

Children's neurorehabilitation

Family handbook

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Your child's keyworker is

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Keyworker contact information:

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The Snow Leopard neurorehabilitation service

The neurorehabilitation unit is based on Snow Leopard ward at St Thomas' hospital. It offers inpatient rehabilitation for children and young people up to the age of 16, who have acquired brain or spinal cord injuries.

Patients who are admitted don't need significant medical treatment, and are ready to begin the rehabilitation process to regain functions that might have been lost as a result of their injury. Patients are usually on Snow Leopard ward for about 6 weeks.

It is expected that one parent or carer will stay with their child on the ward. Other family members can stay locally, see page14.

The neurorehabilitation team works with the patient, their family, school and community services. We help the child develop skills, and to reduce the impact of their injury on their everyday life when they leave hospital.

Personalised, goal-directed programmes of rehabilitation are designed to meet the specific needs of each patient. Understanding the patient's unique set of needs means that therapies and interventions can be finely targeted. This enables us to work towards goals that are personal, important and meaningful to the patient and their family.



The Snow Leopard team

The neurorehabilitation team is a multidisciplinary team (MDT), made up of different healthcare professionals who all work together to support patients.

Your team

These are the different people who will be working with you while you are staying on Snow Leopard. You will be introduced to everyone, and get to know them.

Consultants and doctors

The doctors in the neurorehabilitation team are specialists in neurology and neurodisability. When your child is on Snow Leopard, they will have minimal medical needs, but the doctors are there to help if they are needed.

The therapists will work with the doctors to coordinate your child's care while they are on Snow Leopard, and liaise with local services to make sure appropriate discharge and follow-up support is in place.

Nursing team

The nursing team is made up of the lead nurse, nurses, student nurses and nursing assistants. Each ward has a ward sister and a ward matron who manage the ward.

The nurses will monitor your child throughout the day. Where possible, we encourage parents to administer their child's medicines, but the nurses are nearby to offer support if needed.

It is an important part of rehabilitation for nurses to support patients to be independent, rather than doing things for them. For example, while on other wards nurses help the patient to get dressed, but if getting themselves dressed is a therapy goal, the nurses will try to avoid helping. This approach helps to enhance rehabilitation.

If you have any worries or concerns throughout your stay that are not addressed by our nurses, please speak to the ward sister.

Clinical psychologist

Clinical psychologists assess and offer support with your child's:

- thinking and learning skills
- emotional wellbeing
- behaviour

There are lots of things that can be scary, worrying or upsetting about having a brain or spinal cord injury. Clinical psychologists can help your child explore how an injury has affected them. They can help your child to manage difficult feelings or emotional experiences, which could affect how much progress they make in rehabilitation.

Brain injuries can affect thinking, learning and behaviour. Psychologists will work with your child to explore what effect their injury has had on their thinking and learning. They can also help your child's wider system (like school) understand any areas where extra support might be needed.

We know that brain injuries impact a person's friends and family members, as well as the patient. We offer support to others who might want extra support to help them make sense of what has happened, and to manage the emotional demands of the treatment and recovery process.

Occupational therapist

An occupational therapist works with your child (and caregivers, if appropriate) to reach your child's best possible level of independence in everyday activities. This includes getting dressed, washing, feeding themselves, learning and school, as well as play or leisure activities. If needed, the occupational therapist will provide your child with appropriate mobile seating and any equipment which might help them to be more independent in everyday activities while they are on Snow Leopard.

Depending on your child's needs, you might see an occupational therapist every weekday for a therapy session. These sessions might take place in the therapy gym, or during everyday activities (such as mealtimes, or getting ready in the morning). If appropriate, sessions might be in the community using public transport and accessing local shops.

Speech and language therapist

Speech and language therapists assess, diagnose and support communication needs, and eating, drinking and swallowing needs.

Communication is assessed to identify areas of strength, and aspects of communication that can be more challenging. These might include:

- attention and listening
- understanding language
- speech sounds
- expressive language (talking)
- social skills (including story-telling and using jokes as part of ordinary conversation)

After a period of assessment, the speech and language therapist will work with your child to develop goals that are meaningful for them. Some of the approaches will be directly with your child, while others might involve coaching and practicing target skills in other environments, to support skills being embedded in everyday life.

Physiotherapist

In neurorehabilitation, physiotherapy is used to assess and treat physical capabilities in people with brain injuries, and provide exercise advice and help in returning to independence around the home and outside environment.

