

# Evelina London Children's Hospital

## Journey guide

Information pack to support  
families with children who  
require complex care



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# Chapter 1: Welcome to Evelina London

We provide health services from before birth, through childhood and into young adult life.

Together with the Community teams in Lambeth and Southwark we care for local families and children. We also provide specialist services for children with rare and complex conditions from across South London, Kent, Surrey, Sussex and beyond.

Our vision is to be a world-leading centre of life-changing care for children, young people and their families.

This booklet is a joint venture between health professionals at Evelina London and families whose children we care for. We hope these pages will inform and support you during your time here.

## A parent introduction

“ We are frequent visitors to the hospital – if we could get air miles for admissions we’d be rejoicing right now!

It is always daunting because every admission is different and unpredictable. The nurses are phenomenal, very friendly and approachable. A few tips I’d share: if you’re unsure of any terms and doctor talk, never be afraid to ask. Talk to each other – one thing that makes our hospital admissions brighter is meeting other parents. I’ve learnt so much from other families and enjoy the company. ”

**Serena Pascall**



# Chapter 2: About your child

**This is a section to fill in about your child,  
to help staff get to know your child better**

They like to be called

What is important to them and their family

What they like

What they dislike

They show they are happy by

They show they are upset or in pain by

This is what makes them happy or comforts them

To help them communicate they use/have

# Chapter 3:

## Staying in hospital

Staying in hospital, even for a few days, can be daunting. This booklet will help you get a better understanding of how things work, and who everyone is. There are also practical tips that will make things a little easier for you and your family.

### Your nurse

Your nurse will usually be the first person you meet on the ward. They will settle your child onto the ward.

Part of their role is to monitor your child for changes. This will involve regularly checking their observations (for example, heart rate, and temperature) and this includes overnight. They will give medications and do certain bedside tests such as checking blood sugar levels.



Nurses change every twelve hours and their shifts run from 7.30am-8pm and 7.30pm-8am. They will usually be looking after a few patients. They will introduce themselves at the start of each shift. Your nurse is the best person to ask first if you need help or have questions. If they cannot answer the questions themselves, they will know someone who can.

## Your doctor and medical team

A consultant is a senior doctor who will oversee your child's diagnosis, tests and treatment. They work with a team of doctors, at different levels of training, to support your child's care. There are lots of different terms for doctors depending on their level of experience and their exact role. These include: registrar, senior house officer, fellow and foundation doctor. Always ask if you are not clear who someone is.

Your child's medical care will be provided by a number of different teams. Your child will be allocated a lead consultant who will oversee all of your child's care.



## Ward rounds

Ward rounds take place every day. Ward rounds are when the medical team review all the children on the ward. They run between 8am-1pm. Please be there for the ward round. You will help us to make sure you are updated, and it is the best time to ask questions about your child's care. Different teams of doctors may see your child at different times, but they will try to see you jointly when this is possible.

If you want to speak to a doctor separately to the ward round, your nurse can arrange this for you. For detailed conversations, or those involving multiple people, it is often best to arrange a meeting in advance. On-call doctors, who care for your child overnight and at weekends are not the best people to discuss long-term plans for your child's healthcare.

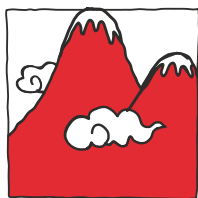
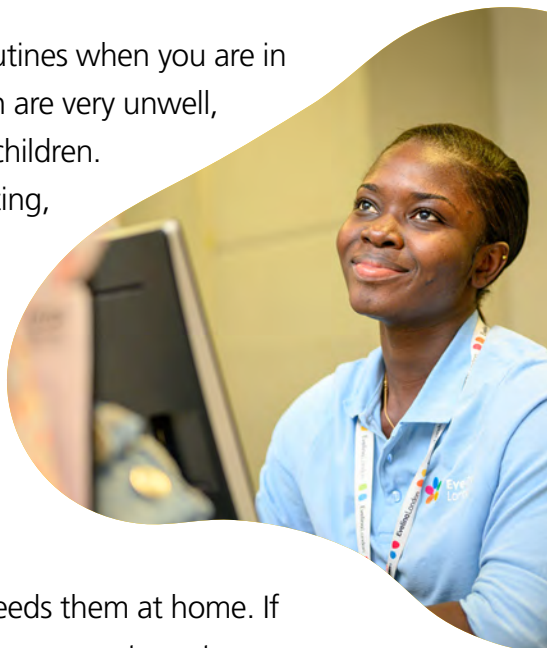
## Routines

We will work with you to help you get as involved as possible in your child's care while they are in hospital. This includes doing everyday things, like bathing and feeding your child, and might include things like measuring out and giving medications, or working with your child's medical equipment, such as oxygen or ventilators.

