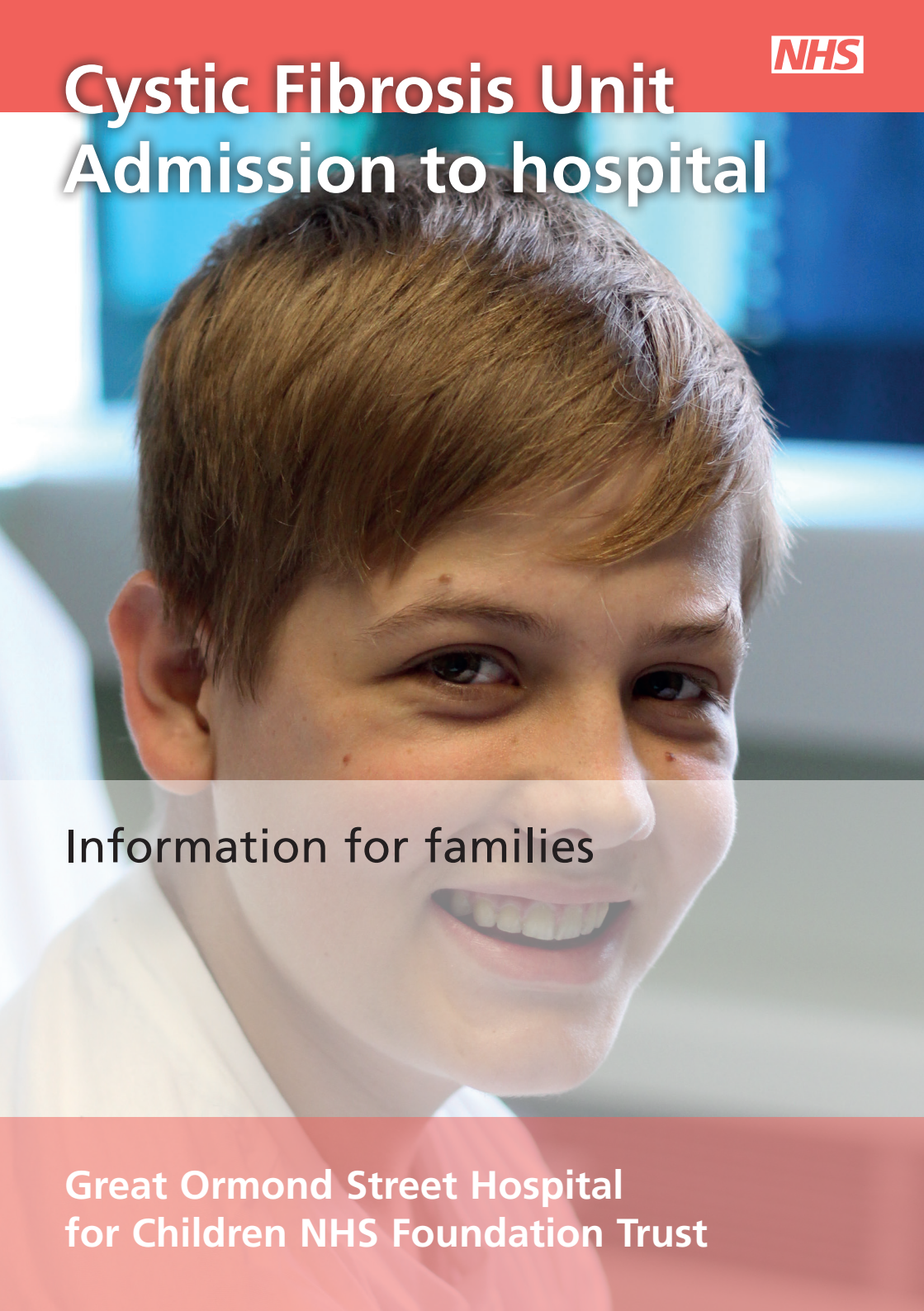


# Cystic Fibrosis Unit Admission to hospital

A close-up photograph of a young boy with short brown hair, smiling and looking slightly to the right. He is wearing a white shirt. The background is blurred, showing what appears to be a hospital setting with blue and white tones.

