

My Neuro-Rehab Journal

Information for patients



This neuro-rehab journal has been designed as a booklet that you will keep and use during your time with us on the East Kent Neurorehabilitation Unit.

The booklet has various pages to fill in and look at over time.

It starts by asking you about yourself, what is important for people to know about your needs, and what type of neurological illness you are experiencing.

The journal also gives information about the unit, the staff, and the rehab journey itself, as well as a safe place to keep copies of handouts and your weekly timetable.

Finally, it acts as a good memory aid for you to jot down any exercises or homework to do in between therapy sessions. It can also be useful for your family to look through and use themselves or leave us messages if they have any.

Your therapists will support you in using it and may ask to see it now and then, so keep it to hand.



About me

This page can be filled in by you, your therapists, or your family

Name: _____

Date of birth: _____

Address: _____

Home phone number: _____

Mobile number: _____

NHS number: _____

Hospital number: _____

GP name: _____

GP practice and address: _____

GP phone number: _____

Emergency first contact: _____

Relationship: _____ **Phone:** _____

Email: _____

Emergency second contact: _____

Relationship: _____ **Phone:** _____

Email: _____

Social background

This page can be filled in by you, your therapists, or your family

I live: _____

Any dependents (children, elderly parents, pets): _____

Type of residence (house, bungalow, care home): _____

Do you work or volunteer? Yes / No (please circle) If so, where and how many hours?

What hobbies and interests do you have?

My team:

My Keyworker: _____

My Physiotherapist: _____

My Occupational Therapist: _____

My Speech and Language Therapist: _____

My Neuropsychologist: _____

My health

My health condition:

My timeline:

When did my injury occur? _____

Dates I was in the various hospitals: _____

Dates of the procedures and surgeries I have had: _____

When I came to the East Kent NeuroRehab Unit: _____

My estimated discharge date: _____

My current communication preferences: (for example keeping sentences short, using pictures or signs, checking I have understood before moving on to the next topic, giving me time to give my response).

What will I need help with in hospital?

To help me move around: _____

Eating and drinking: _____

Washing, dressing, and toileting: _____

What is neuro-rehab?

Brain and spinal injuries

Our brains do all our thinking, reasoning, planning, store memories, control all our physical actions (such as walking, talking, hearing, seeing, eating, sleeping, and breathing), and control all our feelings. Our brain is our control centre and it is connected to the spinal cord, which is a network of nerves that sends messages to and from our brains. It is by far the most complicated and sophisticated system in the world.

Brain injuries (knocks to the head, strokes, and tumours) or long-term neurological conditions (such as multiple sclerosis and epilepsy) can happen to anyone, at any time in their life. Sometimes these types of neurological injuries can change the whole pattern of a person's life, from changes to physical abilities, thinking skills, or emotional needs. Anyone who has had a brain injury has a different story to tell and no two stories are the same.

Injuries to the spinal cord can cause weakness or complete loss of muscle function, loss of feeling in the body below the level of the injury, and loss of bladder and bowel control. Spinal cord injuries can be caused by accidents or degenerative (worsening symptoms over time) changes in vertebrae or some kinds of infection.

You may have other nerve injuries (such as GBS (Guillain - Barre Syndrome) which affects your nerves in your arms and legs, causing weakness and changes in sensation.

Once medical stability has been achieved (meaning you are well enough in yourself and need no major physical procedures), your road towards recovery or partial recovery starts.

If you need more information about your condition, please speak to a member of staff.

How can neuro-rehab help me?

We do not fully understand how the brain recovers its functioning. We know that brain tissue does not spring back in to life. But we also know that brains do seem to recover in the first two years after injury. After that, recovery does tend to slow down but will continue for years (unless the neurological condition is known to be 'progressive' (it gets worse over time)).

When brain injury happens, it is likely that parts of the brain that were not previously used for a particular task can be used to perform functions previously performed by now damaged areas of the brain. In effect, new pathways and thinking routes are being opened up. It is a bit like if a big pothole appeared on the M1, a diversion or new route would need to be set up and put in place so cars can have a new way to travel. The process of recovery and rehabilitation is all about finding those new routes, and practising them as much as possible to get the traffic (or information) flowing again.

