Information for parents and carers

Stroke Patient Information Leaflet

Rehabilitation Medicine
Community & Therapy Services

This leaflet has been designed to give you important information and to answer some common queries you may have.
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The Stroke Pathway

All patients presenting with a suspected stroke in the North and North East Lincolnshire areas are initially taken to the ‘Hyper acute Unit’ (HASU) at Scunthorpe General Hospital.

From there, ongoing rehabilitation could occur at either Scunthorpe, Goole or Grimsby hospitals, a community rehabilitation facility or at home.

Rehabilitation

Following your stroke there may be activities that you are no longer able to carry out. These activities may be things which you previously did easily and without thinking.

Rehabilitation is aimed at helping you to achieve independence in carrying out these activities again.

This may involve many different types of treatment and therapy requiring hard work and commitment by you as well as your carers and health workers.

The rehabilitation team is made up of many professionals who will work together with you and your carer to help you to regain as much independence as possible in the activities which are important to you.

Treatments may include physiotherapy, occupational therapy, speech and language therapy and dietetics. The rehabilitation plan devised for you may be delivered by therapists, therapy assistants or nursing staff in conjunction with you and your carers.

This may involve therapists showing you and your family how you can practice activities or exercises within your daily routine to help you achieve maximum benefit.

What can relatives do to help?

Please feel free to keep nursing staff and therapists informed of any concerns that you might have so that they are able to reassure you or answer any questions you may have.

You are a vital link with our patient. You have a unique insight into the personality of your relative and as such are very valuable to us so that we have a full picture of the individual. Your information is particularly important if your relative can not communicate very well after their stroke.

The therapists are keen to support you if you would like a more active role in your relatives rehabilitation, they can advise you of any specific activities you can undertake with them.

Dietitians

The dietitian will work with you if you have any ‘special’ dietary needs, are unable to eat, need a modification to the texture of your food, have a poor appetite or need to reduce or avoid certain foods in your diet.

The nursing staff will undertake a nutrition screening assessment (MUST) when you are admitted, giving you a score at the end of the assessment. This includes measuring your height and weight - don’t worry if you can’t recall these or are unable to get out of bed the nursing and carers will be able to use other tools to estimate what they need.

If you have a high nutritional risk score or if you, your relatives / carers or nurse feel that you are having difficulties with the amounts or types of food you eat, you will be referred to a dietitian who will assess your diet and discuss with you how you can make alterations to your food and drinks.

The dietitians’ assessment will include asking you questions about your weight, weight
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loss, appetite, meal routine and types / amounts of foods and drinks you normally have at home. With your consent a relative or carer can be present to help you recall the amounts and types of food and drinks that you usually have.

Dietitians work closely with the nurses, speech and language therapists and catering staff to ensure that the correct types and amounts of food are provided for you. If you are unable to eat or drink enough and are losing weight, we will discuss with you the types of snacks you could manage between meals, or supplementary drinks (build-up / enriched milk drinks) that you would be able to take.

If it is not safe for you to eat or drink because of swallowing difficulties, the dietitian can discuss with you a different way to give your body the nourishment and fluids it needs. For example, by using a nasogastric tube (fine tube inserted into the stomach from the nose) liquid nutrients, medication and fluid can be given through this tube after the dietitian has calculated how much you require and so prevent further weight loss.

This form of feeding is short term and lasts no more than 4 weeks. If you are still unable to eat or drink after this then a PEG tube (tube positioned directly into the stomach) may need to be discussed with you and your family or carers.

Clinical Psychologists

Clinical psychologists specialise in the relationship between our minds and our bodies. They use talking therapies to give people the chance to talk about their difficulties since their stroke and the effect of stroke on their day to day lives. They aim to help people develop skills to cope with these changes and assist in their emotional adjustment to a stroke.

They also offer specialist assessment and rehabilitation of cognitive difficulties following a stroke. This could include problems with attention, memory, planning and problem solving. Occupational therapists are also routinely involved in identifying cognitive difficulties and may refer to clinical psychology for further input with complex difficulties.

They generally work one to one with people following a stroke; however in some situations may also work with family or other professionals to offer support.

Specialist Stroke Nurses

“The role of the specialist stroke nurse is vital within this team to ensure patients receive the specialist care needed to make the best recovery possible.”

(quote by: John Barrick, Stroke Association)

• Stroke Responders assess potential patients, either in the emergency department at Scunthorpe, or the wards around Scunthorpe hospital
• Arrange timely investigations and assess whether the patient could potentially receive a clot busting drug
• Organise appropriate transfer to Hyper acute Stroke Unit
• They also monitor your identified stroke risk factors including signs of infections,
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swallowing problems and pain management

• They also provide close monitoring of patients in HASU

Rehabilitation Assistants and Health Care Assistants

Therapy Assistants and Health care Assistants work with nurses and therapists to support the rehabilitation plans for every patient, helping to maximise their recovery. You may see them as part of your recovery.

Social Work Team

The social work provision for stroke services is provided by a specialist practitioner for stroke.

The social work practitioner is part of the acute stroke multidisciplinary team at Grimsby, Goole and Scunthorpe. The practitioner also visits patients in out of area hospitals when required. Patients who are referred to the social work practitioner will be assessed on the stroke unit to determine what their social care needs are. Through multidisciplinary team working risks are identified and plans made toward reducing these to facilitate safe discharge.