Information for families

Great Ormond Street Hospital  
for Children NHS Foundation Trust

**Children with cystic fibrosis (CF) may from time to time need an admission to hospital and this may be for a variety of reasons. Usually the admission is discussed with the family and planned ahead of time but occasionally a more urgent admission may be required. The length of stay will depend on the reason for admission - chest infections usually require at least a two week course of intravenous antibiotics but admissions for other reasons may be shorter. The following information gives some general information about inpatient admissions to Great Ormond Street Hospital (GOSH) and should help you to prepare for the admission.**



## Which ward will my child be admitted to?

Our respiratory ward is called Badger and is located on level 5 of the Cardiac Wing. We are currently undergoing plans to have the ward relocated by spring 2014.

Children with CF are always admitted to a single cubicle and these currently have shared bathroom facilities with the ward. This will not be the case when the ward is relocated and each cubicle will have en-suite facilities. We are very mindful of the issues of cross-infection in CF. It is important to ensure that direct contact between children on the ward is avoided and we would encourage parents and children to be vigilant regarding this. Although we appreciate this is difficult, in order to minimise the risk of cross infection children should stay in their cubicles when on the ward. They are generally not allowed to spend time in the communal areas in order to avoid contact with other children with CF.

Each cubicle has the facilities

to allow for one parent to stay overnight if they wish and contains a small fridge for your use.

## Should I call the ward before coming in?

Badger is a specialist respiratory ward and bed availability changes on a daily basis. It is therefore very important that on the morning of the day you are due to come in, you call the ward and speak with the nurse in charge to check everything is as planned and to find out what time the bed will be available for you. It also gives you the opportunity to ask any last minute general questions you may have about the admission.

If you choose to drive to GOSH, a day parking permit is available on day of admission, this can be obtained from main reception or ask the ward nurses for further information. There is an NCP car park below the Brunswick Centre which is a short walk from the hospital. Please remember if you decide to drive, GOSH is located within the congestion zone for London – refer to Transport for

London website for further details on this ([www.tfl.gov.uk/roadusers](http://www.tfl.gov.uk/roadusers)).

### **What happens if there is no bed available?**

If we do not have a bed, we do our very best to inform you of this before the day of the admission but occasionally, owing to circumstances beyond our control, this is not possible. If this happens then we will arrange admission as soon as a bed becomes available.

### **What happens once we arrive on the ward?**

When you arrive on the ward, you will be met by one of the Badger ward team and allocated a cubicle. If it is your first admission, you will be shown around the ward to ensure you know where things are and what facilities are available. Please ask for directions to the other services that you may need to visit during your stay (such as lung function, x-ray department, school, chapel and patient advice liaison service (PALS)).

The ward registrar will then see you and will go through your child's history and inform you of any investigations required, the treatment plan and anticipated length of stay.

If the admission is for a course of intravenous antibiotics (IVs), it is likely that a venous line insertion (often referred to as a PICC line) will have been booked. Depending on the age of the child and individual circumstances this is undertaken in radiology under either a local or general anaesthetic. If the line is being inserted under general anaesthetic then you will be given instructions before admission regarding not eating or drinking in preparation for the anaesthetic.

Children who have regular IVs are likely to have an implantable port in situ and in these circumstances the nurses on the ward will access the port on the day of admission and take routine admission bloods. We have a responsibility to train junior and new nursing staff on the ward and they may be involved in your care. Whenever this is the case, they will always be supervised by a senior staff member.

## Is there a daily routine?

The daily routine will be discussed with you and we will draw up a timetable for your child. This will give a daily plan for treatments, schooling and reviews. Although we try to stick to the timetable, circumstances may mean that this has to be changed from time to time. This is discussed between you and the nurse allocated to you on admission.

## Intravenous medication:

If the admission is for a course of intravenous antibiotics, the timings of medications needs to be fairly regular. It is important that your child is present on the ward in time for medications to be given. This will be discussed when your timetable is being planned.

## Physiotherapy:

All children admitted to the respiratory ward are assessed by a Specialist CF Physiotherapist. Two or three physiotherapy sessions will take place each day (between 8.30am and 5pm), depending on clinical need. Your child will often receive more physiotherapy and nebulisers than your normal regimen at home to try to make sure we get the best out of the admission and it is very important that you are on the ward at the times these sessions are arranged. Airway clearance

sessions will take place in your room under the supervision of a member of the physiotherapy team. At least one of these sessions will be an exercise session, which will be in either the inpatient gym, Nuffield gym (opposite GOSH) or occasionally in your room. At the beginning and end of each admission, your child will have an exercise test. Weekend physiotherapy arrangements will take place on the ward and will be discussed and arranged by the Specialist CF Physiotherapist.