Research shows that the brain heals better in an 'enriched' environment, such as one that has some difficulty and where you can mix with others, whether that be other patients or hospital staff. That is why neuro-rehab wards are different from hospital wards. They are a place where you will have therapy sessions and practice tasks, such as washing, dressing, walking, feeding yourself, cooking in the kitchen, practising using stairs or getting in and out of cars, and going shopping. You can also practice other tasks such as working on speaking strategies and learning to manage tricky emotions that can come up during illness, such as low mood and anger. The aim of our work is to encourage you to do as much for yourself as possible, to get you as independent as possible.

Rehabilitation can only happen when therapists, families, and patients work together to get your brain back 'online'.

What does rehabilitation include?

Rehab tends to involve the following.

- Assessments to build up a good understanding of your current strengths and weaknesses.
- Planning realistic goals to work towards, in order to improve areas of weakness that have been found.
- Breaking your rehab goals down into achievable steps or skills.
- Teaching, practising, repeating, and learning again those skills or small steps.
- Providing stimulation to all your senses, such as carrying out exercises including touch and eye movements.
- Finding what is stopping you from being motivated and encouraging you to take part in rehab activities.
- Increasing awareness and insight, to improve engagement in neuro-rehab.
- Providing aids (such as walking sticks or wheelchairs so you can move around, and calendars and clocks to support your memory).
- Providing strategies and techniques for managing your difficulties (such as finding 'work-arounds' for tasks or re-learning how to do particular actions such as walking and eating).
- Supporting your family in their journey. This could include educating them on what brain injury means and talking to them about how they can support you in this phase of your recovery.
- Providing advice and support in helping set up your next recovery stage (for example home and further supported care).

The people who will help you in your journey include nursing staff, health care assistants (HCAs), doctors, occupational therapists, rehab assistants, speech and language therapists, physiotherapists, and clinical psychologists.

Frequently asked questions

- **How long will I be in hospital?**

How long you will stay in hospital will depend on your brain/spinal injury and how bad it is. Usually we like to spend a week or two letting you 'get used' to the ward, sort out any medical issues you may have, and assess your 'baseline' (your current strengths and difficulties).

Following this, we can get a better idea of how long you are likely to need our support and we can discuss this with you and your family. You will be given an estimated discharge date at this stage but this can change and depends on a lot of things (whether carers are available if you need them at home or whether you just need a little longer to achieve a bit more), so it is best not to get too fixated on a particular date but focus on the task in hand.

- **How much will I recover?**

Recovery is different for everyone and it is impossible to say at this early stage how much recovery will be possible. Research shows that recovery continues years after the injury. You may not get back to exactly where you were before your injury, but your healthcare team can help you start your rehab journey, so you are well enough to carry it on at home.

Sometimes injuries or neurological conditions are so severe that recovery can plateau (start off well but then not progress any further) or in some cases get worse. If this happens we will work with you to help you in finding a way of managing difficulties on a more long-term basis, and think about what your future needs may be. For example, we may help you think about what type of care you will need from your doctors, personal carers, and community nurses, and can provide equipment to your home or advise a care home what type of aids you will need there.

- **Can my family visit me?**

Yes. In fact we encourage it and we have a visitor policy in place. Please ask your ward manager or one of the nurses about visitor times.

You may find that speaking to your family can be pressured and it can be difficult to find things to talk about after a while of being in hospital. It can also be hard if you have communication difficulties or are very fatigued (tired). We always have ideas and neuro-rehab exercises that your family can do with you, so please just ask your therapists for handouts or advice about this. We also like to include family members in therapy sessions as much as possible, so they have the chance to learn about and be involved in your care (but only if you and they like).

You may find that family visits can be quite draining in the early stages of your recovery. Make sure you tell your family how much you want them to visit and how long to stay, so you can stop yourself from becoming too burned out and too exhausted to do your rehab the next day.

- **What type of things should I try and have with me in hospital?**

It is always good to have some comfy lounge wear or pyjamas to wear in hospital, clothes that are easy to get on and off. Your physiotherapist may also like your family to bring in some trainers or suitable footwear for walking.