The main reason the physiotherapist will see your child is to assess the change in physical capability before and after a brain or spinal cord injury. This can vary significantly between patients, and their physiotherapy programme will be targeted to these needs.

Most patients will have physiotherapy every day. This might take place on the ward, with opportunities to visit our local parks and playgrounds.

Physiotherapy might include the use of equipment such as walking and standing frames, splinting (helping to improve movement at a joint) and having a cast.

Exercise is done using play, computer programmes (such as virtual reality), and in parks and playgrounds, as well as more formal exercise.

Play therapist

Play therapy uses play activities to help children cope with any pain, anxiety or fear they have during their time in hospital. Play is used in several ways:

- to prepare children for treatment
- to distract them when having a procedure
- to help them understand their experiences

Play can be used to reduce anxiety, and explore fears or misunderstandings they have about their condition.

Preparation is an important part of play therapy. It allows children to become familiar with hospital equipment, staff, and environment. It offers positive information and develops effective lines of communication between patients, families and staff.

Specially adapted dolls, books and equipment let children experience through play the procedures they will undergo. Play can also teach patients how to manage and take responsibility for some of their own care.

Distraction techniques are a coping mechanism that encourages a child to relax and feel secure. This technique might be used for procedures such as blood tests, CT scans, and dressing changes.

Evelina Hospital School

School-aged children who are well enough are expected to attend the Evelina Hospital School during term time. However, it is also important that your child does not get too tired, so your therapy team will work with the hospital school to find a balance.

There will also be liaison between the hospital school and your child's local school, to make sure there is consistency of subjects, and to offer support with the return to school.

Your child's neurorehabilitation journey

At the beginning of your child's admission, you will be allocated a keyworker. This is a member of the therapy team who you will see regularly throughout your child's stay and who will be involved in the coordination of your child's care.

The neurorehabilitation team will work with you to identify a set of goals to be worked towards. You might also discuss longer-term goals that will continue after your child has left hospital. You will have weekly goal meetings to review progress, and to adapt goals if necessary.

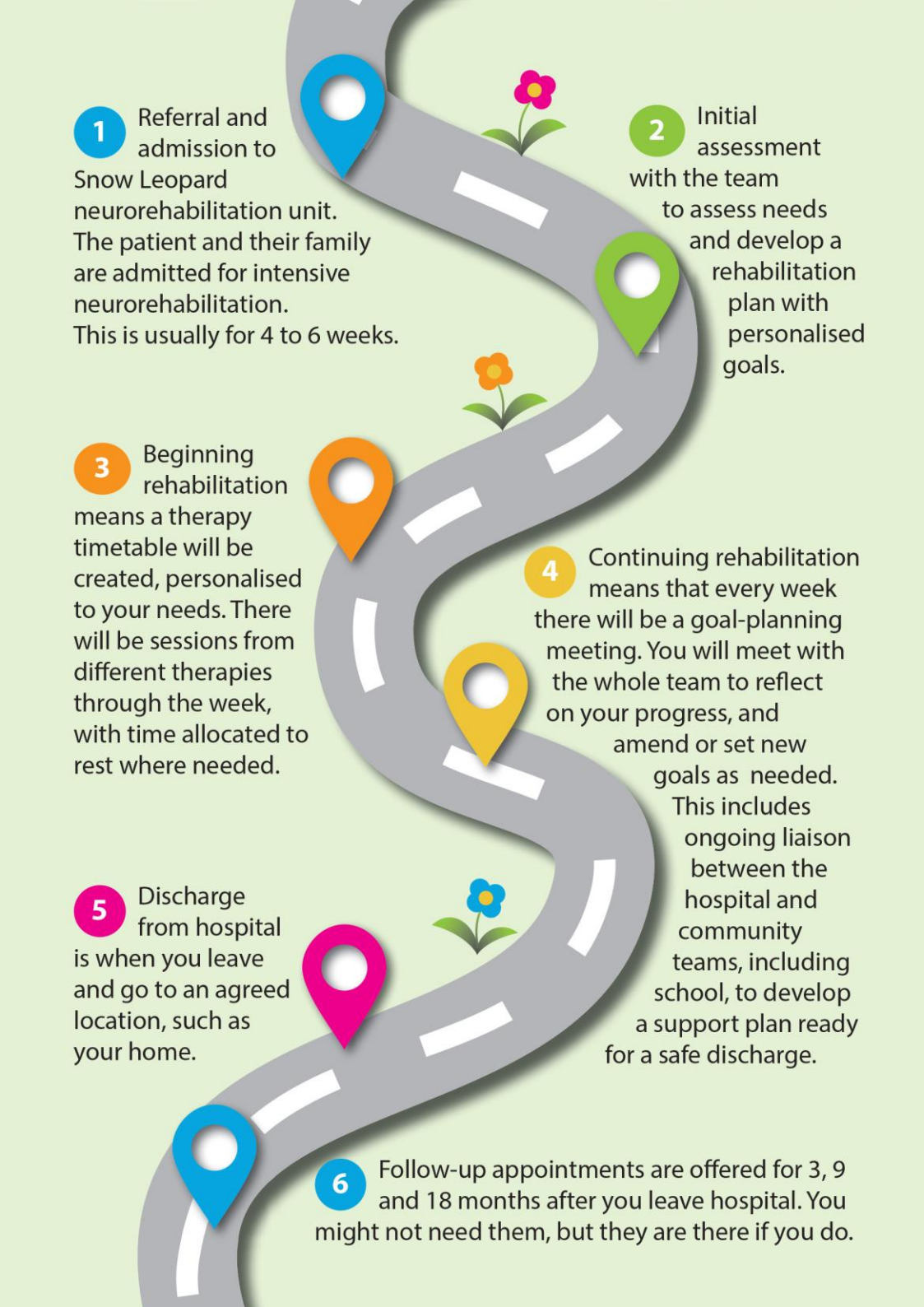
We know that the process of recovering from a brain or spinal cord injury is an unpredictable and tiring process. Neurorehabilitation relies on finding a balance between activities to give people a chance to develop skills they need to achieve their goals, while having enough rest to allow the brain time to heal. Rest is also important to help new skills and information to be processed.