It can be difficult to maintain routines when you are in the hospital, especially if children are very unwell, but they will really help all your children.

Things like waking, sleeping, eating, playing, and spending time as a family, are all really important, and will help the whole family cope better.

It is really important that you are familiar with any new skills you need to learn, and are confident for when your child needs them at home. If we are teaching you a new skill, we expect you to engage with the training and come to the planned training sessions.



## Mountain Ward

Mountain Ward is on the fifth floor of Evelina London. We look after children with different medical and surgical needs.

**The following teams are based here:**

- general medicine
- gastroenterology (digestive system)
- endocrinology (hormones, including diabetes)
- haematology (blood conditions)
- respiratory medicine (breathing).

There are also high dependency unit (HDU) beds for children who need more intensive observation and nursing care. This is a higher level of care than on a general ward, but less than in intensive care.

Key people on the ward are the matron and the ward sisters.

## **Contact**

Medical reception, tel: **020 7188 8845**

## **Mountain Ward layout**

Toilets are in each bay with wheelchair-accessible toilets in every bay, apart from 24-29. The shower is next to cubicle 19. There is an assisted shower located next to the parent's room. Please check with your nurse if you need to use these facilities. Baby baths are available on request, please ask your nurse.

The purpose of some spaces in the hospital can be changed, so you'll need to check the signage or ask a member of staff.

# Chapter 4:

## Practical tips

### Food and drink

We provide food and drink for the children who are patients on the ward, and breastfeeding mothers. Please be aware that we do not provide food for any other family members.

- Meal times are: breakfast 8.30am, lunch 12pm, and dinner 5pm.
- Tea and coffee are available for all visitors in the parents' room.

There are a fridge, toaster and microwave available in the parent's room. Please use with care and label all food and drinks for the fridge with your name and the date.

There are a number of other food options on site;

- **AMT Coffee:** 24-hour cafés in St Thomas' Hospital entrance and in Evelina London atrium 3rd floor, open 8am-5pm for sandwiches, soups, hot and cold drinks.
- **M&S Simply Food:** Located at St Thomas' Hospital main entrance, Monday to Friday 7am-9pm and Saturday and Sunday, 8am-8pm, for sandwiches, salads and basic groceries.
- **Toms @ Riverside:** Located on the ground floor, North Wing at St Thomas' Hospital. Monday to Friday, 8.30am-3pm, for hot and cold dishes to take away).
- **Toms @ Shepherd Hall:** Located on the ground floor, South Wing at St Thomas' Hospital, Monday to Friday 7.30am-3.30pm, for a wide range of hot meals, and daily-changing menu.

## Breastfeeding support

You can breastfeed by your child's bed or we have a dedicated quiet room. The ward has a supply of expressing pumps if you need one. The milk can be refrigerated or frozen by us for you to use in the future. Please make sure that bottles are labelled with your child's name, date of birth and hospital number – the labels will be provided by your nurse. Let us know if you are bottle-feeding and/or using dummies, so we can support you and your baby.

## Visiting times and staying overnight

Parents, legal guardians and carers can visit at any time. We only allow other people to visit when a parent, legal guardian or carer is also present. Two visitors are welcome for each bed space from 10am-6pm. Your child's brothers and sisters are welcome to visit, but we might have to restrict visiting at times, to prevent the spread of infection. Children visiting the ward must be supervised at all times.



Only one parent, legal guardian or carer can stay overnight for each bed space. Drop-down beds are provided from 7pm-7am. In HDU areas, there is no space for parents to sleep overnight. This is because the level of care is higher and we must have access to the bedside at all times in case of an emergency.

Please leave bedside curtains open at all times, except during personal care or breastfeeding. This will allow us to monitor your child properly. Parent's beds need to be put away by 7am for safety reasons. We provide linen, towels and showering facilities. There are also washing machines on the ward which you can use – please ask your nurse for more information.

Always clean your hands with alcohol gel when you enter or leave the ward, to reduce the risk of infection. If you have been in contact with someone who has an infectious disease, such as chicken pox, you must speak to the nurse in charge before entering the ward. Some of the children are very sensitive to infections and it is important we protect them.

For the same reason you must not visit if you have diarrhoea or vomiting. Speak to your nurse about visiting if you have symptoms of a cold or flu.

## **Ronald McDonald House Evelina London**

Ronald McDonald House provide free home-away-from-home accommodation and support for families with children at Evelina London. Having a sick child affects the whole family. Ronald McDonald House lets families keep a sense of normal life during an incredibly stressful time. It provides a safe environment to potentially share experiences with others families in similar situations

We have 59 en-suite bedrooms, and communal living areas such as kitchens, playrooms, lounges and laundry facilities. Families can stay at the House free of charge (a £25 key deposit is required on arrival which can be donated or returned when you leave) for as long as their child is being treated as an inpatient at the hospital.