## Nutrition:

Children's meals are ordered daily and you or your child can choose something specific they like. Meals are catered for by the main kitchen unless your child has a specific food allergy. If your child requires a special diet please inform the nursing staff or dietician prior to admission. We are working hard with the catering



staff to ensure we provide a menu that meets your child's needs. This includes a cooked breakfast which we recommend for children with CF.

Meal times are as follows:

- **Breakfast:** cooked breakfast is delivered at approximately 9am, there is toast and cereal available from the kitchen if you child wakes earlier.
- **Lunchtime:** 12 midday to 1pm
- **Dinnertime:** 4 to 5pm

The ward dietitian is available on weekdays. Patients are seen twice a week during admission and this tends to be on the same days as the Consultant ward rounds (see below). The dietetic review is similar to clinic where your child's weight, height and Body Mass Index will be checked, along with their appetite, dietary intake, supplements, vitamin and enzyme doses.

Most gastrostomy feeds and oral supplements drinks are stocked in the hospital and these will be provided if required.

## Ward Rounds:

The ward doctors will review your child every day, usually in the morning unless the ward is very busy. Every Monday afternoon and Thursday morning there is a Consultant ward round. It is very important that you are present on the ward for this. The nurse looking after your child can give you an approximate time that your child will be seen so that you can plan things around this.

## Procedures and Investigations

Any pre-organised tests or procedures which have been discussed with you and arranged for the admission will be added to the timetable as appropriate. Occasionally the doctors will request further tests. These will always be discussed with you and your child before they are carried out. Most children receiving intravenous antibiotics need to have blood tests to ensure that the antibiotic levels in the blood are correct.

The Play Specialist also helps with preparation and distraction for medical procedures and interventions such as blood tests. Our psychologist is also available to help with further preparation if required.

### **Do we need to bring our routine medicines with us?**

You should bring in all your usual daily medicines in to hospital with you (this includes enzymes, vitamins, oral antibiotics and all nebulised medicines). We will take these when you arrive and keep them in a locked cupboard for use during your stay and you can request them as necessary. Although this is our current policy, it is hoped that when we move to our new ward there will be a medicines cabinet in each cubicle.

**Please note:** On occasion we may have to move you and your child from their current cubicle to another and very rarely, another ward. This is only done if it is essential so please cooperate with staff.

### **What else do we need to bring in with us?**

Please remember to bring the following with you:

- Your child's airway clearance device (such as Acapella, PEP, Flutter, Infant PEP)
- Nebuliser equipment
- Clothes – nightwear/daily clothes/ clothes which your child can exercise in
- Slippers for the ward/outdoor shoes/trainers for exercise
- Bath towel
- Favourite food/snacks
- Favourite toys/games/DVD/music
- You can bring your child's duvet/ blanket if this will make them feel more comfortable
- There is an inpatient laundry room located within the hospital. If you would like to use these facilities then please bring in your own washing powder/liquid. This is situated on Level 2 of the Main Nurses Home.

You will have your own fridge in your room in order for you to keep all your food and drink in your own room.

## What are the visiting arrangements?

All cubicles have the facility for one parent to stay and other family members and friends are encouraged to visit during the day. We ask that all visitors have left by 8pm. We recommend no more than three visitors at the bedside at any one time. It is advisable for your visitors to contact you on the day of visiting to avoid coming to the ward if your child is in the schoolroom, activity centre or having investigations done.

## Are there any play facilities?

We have a small playroom on the ward and a part time play specialist, who will also come to see you in your room to help your child settle in and find activities to keep your child occupied during their stay. It is also a good idea to bring in a small selection of your child's favourite toys, games, music, DVD's and/or books. A small DVD player can be supplied by the play team if available for your use. The play specialist will also provide you with

a list of activities that are taking place each day and where they are.

The play specialist will always help to explain and prepare your child if you are worried about any procedure that it may cause them anxiety.

Radio Lollipop visit the ward on Mondays and Wednesdays between 6pm and 8pm and Sunday afternoons between 4pm and 6pm. This gives you and your child an opportunity to request your favourite songs!