Neurorehabilitation roadmap

On the opposite page there's a 'roadmap' of what your child's rehabilitation journey might look like.

Please remember that everyone's journey will be different, and will take place at different paces.



1 Referral and admission to Snow Leopard neurorehabilitation unit. The patient and their family are admitted for intensive neurorehabilitation. This is usually for 4 to 6 weeks.

2 Initial assessment with the team to assess needs and develop a rehabilitation plan with personalised goals.

3 Beginning rehabilitation means a therapy timetable will be created, personalised to your needs. There will be sessions from different therapies through the week, with time allocated to rest where needed.

4 Continuing rehabilitation means that every week there will be a goal-planning meeting. You will meet with the whole team to reflect on your progress, and amend or set new goals as needed. This includes ongoing liaison between the hospital and community teams, including school, to develop a support plan ready for a safe discharge.

5 Discharge from hospital is when you leave and go to an agreed location, such as your home.

6 Follow-up appointments are offered for 3, 9 and 18 months after you leave hospital. You might not need them, but they are there if you do.

An example of a weekly timetable

While they are on Snow Leopard ward, children have therapy sessions to address their specific needs. These will be booked in. Here is an example of how a patient's timetable might look.

OT = Occupational therapy

Physio = Physiotherapy

SLT = Speech and language therapy

Psych = Psychology

To support your child with daily tasks and routines,

	Mon	Tues	Wed	Thurs	Fri
8am	Breakfast				
9am	SLT			School	
10am		Physio	OT	Physio	Play therapy
11am	Physio	School	SLT	Psych	SLT
Noon	Lunch				
1pm	Rest				
				Goal meeting	OT
2pm	OT	SLT			
3pm			Physio	OT	School
4pm	Play therapy	Psych			
5pm	Dinner				

visual schedules can be provided. These can help develop routine and learning (or re-learning) skills that might have been impaired.

If appropriate, we encourage families to go home at weekends, to support the preparation for discharge. It also offers children the opportunity to practice the skills they have learnt during the week.

Accommodation

A bed, linen, towels, and showering facilities are all provided for patients and a parent or carer. Your therapy team will discuss any necessary arrangements with you.

If other family members want to stay nearby, Ronald McDonald house provides a home for families of children being cared for at Evelina London. Staying here is completely free and only a few minutes' walk from the hospital. There are 59 en-suite rooms, each accommodating up to 4 people (a few can accommodate 6). There are communal lounges, kitchens and playrooms. When you have a room, you can stay for as long as you need.

If you are interested in using Ronald McDonald House, speak to a member of ward staff and they can refer you.