If a family would like a room at the House they must be referred by the ward. This makes sure that all requests are dealt with promptly and fairly.

Please do not contact the house directly.

Ronald McDonald House Evelina London can also offer non-residents the use of the day facilities between 9am-9pm every day. In the dayroom, there is a kitchenette, dining area, lounge and children's play area. There are also shower facilities and a laundry room available to use (please ring before your visit to arrange a suitable time).

Ronald McDonald House  
Evelina London  
216 Lambeth Road  
London SE1 7JY  
Tel: **020 3040 1888**

## Car parking and travel

Parking for patients and visitors is very limited. There is often a queue and we do not subsidise the car parking charges. The car park is 'pay on foot' so please have the correct change. You can also pay by credit or debit card. Pay and get your exit ticket before returning to your car.

## Parking charges

Charges are £3.20 per hour. Disabled patients are given free parking in the main car park on production of a Blue Badge registered in their name, with an appointment card. Parking charges apply 24 hours a day.

Evelina London and St Thomas' Hospitals are located in the Congestion Charging Zone. The Congestion Charge applies 7am-10pm every day (including weekends and bank holidays).

Website: [www.tfl.gov.uk](http://www.tfl.gov.uk)

Please use public transport whenever possible. There are very good public transport links and taxis available. We do not pay for transport home even if you were brought to the hospital by ambulance. If your child is going to another hospital we will arrange and fund transport.

## Patient transport service

You may be entitled to use our patient transport service if you or your child is unable to use public transport, for example, due to disability or illness.

To find out if you qualify, you will need to be assessed by a member of the patient transport assessment team. This involves a brief telephone interview and is completely confidential.

If you think you may be eligible, tel: **020 7188 2888**.

## Help with travel costs

If eligible, you may be able to claim back some of your travel costs to Evelina London. There are two types of reimbursement: claiming for public transport expenses, and claiming for the London Congestion Charge.

### Claiming for public transport

If you are on a low income or benefits you may be entitled to reclaim your travel costs, for appointments you attend after your child is sent home.

**You will need to provide proof that you are receiving one of the following:**

- Income Support
- Working Tax Credit
- Income-based Job Seeker's Allowance
- Certificate of low income (HC2 (AG2) or HC3 (AG3)).

When you arrive for your appointment, let the reception staff know you want to claim back transport fares. They can fill out the right form for you.

To reclaim the money, take the completed form, with proof of your travel costs to the cashier's office. This is on the ground floor, North Wing corridor in St Thomas' Hospital.

## Claiming back Congestion Charge payments

You might be able to claim back your Congestion Charge for your child when attending appointments at the hospital following your discharge if he or she:

- has a weakened immune system, needs regular therapy or assessment, or needs recurrent surgical treatment

and

- the member of staff caring for you has completed the appropriate claim form, confirming your child cannot travel on public transport.

You will need to pay the Congestion Charge for the day that you drive to the hospital. At your child's appointment, the staff caring for them will assess whether you are eligible for reimbursement.

If you are, you will need to provide your Congestion Charge receipt or receipt number, and the registration number of the vehicle that you travelled in.

A travel claim form will be completed and signed by your doctor, nurse or other health professional. You will then be able to claim the charge back through our cashier's office. This is on the ground floor, North Wing corridor, at St Thomas' Hospital.

Find out more about the Congestion Charging NHS reimbursement scheme on the Transport for London website: [www.tfl.gov.uk](http://www.tfl.gov.uk)

## Support

If your child has been in hospital for a long time, or if you are struggling with their stay, you may be eligible for further support. This could include financial advice, emotional or spiritual support. Please speak to the nurse looking after your child for more information, or see resources later in this booklet.

## Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch or ask a member of staff to by calling, tel: **020 7188 8815**, email: [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

## Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline. tel: **020 7188 3003**, Monday to Friday, 10am-5pm, email: [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

# Chapter 5:

## Things to do

### TV and radio

We have a bedside television service, provided by Hospedia.

It is free for children under 16 years. For older children, various TV packages are available to buy, ranging from 2 hours-12 days. There are discounts for long-stay patients. More about Hospedia rates for older patients is on the Guy's and St Thomas' Hospital website.

Radio stations are also available through the bedside TV service. These are free for all age groups.

### Pay-per-view films

Hospedia offers a pay-per-view film service. You can see free trailers, the film schedule and how to buy films on channel 22.