## What arrangements are there for schooling?

The Hospital School offers teaching to inpatients of school age. Priority is given to long-stay or recurring pupils, those studying for and sitting exams and those with a statement of special educational needs.

We have a highly qualified team of teachers and teaching assistants who specialise in teaching children in the early years, primary and secondary phases. We offer an exciting and enriched curriculum tailored to the needs of the individual.



During the admission there will be daily input from school. This will be part of a timetable and will be planned around ward treatments and other activities.

Pupils will attend the schoolroom (the timetables are carefully arranged so that only one pupil with CF attends the schoolroom at a time). Where this is not possible they will be taught on the ward.

Since the admission is likely to be planned for in advance, we would expect pupils to come with work collected from their home school. If this has not been possible we can liaise with the home school for you.

Outside of school hours, pupils can attend our Activity Centre. It is full of excellent resources, art activities, toys, games and consoles. It is open throughout lunchtimes, after school and during most of the school holidays. The Activity Centre can also be attended by nursery school age children.

## **When is the CF psychologist available?**

Clinical psychologists are available to all children and families during an inpatient admission. Inpatient stays can be stressful for families for many reasons, so families can ask to see a psychologist during this time. This might be to help with issues relating to the hospital stay or for different psychosocial concerns.

Generally, parents use the opportunity of the admission to have longer consultations with the psychologist about daily living with CF and impact on all members of the family. Children sometimes worry about being made to do treatments that they do not normally do at home, they get anxious about being away from home and about possible painful procedures. Children sometimes take the opportunity to talk at length about having CF and what it means for them.

The CF psychologists are happy to be contacted by a family before admission or to be approached directly during the admission. The psychologists visit the ward on a regular basis throughout the week,

but can be called specifically by any child or family via the nurses or other CF team member.

## **Will the Social Worker be available?**

Social work services are available to all children with CF attending hospital. Coming to hospital can be for some families very expensive and time consuming and the social worker can help with incurred expenses.

The social worker provides an assessment of the emotional, practical and financial impact of CF on a family and can provide support in the following areas:

- Housing
- Appropriate benefits, entitlements and other resources
- Grants/Wishes/Other Financial support
- Care and disability support services
- Family, relationship and carer issues (including support for siblings and parenting skills.)
- Advocacy and emotional support around new diagnosis

- Education
- Child protection (child safeguarding and protection, effective information sharing and referral and liaison with other safeguarding agencies)

Our aim is to make things less stressful for you and your child while you are at GOSH. We can:

- talk to you and your child if you are worried
- provide support, advice and guidance to help you cope with day-to-day issues
- speak to other hospital staff on your behalf
- talk to community services about arranging help at home for when your child leaves hospital
- support your other children if they are worried about their brother or sister who is ill
- support your child in coping with their illness
- talk to staff both at GOSH and in your local area so that everyone understands your child's needs.
- identify children at risk of harm and work to protect them

## Our commitment to you

While we work with you and your family, we will always try to respond to your child's needs in a way that respects individual and cultural differences. We will always try to understand and respect your views about your child's welfare and take these into account when working with you. We will arrange for an interpreter if you and/or your child need one.

## Family Support Workers

All families can also use the services of the CF family support worker. The family support worker works together with other services to enable children and families to cope with the stress of diagnosis and the experience of coming and staying in hospital. They can provide practical advice and assistance to children and families, including advice on welfare, benefits and financial support.

## Is there a chaplaincy service?

Chaplaincy is here to meet spiritual and religious needs of patients, families and staff at the hospital. Everyone has a spiritual side. It can help us deal with life's challenges, gives us hope and meaning, and lets us see how our experiences are part of a bigger picture. There are times when our spiritual side needs some support. We understand that it can be stressful when your child is ill, at home or in hospital, or when you are preparing for an admission or a procedure.

Spiritual support can take many forms, such as listening, talking, prayer or just being there. Belonging to a religious or faith community nurtures the spiritual side for some. Others do it in different ways. Regardless of whether you belong to a religious or faith community or not, members of the Multi-faith Chaplaincy and Spiritual Care Team at GOSH are here for you. You can contact us directly on 020 7813 8232 or ask a member of the ward team to contact us.

The Chapel is open 24/7 and is located on Level 2 of Variety Club Building (VCB). Also, there is a Multi-faith Prayer Room in Southwood Level 2.