Other places to stay

Travelodge, 195-203 Waterloo Road, SE1 8UX

Ibis Hotel, 43-47 Southwark Bridge Road, SE1 9HH

Tune Hotel, 118-120 Westminster Bridge Road, SE1 7RW

Premier Inn, County Hall, Belvedere Road, SE1 7PB

Settling in to the ward

While you're staying on the ward, there are a few rules you need to follow. This is to make sure that the ward is a comfortable, pleasant place to be for patients and their families.

- Visitors are allowed, and encouraged, but we ask that you only invite 2 visitors at a time, and no one after 8pm. This is to maintain safety, and to make sure there aren't too many people on the ward.
- You must let the nursing staff know when you are leaving and returning to the ward, before you leave.
- Use the intercom system at the front door to the ward. This lets us know how many people are on the ward, and who they are.
- Noise should be kept to a minimum in the evenings and early mornings.

What if you can't stay?

Lots of parents have responsibilities which make staying difficult. Please discuss this with your keyworker so we can find a solution together.

Mealtimes

- Breakfast at 8.15am
- Lunch at midday (hot and cold options)
- Dinner at 5pm (hot and cold options)

Food menus are provided by the Food Standards Agency.

You can bring your own food to the ward and eat this whenever you like. There is a small kitchen area on the ward, with a fridge. All food must be labelled, and please make sure there is room for other families to use these facilities too.

Facilities for parents

The parents' room is a place for you to relax. It has a TV, microwave, fridge, and tea and coffee making facilities.

There is also a washing room, with a washing machine and dryer for families to use.

Leaving the ward

As long as your child is well enough, and supervised, they can leave the ward when they want to during their free time.

Parents can also leave the ward, but please tell a member of the nursing team when you leave, and when you expect to return.

Visitors

Your friends can come and visit when you are not in therapy sessions. Ward visiting times are 10am to 8pm. However, there is an afternoon quiet time from 12.45pm to 1.30pm.

What to do if you need help

If it is not an emergency, you should go to the nursing station where someone will be able to help you.

In an emergency, there is a red cord in each room for you to call for help.

Spiritual health care

This includes a 24-hour chaplaincy service, and religious services for different faith groups, or people of no particular faith, who would like someone to talk to.

A packing checklist

We encourage you to make the room your own, so please bring items that will relax your child and make them feel at home, such as cuddly toys and their own duvet covers and pillows.

There are magnetic boards, so you can bring photographs from home, and space for personal items that would make your child feel more at home.

Other things you might like to consider bringing are:

- Blankets
- Eye mask and ear plugs
- Headphones
- Tablet (and charger) to watch films
- Phone (and charger)
- Colouring books
- Warm socks or slippers
- Trainers
- Comfortable clothes that are suitable for exercise
- Books
- Games

Tips from other parents

We asked families who have stayed on the ward for advice on what made their stay more comfortable. Here is what they said:

‘Try not to feel guilty about taking a break when you need to. Ask the ward staff to watch your child while you get some fresh air.’

'Keep positive and work with all the specialists to help your child. The support you receive is amazing.'

'The rooms are quiet at night so there's no need to worry about you and your child not being able to sleep.'

Things to bring with you

- Cards, posters, pictures to personalise the space
- A nice mug!
- A teddy or cuddly toy that your child loves, and a tablet to distract your child or yourself.

Some parents choose to bring their own duvet and pillow.

Funding or charity support

Alongside continued support from Evelina Hospital, there are several charities which provide grants to families to make life after leaving hospital easier.

Child Brain Injury Trust

National charity that offers parent and sibling support. Also runs events for parents to meet others in a similar situation, and offers legal support, counselling, and e-learning courses. Has 'Give a child a chance' (small grants for children to do activities), grants towards professional reports and assessments for special educational needs.

Web www.childbraininjurytrust.org.uk/

Roald Dahl's Marvellous Children's Charity

Offers grants for families facing financial hardship with a seriously ill child. Grants for things such as educational needs, specialist equipment, physiotherapy, and for parking and travel costs. **Web** www.roalddahlcharity.org

Children Today (Charity)

Offers grants for life-changing specialist equipment for children with serious illnesses.

Web www.childrentoday.org.uk

Headway

Website for specific areas of the UK offering detail on local support groups. Also hosts the podcast, 'The world beyond my head'. Each episode follows survivors of brain injuries and the topics important to them. **Web** www.headway.org.uk

Stress

Recognising stress

Having an unwell child is very stressful and worrying. Feeling stressed in this situation is completely normal. However, your wellbeing as their caregiver is very important, so please do not ignore your own feelings.