## Free Wi-Fi

Wi-Fi in our hospital is free. You can connect by:

1. Going to your Wi-Fi settings and connect to 'NHS\_WiFi'
2. Open your internet browser
3. Read the terms of use, and then click the button to accept and continue.

If you are having trouble connecting, this might be because the security software on your phone may drop the Wi-Fi when your phone is locked.

For any connection issues, you can call the Wi-Fi helpdesk 24/7, tel: **0344 848 9555**.

Please note that some internet content will be automatically blocked.

Free computer access is also available at the Knowledge and Information Centre (KiC), on the ground floor, North Wing, St Thomas' Hospital.

## Phones

You and your child can use the bedside telephone for a fee. There are also two payphones on the ground floor.

### Calls made:

- from the bedside are 10p/minute at all times
- to the bedside by friends and family are charged at 39p/minute off-peak (7pm to 7am), and 49p/minute at all other times.

You and your child can bring your mobile phones into hospital, but please keep them on silent mode (or use headphones) and be considerate to other patients when using them.

If you've forgotten your mobile phone charger, there is a secure recharging unit available for all smartphones in Ocean, Evelina Outpatients, Ground floor just before the nurses' station. It is free to charge for 30 minutes. This should charge it to 40%. There are more charging points at the Knowledge and Information Centre (KiC), South Wing, and in the main entrance, at St Thomas' Hospital

## Other activities

Being in hospital can be scary for children and the days can seem longer, but at Evelina London there's always something going on.



## Radio Lollipop

Radio Lollipop is our hospital radio station. They play lots of great music. The DJs chat to staff and patients to find out what is going on at Evelina London.

You can listen to Radio Lollipop on your bedside radio (button number five). Listen on 'Toptastic' Tuesdays and 'Thrilling' Thursdays, 6.15pm-8pm.

Radio Lollipop's studio is on Level 3 (Beach), in our atrium.

Look out for Radio Lollipop volunteers on your ward. You or your child can request a song.

## Hospital dogs

Friendly therapy dogs, come and visit Evelina London regularly. They love to be stroked and cuddled.

Ask your nurse if you would like to meet them on their next visit.

## Giggle Doctors

Giggle Doctors can show you magic, make model balloon animals and, most importantly, make everyone laugh! You can ask your nurse when the Giggle Doctors will be visiting your ward.

## Play rooms

Play is an essential part of your child's recovery. The playroom is available during the day and you can take toys to your bed space.

Please make sure that your child and their siblings are always supervised in the play room. The play team are available Monday to Friday, 8am-5pm and can provide activities and distraction therapy. Please ask your nurse to contact them. The ward has two playrooms, one at each entrance to the ward.

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doctor AGCS



no

## Evelina Hospital School

Our school provides daily education for children and young people aged 2-19 (pre-nursery to the end of year 13 in secondary school). Deemed 'Outstanding' by Ofsted in 2009, 2013 and 2017, the school caters for over 1,500 students each year.

The school staff teach a broad and creative curriculum, working closely with children's families, home schools, hospital staff and other professionals involved in the children's care. They aim to make sure children are, as far as possible, accessing the same work as their classmates.

Teaching takes place in the school in the main atrium on level 3 (Beach) for those who are well enough to leave their ward. The space is divided into Sun classroom for children in the Early Years and Foundation Stage and Key Stages 1 and 2, and Moon classroom for young people in Key Stages 3, 4 or 5.

Children who are not yet ready to come down to the atrium school are taught at their bedside, generally in shorter sessions of 25-45 minutes, made to fit the needs of the pupil.

The school is open during term time from 10am-12pm and 1.30pm-3pm.

# Chapter 6: Other wards

The Evelina London Children's Hospital is themed around the natural world, from the ocean at ground level to the sky at the top. Visual symbols and colour themes are used to make finding your way around easier.

## Arctic



Arctic is an area on the first floor, where children may come for scans or specialist investigations. There are no wards and children do not stay overnight in this area.

## Ocean



Ocean is an outpatient area where children come for appointments. You might come back here after discharge to see some of the team in clinic. There is an AMT café, and activities for children including a helter skelter!

## Forest Ward

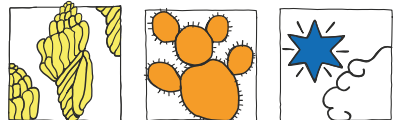


Forest Ward is on the second floor of Evelina London. It is also called the paediatric intensive care unit (PICU). Children who need the most intensive treatment or closest monitoring are cared for here. Children may be transferred from another clinical area, or sometimes another hospital, because they need intensive treatment. Children may also come to intensive care after a planned operation. The South Thames Retrieval Service (STRS) are based there. Most of our operating theatres are on the second floor.