In the quieter moments you will need things to keep you busy or connected with loved ones. A mobile phone or tablet with their chargers can be handy, along with books or magazines. Make sure you have some headphones, so you can watch videos or listen to the radio, and any glasses or hearing aids. Some people find an eye mask or comfy earphones also help them sleep better at night by tuning out background noise or light.

- **Why are you always asking me to make cups of tea?**

It may seem odd when we ask you to make a cup of tea or cook a meal, but these are just one of many practical ways of practising the whole range of your brain's skills. For example, to make a cup of tea you not only need the physical ability to stand and move about the kitchen, but you also need to be able to plan how you are going to do it, be aware of danger such as hot water, and use your memory to remember where things are kept and so on!

These are skills that usually go on in the background that we take for granted. After a brain injury the coordination of all these things becomes that much harder, so even though it may seem silly, all these types of tasks give you good opportunity to practice and learn to coordinate all these complex things once again.

- **What happens when I have to leave hospital?**

Discharge planning is a shared decision with yourself, your team, and your family and friends. The team will make sure you have everything set up for a safe discharge. You may need some support to be home safely and this will be decided based on what you can do at that time.

Once you are home you may be referred to your local Intermediate Care Team (ICT). This team will provide you with support (often in your own home) to meet any further rehabilitation goals you may have.

For some patients their care needs may be so high that they are not able to return home or they do not wish to, at least in the short-term. Support around this time will be given, mainly from social services.

Who is involved in my care?

- **Occupational therapists**

Occupational therapists will look at all of your needs - physical, psychological, social, and environmental. We will empower you to regain ability, confidence, and independence in performing everyday tasks such as washing and dressing yourself, cooking, and cleaning. We will also help you develop skills which underlie these activities such as budgeting, planning, and improving thinking and finding ways around problems. We may also give you special equipment and adaptations for around your home, and offer you support within your community. We wear a white T-shirt, with green trim and green trousers.

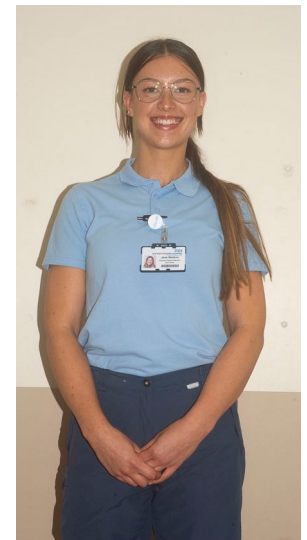


- **Physiotherapists**

We will support you by creating a treatment plan that encourages recovery of movement where possible. Building on this through strengthening exercises, sensory stimulation, and verbal feedback to help recover your ability to use muscles and joints to sit or stand without losing balance, coordinate movements, walk and use fine hand movements. We educate you on techniques that can help you with your recovery, and show you exercises to do in between your therapy sessions. We wear a white T-shirt, with navy trim and navy trousers.

- **Therapy support workers**

We provide an extra pair of hands for physiotherapists and occupational therapists to ensure a safe therapy session. We also help with washing and cooking assessments and are involved in helping measure you for a wheelchair and do the odd wheelchair repair. We will also do arm and hand (upper limb) sessions with you, to help you regain feeling and movement in these. We usually take the lead in putting together your therapy timetables, to make sure your sessions are planned ahead. We are happy to be your friendly point of contact for any therapy concerns, so do grab us for a chat if you ever need to. We wear a pale blue top with navy trousers.



- **Clinical neuropsychologists**

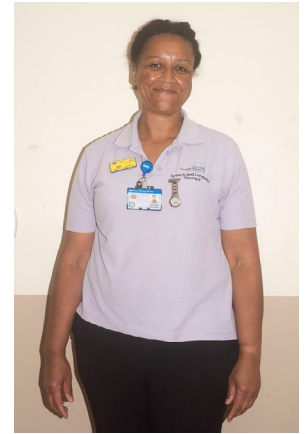
Clinical neuropsychologists / psychologists tend to have two main roles in your care. Our first role is to help in understanding and looking at your thinking skills such as memory, concentration, and planning. We do this using specially designed tests, which are usually in pen and paper format. Once these are understood, we can give you information and advice on how to manage cognitive difficulties.