High levels of stress for long periods of time (chronic stress) can be detrimental to our mental and physical health. It is easy to ignore symptoms of stress as they often disguise themselves as smaller problems. It is important to notice symptoms in order to reduce them.

Physical symptoms: headaches, upset stomach, insomnia (not being able to sleep), chest pain, frequent colds or infections, dry mouth, clenched jaw, grinding teeth, aches and pains.

Emotional symptoms: easily agitated, frustrated or moody, feeling as though you're losing control, feeling bad about yourself (low self-esteem), feeling worthless or depressed, avoidance.

Cognitive symptoms: constant worrying, forgetfulness, disorganised thinking, inability to focus, poor judgement.

Behavioural symptoms: change in appetite (increased or decreased), procrastination (not being able to make decisions), increased alcohol or cigarette consumption, nail biting, fidgeting, and sleeping too much or too little.

Managing stress

Exercise

Physical activity produces endorphins, which are hormones in the brain. These act as natural painkillers and help improve mood and regulate sleep cycles. Just 5 minutes of exercise can produce these.

Connect with people

Research shows that talking to others alleviates stress. Support groups are a great way of meeting parents with similar experiences, and of sharing experiences and ideas.

Avoid caffeine, nicotine and alcohol

An intake of these, increases the number of stress-related hormones in your body, which can trigger the 'fight or flight' system, increasing stress.

Mindfulness

This is the process of paying attention to your thoughts without judging them. This can improve feelings of anxiety and depression. Resources include: Headspace[®], Calm, and Insight Timer (all available from Google Play and the App Store, but in-app charges might apply).

Have 'me' time

Taking care of yourself helps maintain physical, mental and emotional reserves, to prevent and manage future stress. Try to challenge yourself to do something for you.

Places to go when you need a break

There are some facilities at St Thomas' Hospital where you can buy a drink or snack:

- M&S café and food hall
- Costa
- WHSmith
- Shepherd Hall Restaurant
- Riverside restaurants

There are lots of other places within walking distance, if you need a break:

- Tesco Express, SE1 7AA (7-minute walk)
- Co-op, SE1 7NT (4-minute walk)
- Pizza Express, SE1 8YP (8-minute walk)
- Pure Gym, SE1 8TS (7-minute walk)
- Jubilee Gardens, SE1 7PG (4-minute walk)
- Waterloo Public Library, SE1 7QP (8-minute walk)
- Starbucks, SE1 7GQ (8-minute walk)
- Sainsbury's, SE1 7HR (6-minute walk)
- Archbishop's Park, SE1 7LE (8-minute walk)
- Boots, SE1 7ND (10-minute walk)
- Pret A Manger, SE1 7HR (5-minute walk)

Glossary

During your time on Snow Leopard ward, you might hear some unfamiliar words or phrases. You can always ask the team if you do not understand something. Here are some common medical words and phrases you might hear, and what they mean.

CT scan – computerised tomography scan, that produces detailed images of the inside of the body using X-rays.

CYP – child or young person

EEG – electroencephalogram (that assesses the electrical activity of the brain)

ELCH – Evelina London Children’s Hospital

EHCP – education health and care plan

EMG – electromyography, a procedure that assesses how well your nerves respond to being stimulated.

MDT – multidisciplinary team (a team made up of different types of healthcare professionals, such as physiotherapists, doctors, and psychologists).

MRI – magnetic resonance imaging, which uses a large magnet to produce detailed images of the inside of the body.

OT – occupational therapy

SLT – speech and language therapy

Notes

Support and more information

Cambridge University Hospital, for information about recovering from acquired brain injuries, **web:** www.cuh.nhs.uk/patient-information/recovering-from-an-acquired-brain-injury-abi/

The Children's Trust, for information about brain injury, **web:** www.thechildrenstrust.org.uk/

Encephalitis Society, **web:** www.encephalitis.info/

Child Brain Injury Trust,
web: www.childbraininjurytrust.org.uk/

Stroke Association, **web:** www.stroke.org.uk/

Contact us

Paediatric neurorehabilitation, Snow Leopard ward, 2nd floor, Block C, South Wing, St Thomas' Hospital. If you have any general enquiries about our service, please contact us, **phone:** 020 7188 0107, **email** gst-tr.paedsneurorehab@nhs.net.

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web:** www.evelinalondon.nhs.uk/leaflets

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