There is a separate information leaflet with more information, Forest Ward Paediatric Intensive Care Unit. For reception, tel: **020 7188 4500 / 4501**.

## Neonatal Unit (NICU)

The Neonatal Unit is based at St Thomas' Hospital. It provides specialist care for premature and sick babies and includes an intensive care unit (NICU), high dependency unit (HDU) and a special care baby unit (SCBU). The Neonatal Unit is on the Sixth floor, North Wing, St Thomas' Hospital.



## Other wards

Beach Ward (third floor), Savannah (fourth floor), Mountain (fifth floor) and Sky (sixth floor) house different specialty teams. The Evelina London website has more information on these wards and the type of patients they care for: [www.evelinalondon.nhs.uk/parents-and-visitors/wards/our-wards.aspx](http://www.evelinalondon.nhs.uk/parents-and-visitors/wards/our-wards.aspx)

# Chapter 7:

## The teams

During your time in the hospital you will meet a lot of different people. It can be overwhelming and difficult to remember who they all are. This part of the booklet will help you understand who some of the professionals are, and what they do.

### Compass team

#### **Why is there an Evelina London Compass team?**

Being in hospital can be a worrying time for children and families. It can be confusing when lots of health professionals are involved, each looking after a different medical specialty. In response to feedback from families, we have a dedicated Compass team to help join up care. We aim to work with the wider team to provide better communication, coordination and continuity of care.

## Who is the service for?

The service is for children and young people with medical conditions that need the input of at least two different teams. The Compass team's focus is long-term plans, including planning for home. Your child's condition needs to be stable enough to allow for this stage of care.

We work with community and local hospital teams to help identify what care is needed in hospital and what can be given closer to or at home.

We work closely with the acute (emergency) general paediatric team. If your child's condition changes so that daily clinical reviews are needed, care will be transferred back to their team. The Compass team are on site Monday to Friday, 9am-5pm. If any concerns arise outside of these hours, the acute general paediatric team are available. Questions relating to the longer-term plan for your child's health can be answered by the Compass team.

The team is made up of a general paediatric consultant, clinical nurse specialist and family support worker. We work closely with the WellChild discharge coordinator. There will be others involved and some of those roles are explained below. The professionals in charge of delivering care will change at different stages of your child's medical journey.

**Compass consultants** are expert general paediatricians who see children with a wide range of health problems. They will have an overview of the different teams and will see your child twice a week.

They will work with others who are involved in your child's care to answer queries and coordinate plans with you. The consultant changes each week but they pass on the information to make sure there is continuity of care. You will have a **lead consultant**, often different to the compass consultant, who will be the consultant that follows-up your child in clinic if needed.

The **complex care clinical nurse specialist** is a senior nurse and will be a point of continuity across your child's hospital stay. Their focus is care given on the ward, ensuring you are involved, informed and supported during your admission. **The Family Support Worker (FSW)** provides emotional and practical support to families during their stay in hospital. This includes aid accessing relevant services related to finance, education and housing.

## Compass work

We make sure there is regular communication with children, young people and families. There is a space at the end of this booklet to write down yours and your child's goals, concerns and questions. We talk through these to help plan care together.

Discussions will take place between different teams in and outside of the hospital to help us see the whole picture. We try to give clear, consistent information, but at times there may be differences of opinion or reasons to change plans. This will be discussed openly with you.

Sometimes large meetings are held, with all the teams, to discuss care. You will be asked how you would like to be involved in these



meetings. You might want to join the meeting or be updated after.

You will be offered the chance to speak to psychologists about your own experiences. The experience of having a child in hospital can be very difficult, and many families have found this really helpful.

Growth reviews monitor weight and height twice a week, with input from dietitians as needed.

Immunisation reviews keep children on track as ill health and hospital admissions can often interrupt the normal schedule.

Your child's development will be monitored and supported by physiotherapists, speech and language therapists, and occupational therapists as needed. The school and play therapists will offer developmentally appropriate social and educational support.

You will be supported in learning new skills. We expect you to engage and attend planned training sessions. The timings will be arranged with you in advance.

If you have any questions or concerns about the complex paediatrics service, please ask your nurse to contact the clinical nurse specialist via switchboard, Monday to Friday, 9am-5pm. Out of hours, please contact the on-call general paediatric team.

We really value your feedback to help us understand how to improve and our impact. We would be grateful if you would answer the survey below. All answers are anonymous.