Our second role is to support people with their emotional wellbeing and behaviours. We give you and others advice on how to adjust and cope with tricky or unpleasant emotions, that often come up when someone has been unwell. We do this through counselling or talking therapy methods. We do not have a uniform.

- **Speech and language therapists**

We support you by looking at and managing any communication difficulties (both speaking and listening) as well as swallowing difficulties. We use a variety of ways to help you communicate more effectively, using both the spoken and written word.

We may work with other staff and relatives to improve your all-round communication. We also advise on safe eating and drinking. We wear a purple top with navy trousers.



- **Nurses**

We are ward staff that are trained in all aspects of general health care. We will help you with dressing, washing, feeding, toileting, giving medication, and taking routine observations (such as blood pressure).

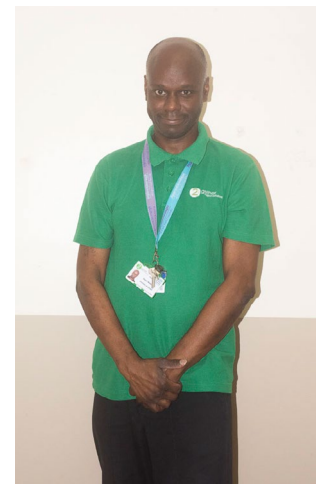
A ward will be run by a sister or charge nurse (dark blue tunic), accompanied by a staff nurse (blue and white striped tunic).

- **Health care assistants (HCAs)**

We help nursing staff when necessary. We help with eating, dressing, transfers, toileting, and making beds. We also monitor conditions by taking routine observations such as temperature, pulse, respirations, and weight. We are here to make you comfortable. We wear a white tunic.

- **Domestics**

We uphold hospital standard cleanliness, making it safe and hygienic. We provide your meals and hot drinks, and always like to say hello or give you a wave as we work. We wear a green top and black trousers.