### **Can we leave the hospital when there is nothing planned?**

We do encourage you to take your child out to get some fresh air and exercise during times where there are no scheduled treatments.

Coram Fields is a park very close to the hospital which has good outdoor play facilities for children.

If you would like to have a browse around the shops, the Brunswick Centre is just around the corner. It has a Waitrose supermarket, several shops, restaurants and cafes.

There are also museums and other places of interest nearby and information on these can be found on the internet via the following link: [www.gosh.nhs.uk/parents-and-visitors/advice-for-when-you-stay](http://www.gosh.nhs.uk/parents-and-visitors/advice-for-when-you-stay). Click on 'what to do in between appointments' under

the heading 'Useful documents' located to the middle of the right hand side of the page.

It is really important that before you take your child off the ward, you let the nurse looking after your child know, so that they can ensure that all treatments are up to date and let you know what time you need to be back.

### **Are there any facilities for parents?**

The Nuffield Gym Bloomsbury has kindly agreed to also allow parents/caregivers to have use of the gym facilities at a cost of £10 per week. Unfortunately children are not allowed in any gym without the supervision of a member of the physiotherapy team.

Parents need to cater for themselves regarding food. However, there is access to the ward kitchen where you can prepare meals and there is a microwave available.

## What is the arrangement for discharge?

Discharge planning normally starts at the beginning of your admission. We look at all options and discuss within the team to see if it would be beneficial or appropriate for part of your inpatient treatment to be transferred to your local hospital.

If you are prescribed any new medicines then the team on the ward try to organise with pharmacy for these medicines to be issued to the ward the day before discharge. You do not always need to wait for the ward round on the day of your discharge, but you will be informed by the ward nurses if you need to do so.

A day parking permit is available on the day on discharge, for further details ask the ward nurses during your admission.

## Can I do any of the treatment at home instead of hospital?

We do ask that you plan for a two week admission unless you have been specifically informed otherwise. Sometimes, in appropriate circumstances, it is possible to complete a course of treatment at home. This will be arranged by the CF Clinical Nurse Specialist (CNS) in conjunction with the CF team and the local community team. Before home IV antibiotics all parents must undertake a specific teaching plan to learn about home IV administration, and a work booklet/competency booklet must be completed.

## Who should I contact if I have any concerns?

If you have any worries and want to discuss them with the medical staff or any members of the CF team please ask the nurse looking after your child to arrange this for you.

Patients Advice and Liaison Service (PALS) is also available. This is a free confidential service which offers advice and guidance on any issues relating to your Childs hospital admission or experience. Once you have made contact with PALS they promise to contact you within two working days. PALS are located in main outpatients, next to the hospital shop. PALS can be contacted by telephone on 020 7829 7862 or by email to [pals@gosh.nhs.uk](mailto:pals@gosh.nhs.uk)

The Cystic Fibrosis manager can also be informed of any issues if you have been unable to get them resolved by speaking with the ward manager, medical team or CF team. Contact details below:

Ammani Prasad  
Cystic Fibrosis Unit Manager  
Telephone: 020 7762 6714  
Fax: 020 7829 8514

## Notes





**Contact us on Badger Ward:** 020 7829 8813

**Social services team:** Please talk to a Family Support Worker or a Social Worker if coming and/or staying in hospital might be very difficult for you financially and/or practically as they can help you and your family.

Social Work Service, Level 2 VCB/Southwood Link Corridor

Open Monday to Friday from 9am to 5pm

Tel: 020 7829 8896 Fax: 020 7829 8847

Website: [www.gosh.nhs.uk/parents-and-visitors/clinical-supportservices/social-work](http://www.gosh.nhs.uk/parents-and-visitors/clinical-supportservices/social-work)

**Chaplaincy:** 020 7813 8232

**Lagoon Canteen:** Open 8am to 7.30pm seven days a week

**Coffee bar:** Open 8am to 5pm seven days a week

**Hospital shop:** Open 9am to 5pm Monday to Friday

**Citizen Advice Bureau:** There is also Citizen Advice Bureau located at GOSH on Level 2. The Citizens Advice Bureau service provides free, independent, confidential and impartial advice to everyone (inpatients or outpatients) on their rights and responsibilities and can help resolve legal, financial and other problems.

**PALS:** Tel: 020 7829 7862

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