<https://forms.gle/LuvAFh6wjFavda4N7>

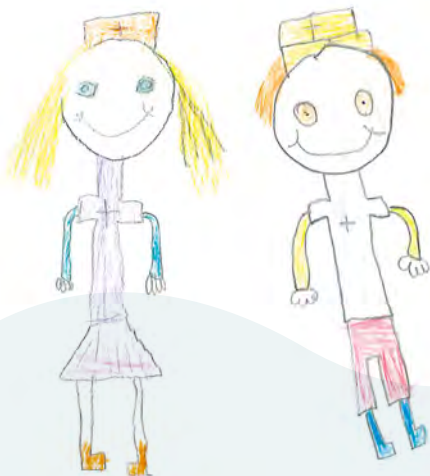
## Everyone else

There are many other people who might be involved in your child's journey. You might have other consultants, for example, a cardiologist or surgeon, who will take the lead for their areas.

There is always an acute general paediatric team, led by a consultant on the ward, responsible for acute/emergency care 24 hours a day, 365 days a year.

Many of the other professionals involved in your child's care are explained in the following pages. Please see our website for more information. Staff should always introduce themselves and their role, but please ask if you are not sure.

**Discharge coordinator (WellChild nurse)** is a senior nurse who specialises in discharging children with complex needs. Their role is to coordinate your child's discharge from Evelina London Children's Hospital, either back to your local hospital or home.



They will meet with you to talk about the discharge process and what it means for you. They will help organise multidisciplinary team (MDT) meetings with all the professionals involved in your child's care. A final discharge planning meeting will be arranged, usually a week before your child goes home.

If your child has been in hospital for a long time a phased discharge might be suggested. This means taking your child home for one or two nights, before the agreed discharge date, to help build confidence. They visit the wards each day and can also be contacted on the phone.

## Psychology team

Clinical psychologists support people to understand and manage their experiences, thoughts, feelings and behaviour. They help young people and their families cope with some of the difficulties that may come from having a health condition, and/or its treatment.

The paediatric psychology team is made up of different clinical psychologists. They are supported by trainee and assistant psychologists.

They work as part of the medical teams, alongside medical and nursing staff. They are here to support children and young people who have a health condition and their families at Evelina London.

The psychology team often meet young people and their families while they are staying in hospital or before they are admitted. If you would like to talk to them, you can ask a nurse or any member of the team to contact them. The medical team might offer you the opportunity to meet with them.

**Here are some of the things they might be able to help you with:**

- Preparing for and coping with medical treatments and hospital appointments, for example MRI, ECG, blood tests, injections and hospital visits.
- Coping with changes in day-to-day activities.
- Coping with being in hospital for long periods of time.
- Dealing with concerns regarding the future.
- Managing symptoms such as pain, breathlessness or tiredness.
- Managing worries or concerns about difference, for example surgical scars or reduced exercise tolerance.
- Managing the impact of a health condition and/or treatment on wider life, such as school, friendships and family relationships.
- Supporting siblings.

Sometimes they may not be the best team to help you. If this happens, they can help you to access the right services.

When you first see the psychologist, they will talk with you and your child about how things are at the moment and any difficulties that they/you would like some help with. They often meet families together at first, but can also meet with parents and children separately, depending on what is felt to be most helpful. If you would like to discuss anything before the appointment please call them.

The psychology team work as part of the Evelina London healthcare team, and often share information within the team to provide joined-up care for your child. If there is any information that you do not want shared with the wider team, please let them know.

Everyone working at our hospitals and the NHS has a legal duty to keep your child's information secure and confidential. However, they also have a responsibility to protect your child and others from harm. So, there may be times when they need to share information with other professionals. They will discuss with you and your child what information needs to be shared and who with.

“ My son's condition has greatly improved from his diagnosis when things looked really bad. I would have liked to have been advised not to give up hope. ”

**Parent at the focus group**

## Palliative care

The palliative care service supports babies (before and after birth), children and young people with life-limiting and life-threatening conditions, as well as their families and carers.

The aim is to make sure your child and family are supported to live as well as they can for as long as they can, within the limits of the illness. The palliative service manages a wide range of conditions. Lots of the conditions are rare and the prognosis is often unpredictable. There are times when the palliative care team will work alongside teams who are working towards curing or modifying the disease.

Each child and their family are different. The role the team plays will depend on your child, where they are on their medical journey and your wishes. Care can include management of distressing symptoms and help accessing respite (short breaks). It can also include advance care planning and support with end of life care.

This service is available to children who are inpatients at Evelina London, in hospices, and in their own homes. They offer care and support to children and their families from across south east London and the south east of England. They work closely with local teams in the community and with colleagues in adult services.