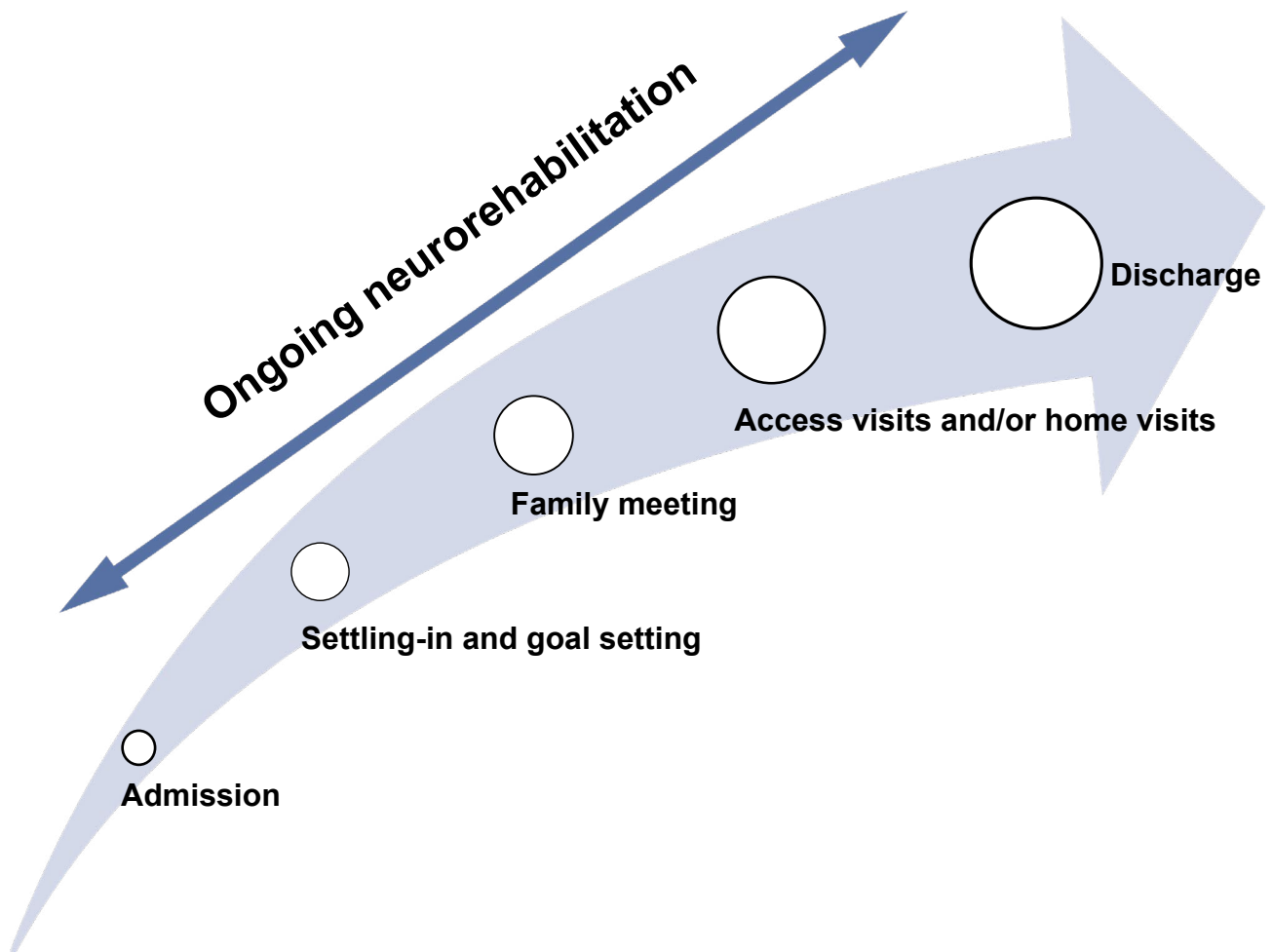
- **Doctors**

We can often make, diagnose, and use investigations to provide safe management of your illness. We will co-ordinate your day-to-day medical care, carrying out examinations and prescribing medications. The consultant is head of the medical team and will be assisted by junior medical staff such as registrars and house officers, who will spend more time on the ward than the consultant. We tend to wear normal clothes or scrubs.

- **Social workers / Rapid Transfer Service**

The RTS (Rapid Transfer Service) helps co-ordinate your discharge home and arranges the support you need on discharge, for example arranging carers to come in or setting up a care home placement.

Your rehabilitation journey



My timetable

- Here is a copy of your weekly therapy timetable.
- Another copy can also be found on the whiteboard behind your bed

Messages

If your family have any messages, queries, or concerns that they want to pass on to your therapists and cannot find them in person when they come to visit you on the ward, they can write down their message here and we will do our best to look at it and get back to them.

Date: _____

Message: _____

Date: _____

Message: _____

Date: _____

Message: _____

My exercises

In this section there is space to keep your handout sheets of therapy exercises safe during your time on the ward. There is also space below for your therapist to write down any other exercises they would like you to complete in between sessions, or with your family for practice when they visit.

Exercise: _____

What to do: _____

How often: _____

Exercise: _____

What to do: _____

How often: _____

Exercise: _____

What to do: _____

How often: _____

Exercise: _____

What to do: _____

How often: _____

Useful terms

This page is a list of words or terms that you may hear during your time on the ward. If we use any words you do not understand, please ask us to explain them, but here is a quick list as well, just in case.