The team of clinical nurse specialists, clinical fellows and consultants are based at Evelina London, but also visit their patients in a variety of care settings and in patients' homes. The service operates within Evelina London Children's Hospital, Monday to Friday, 9am-5pm, and also provide 24/7 phone support to the families under their care, tel: **07747 267799**, Monday to Friday, 9am-5pm (except bank holidays), email: **paediatricpalliativecare@gstt.nhs.uk**

Out of hours contact them through the switchboard.

## Occupational therapy

Occupational therapy can help babies, children and young people to learn and play so that they can develop, and reach their full potential. It allows them to participate in daily life to improve their health and wellbeing. Daily life is made up of many activities (or occupations). Occupations for children or young people may include self-care (bathing, eating a meal, or toileting), being productive (going to nursery or school) and leisure (playing with friends or doing hobbies).

**If your child has complex needs or is experiencing a long hospital stay, the occupational therapist can advise and support with:**

- assessing your child if their functional skills have changed or got worse and give advice or therapy intervention as needed
- how to manage daily self-care occupations on the ward if you are having difficulties

- assessing your child's development and providing a therapy programme, where needed, to support with physical or cognitive skills through play
- helping screen your home environment if you have any concerns over the suitability for safe discharge (but they do not have a role in offering you alternative accommodation).
- reviewing existing equipment, such as seating/wheelchairs, if you have any concerns, or assessing and loaning equipment for use on the ward if necessary
- linking up with your community teams to update them or make referrals as required.

## Dietitians

The dietitians can assess and monitor growth and nutrition, and the need for specific dietary input. This can include designing personalised feeding plans to make sure your child's needs are met.

## Speech and language therapy (SLT)

The SLT team support feeding and communication. They work with children who have difficulties eating and drinking to make sure swallowing is safe and mealtimes are enjoyable. They can also help with communication while your child is in hospital. They assess and support children who have had changes to their speech,



language, understanding and voice quality. If your child is going to be in hospital for a long time, they can provide developmental communication advice and support to promote your child's communication skills.

## Physiotherapy

Physiotherapists assess and treat babies and children with a wide range of physical problems and conditions caused by illness, injury or disability including:

- conditions affecting joints and bones
- neurological conditions
- heart and chest conditions
- prematurity.

They use a range of techniques to educate and support recovery, and to maximise functional ability.

## Community therapy teams

The hospital dietitians, occupational and physiotherapy teams have colleagues working within the community. When it is felt to be needed they will hand over information about your child to make sure they get the right support on discharge and when back at home too.

# Chapter 8:

## Useful sources of information

### WellChild

WellChild is the charity which established the discharge coordinator role in 2013. The WellChild philosophy is that every child, however complex their needs, should be able to live at home.

Families are able to access the WellChild Family Tree Network for peer support, and they also provide fun days out for families, website: [www.wellchild.org.uk](http://www.wellchild.org.uk)

### Family Action

Family Action give practical, emotional and financial support to those who are experiencing poverty, disadvantage and social isolation across the country. website: [www.family-action.org.uk](http://www.family-action.org.uk)

### Contact

Contact give online, printed and helpline advice on education, benefits and finances, childcare, social care, medical information and more, website: [www.contact.org.uk](http://www.contact.org.uk)

## Other useful links

### Health, conditions and treatments

NHS, website: [www.nhs.uk/pages/home.aspx](http://www.nhs.uk/pages/home.aspx)

Evelina London resources, information leaflets on conditions, procedures, treatments and services offered at our hospitals, website: [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

### Link collating useful websites for accessing support

[www.evelinalondon.nhs.uk/our-services/community/community-paediatrics/useful-websites.aspx](http://www.evelinalondon.nhs.uk/our-services/community/community-paediatrics/useful-websites.aspx)



## Guidance and help accessing support

**Scope** – Disability equality charity providing practical information and emotional support, tel: **0808 800 3333**, website: [www.scope.org.uk](http://www.scope.org.uk)

**Mencap** – Supporting people with learning disability, as well as their families and carers, tel: **0808 808 1111**, website: [www.mencap.org.uk](http://www.mencap.org.uk)

**Cerebra** – Provide research driven, high quality health and social care advice and support for the families of children with brain conditions, tel: **0800 328 1159**, website: [www.cerebra.org.uk](http://www.cerebra.org.uk)

**Council for Disabled Children** – Umbrella body for the disabled children's sector bringing together professionals, practitioners and policy-makers, website: [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)

**The Disabled Children's Partnership** – Coalition of more than seventy organisations campaigning for improved health and social care for disabled children, young people and their families, website: [www.disabledchildrenpartnership.org.uk](http://www.disabledchildrenpartnership.org.uk)

**Evelina London mediation service** – An independent, confidential service supporting families, patients and health care professionals, tel/text: **07543 244043**, email: [evelina@medicalmediation.org.uk](mailto:evelina@medicalmediation.org.uk)