- **Access visit** is where your therapists go to your home to check if you need any equipment to help you move around your home, or any ramps or rails to help you get in to your property on your return home.
- **Activities of daily living (ADLs)** is the name we give to all the tasks you complete throughout your day, such as cooking, shopping, and general life tasks. Occupational therapists in particular work on these tasks with you to help you regain your independence.
- **Aspiration** is when food, drink, or a foreign object is accidentally breathed in to your lungs. This is usually caused by a reduced ability to swallow safely.
- **Brain.** This is the organ in the body that is responsible for thought, memory, sensory interpretation, movement, emotions, and other vital functions.
- **Bowel regime** is a schedule to help you with incontinence issues, usually led by the nurses.
- **Cognition** refers to your thinking skills.
- **Catheter.** A tube inserted into your bladder to collect urine in a drainage bag.
- **Craniotomy** is an operation to open the head in order to expose the brain. The word craniotomy means making a hole (-otomy) in the skull (cranium). The operation is carried out by a neurosurgeon who specialises in surgery of the brain and spine.
- **EDD (Estimated Date of Discharge)** is a date patients are usually given to work towards, providing rehab goes to plan.
- **EKNRU (East Kent Neuro-Rehab Unit)**, also called Harvey Ward which is where you are now.
- **Encore** is the name of the power assisted standing hoist, which is a piece of apparatus to help you stand.
- **Flip-flow** is a tap attached to a catheter, which you can open and close when needed to help you re-train your bladder muscles.
- **Family meeting** is an informal meeting with your family, therapists, nurses, and doctors to update on your rehab and to discuss your future plans/goals. This meeting is usually carried out half way through your stay.
- **Goals** are weekly targets for you to achieve, which are set during discussions with your therapists.
- **Harvey Ward** is the ward you are on now, which is a specialist neuro-rehab ward.
- **Home visit** is a visit you carry out with your therapists where you visit your home.

- **Hoist.** A device that lifts someone up from a bed or chair and moves them to another surface, such as another bed or chair.
- **Mobilise** is walking.
- **MDT (Multidisciplinary team)** is a group of healthcare staff who are all in different professions (for example doctors, nurses, occupational therapists, physiotherapists, speech and language therapists, and clinical neuropsychologists) who are all involved and help make decisions around your care.
- **Orthoptist.** A doctor who specialises in conditions of the eye and visual system.
- **Optician.** A practitioner who assess eyesight and can supply and fit glasses.
- **Orthotics** is the department responsible for assessing and providing supports for your arms and legs.
- **OT (Occupational Therapy).**
- **PADL (Personal Activities of Daily Living)** focus on personal tasks such as washing, dressing, and toileting.
- **Plinth.** A padded table for you to sit or lie on, usually used in physiotherapy sessions.
- **PT (Physiotherapy).**
- **Ψ.** This is the short-hand symbol for 'Psychology', you may see it written on your timetable.
- **RTS (Rapid Transfer Service)** is a team that may support you when it comes time for discharge. They help to arrange care packages (carers to come and help you in your home), placement (somewhere else to live that is not your home, with a higher level of support), or other community services.
- **Sara Steady** is a transfer aid that you stand up in and helps move you from one place to another.
- **Stroke** is a disruption of blood flow to the brain caused by a bleed or a blockage.
- **Spinal cord.** A thick bundle of nerve fibres that runs from the base of the brain to the hip area, running through the spine (vertebrae).
- **Transfer** is moving from one surface to another which are next to each other.
- **Tower Ward** is the area you will often go to for rehab. It houses the gym, therapy rooms, and the clinical neuropsychology office.
- **TWOC (Trial without a catheter).**
- **UL (Upper limb)** refers to your arm. You may have upper limb sessions, which is when we do exercises specifically for your arm.
- **Walking aids** are equipment given to you to help your walking; such as Zimmer frames, 4 wheeled walkers, 3 wheeled walkers, and quad sticks.

Useful contacts

- **Therapy Office**
Telephone: 01227 86 86 96 or 01227 86 87 14
If you cannot get hold of your therapist on the ward and need to talk to them, or if your family need to contact any of the ward therapists during your time in hospital, you can use these numbers to reach them.
- **Harvey Ward**
Telephone: 01227 86 87 13
Use this number if you need to contact any of the nurses, doctors, or healthcare assistants.
- **Wheelchair Services**
Telephone: 0300 7 90 01 28
This service is involved in supplying wheelchairs and accessories (like pressure cushions). Your OT will be the one to speak with them most, but if you need to have a new assessment once you go home, you can call them on the above number.
- **NRS (Equipment Services)**
Telephone: 01622 23 53 00
This service provides and delivers equipment. Your OT or PT will liaise with them, but it is handy to have their number once you go home or when you are ready to return your equipment.
- **Carer Support**
Telephone: 03000 81 00 05
This is an organisation who can be there to support your family members. It is never too early to contact them and see what they can offer.

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhuft.nhs.uk/patientinformation