**Citizens Advice** – Confidential free advice on a range of issues, including benefits, housing, immigration and more, website: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

## Specific practical support

**Queen Elizabeth's Foundation for Disabled People** – Provide practical, caring and innovative solutions to enable people, whatever their disability, live their lives to the fullest extent possible, website: [qef.org.uk](http://qef.org.uk). A specific page linked to this charity is dedicated to making it easier for disabled people to fly with lots of pragmatic support detailed. website: [www.tryb4ufly.co.uk](http://www.tryb4ufly.co.uk)

**Changing Places** – Identifies toilets in the UK with height-adjustable changing spaces and hoists, website: [www.changing-places.org](http://www.changing-places.org)

**Dial-a-Ride services** (on behalf of Transport for London) – Free, door-to-door transport service for people with a mobility difficulty and/or disability, tel: 0343 222 7777, website: [www.tfl.gov.uk/modes/dial-a-ride/](http://www.tfl.gov.uk/modes/dial-a-ride/)

## Local community resources

**Lambeth Council** – Support for children and young people with special educational needs and disabilities within Lambeth, website: [www.lambeth.gov.uk/lambeths-send-local-offer](http://www.lambeth.gov.uk/lambeths-send-local-offer)

**Southwark Council** – Support for children and young people with special educational needs and disabilities within Southwark, website: [www.localoffer.southwark.gov.uk](http://www.localoffer.southwark.gov.uk)

## Financial/debt resources

**Money Advice Service** – Free and impartial money advice set up by the government, website: [www.moneyadviceservice.org.uk](http://www.moneyadviceservice.org.uk)

**UK Bill help** – Information and assistance with rent, bills and debts, website: [www.billhelp.uk](http://www.billhelp.uk)

**National Debtline** – Free debt advice over the phone and on line, tel: 0800 808 4000, website: [www.nationaldebtline.co.uk](http://www.nationaldebtline.co.uk)

**Step Change** – Free debt advice over the phone and on line, tel: 0800 138 1111, website: [www.stepchange.org](http://www.stepchange.org)

## Providing essentials

**The Trussell Trust, foodbanks** – Find a foodbank near you, website: [www.trusselltrust.org](http://www.trusselltrust.org)

**Shelter** – Advice, support and legal services for people struggling with bad housing or homelessness, website: [england.shelter.org.uk](http://england.shelter.org.uk)

**Healthy Start** – Free fruit and veg, milk and vitamins, tel: 0345 607 6823, website: [www.healthystart.nhs.uk](http://www.healthystart.nhs.uk)

## Supporting the family

**Family Lives** – Advice on all aspects of family life from bonding with your new baby, dealing with tantrums, positive discipline, bullying, communicating with teens, divorce and separation.

Tel: **0808 800 2222**, website: [www.familylives.org.uk](http://www.familylives.org.uk)

**The Mix** – A charity that provides free, confidential support on any issue for young people under 25, tel: **0808 808 4994**, website: [www.themix.org.uk](http://www.themix.org.uk)

**Home Start** – A community network of trained volunteers and expert support helping families with young children through their challenging times, website: [www.home-start.org.uk](http://www.home-start.org.uk)

**Kooth** – Anonymous and free on line counselling and emotional well-being support service for young people aged 11-25 years, website: [www.kooth.com](http://www.kooth.com)

# Chapter 8:

## Your space

### Helpful notes

We encourage you to ask the team questions that you have about your child's care and future direction. Please use this space to write these questions down. You can also write down what is important to you and your child and set your goals for the week ahead, to help guide conversations with professionals.

For children, young people and families who are in hospital for long stays it is helpful to agree a date for parents or carers to receive regular updates from the lead professionals and share any concerns. Please can you detail a preferred date and time for this between Monday to Friday 10:00-17:00. The teams will do their best to try and align with this.





# Notes

# Notes

## Key appointments and contacts

Space to make a note of important appointments and/or the names of professionals involved in your child's care. The names are particularly important when you leave the hospital. You need to be clear who you should contact with a particular concern.



# Notes

## Comments, complaints and compliments

All comments and feedback are greatly welcomed. In the first instance, please speak to the nurse looking after you or the nurse in charge. When you are discharged you will be given a questionnaire to rate and feedback about your stay.

If for any reason you feel that we are not communicating with you as well as you would like, please feel free to contact our ward managers or matrons. We also have an independent Evelina Mediation Service and the Patient Advice and Liaison Service (PALS).

Tel: **020 7188 8801** (PALS), email: [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

Tel: **020 7188 3514** (complaints) email: [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

Tel: **0800 731 0319** email: [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk)

Website: [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)



**Thank you to all the families  
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