An agreed discharge process might include:

• A care package can be requested for patients who can return home but need support and assistance to enable them to safely return home and continue to live independently in the community

• Patients who are identified as needing a short period of further rehabilitation will be referred to a community rehabilitation facility. This is a time limited service and patients have to meet the criteria to be referred and demonstrate that they are motivated to continue with rehabilitation and therapy

• Patients who requires 24 hour care in a Residential care or Nursing care setting will be assessed for a short stay placement

The social work practitioner provides a seamless discharge process for stroke patients. They will be followed up in the community and their needs will be reviewed in conjunction with the wider multidisciplinary team as their rehab progresses.

Patient and family can request a referral to the social worker.

Speech and Language Therapy

Speech and language therapists are trained to provide support to people with swallowing and communication difficulties.

After a stroke people can have difficulties with swallowing and / or communication.

Recovery varies. Some people only recover a little and take a long time to recover (months and years), some people recover fully and quickly.

This depends upon the type of stroke, how severe it is and how well you are able to participate in rehabilitation.

Swallowing

The Risks of Swallowing Difficulties:

• The coordination and / or strength of the swallowing process can be affected by stroke

• Some people cannot swallow at all and many people will be able to swallow but it will not be a safe swallow. Also, some people will be able to swallow safely without any difficulties

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- The possible risks from swallowing difficulties are:
  1. 'Aspiration' - This is when food and fluid falls into the airway and / or lungs. It can lead to chest infections or pneumonia which can be severe and in some cases fatal
  2. Choking - This is when something solid falls into the airway and blocks it. This can also be fatal
- Because of the risks, swallowing difficulties are dealt with cautiously

How Speech and Language Therapists Might Help

The Speech and language therapist assesses and advises on how to manage swallowing difficulties. Advice is individual, but could include the following:

1. **Nothing to eat or drink for a while (Nil by mouth, ie: NBM)**. In this case you may be given fluids via a drip or given liquid food through a tube. The doctors, nurses, speech and language therapists and dietitians can give you more information about this

2. **Thickening drinks**

3. **Modifying your food**. For example pureeing, mincing or mashing food or just sticking to food that is soft, moist and easy to chew

You may be advised to eat and drink a particular way, for example, putting your head in a special position or consuming everything using a teaspoon or a special cup.

You may be given exercises for your swallowing. These will need to be completed very regularly.

If you are given advice like this the recommendations will be placed by the bed. The advice will be reviewed regularly by the Speech and language therapist.

Things You Can Do to Help

It is very important that you follow advice provided.

- Relatives and friends can sometimes come and help at mealtimes. **This should be discussed first with nursing staff**
- Relatives and friends should also check what is suitable before bringing food and drinks in if you have difficulties swallowing
- Completing any exercises regularly can help. Relatives and friends can sometimes help with this

General Advice

If you have swallowing difficulties, the following advice may help:

- Make sure you are sitting upright, with your head in an upright position
- Try to have your meals in a quiet room and avoid distractions
- Allow plenty of time - eat and drink slowly
- Try to relax

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Swallowing Difficulties

- Swallowing difficulties can make your swallowing unsafe.

- You may not be able to swallow anything safely.

- You may need to follow special instructions for swallowing safely.

- You may need modified food.

- You may need thickened drinks.

- You may need to eat and drink in a special way.

- You may need to do exercises.

- Is it important that you follow the advice.

- Relatives and friends may be able to help.

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Communication

What is communication?
Communication is about someone conveying a message and someone receiving that message.

People communicate in many different ways:

- Understanding what other people say
- Speaking
- Reading
- Writing
- Non-verbal communication - These include facial expression, body orientation and posture, gesture and pointing, intonation, eye contact
- Using objects and pictures / drawings

How can communication be affected by stroke?
The main types of communication difficulty after stroke are as follows:

- **Aphasia / dysphasia** - This is a difficulty with language. It can include difficulty understanding others when they speak, difficulty reading, problems thinking of the correct word for things, difficulty making a coherent sentence and problems spelling / writing sentences
- **Dysarthria** - This is when the muscles used for speaking are weak and therefore speech sounds slurred. Speech may also sound too loud or too quiet, it may sound ‘nasal’ or be too fast or too slow
- **Dyspraxia** - This is when the person is able to think of the right words to say and has the muscle strength to speak, but has difficulty coordinating the muscles.

Speech sounds distorted. Intonation may sound different. Speech will usually sound as though it is made with effort.

How the Speech and Language Therapist Might Help

The Speech and language therapist:

- Will assess your communication if you have been found to have some difficulties
- Will explain the difficulties to you and your family
- Will give you some advice / strategies to help make communication a little easier
- Will set some goals with you and help you to work towards these
- May give you some therapy work / exercises to do to achieve your goals
- May give you some alternative methods of communication
- May help you to practice strategies to help you get your message across

Things You or Friends and Family Can Do to Help

The Speech and language therapist can give you some specific advice about things that can help your individual difficulties.

Here are some general tips to help with communication:

- Encourage and accept any way that helps get the message across, for example facial expression, gesture, drawing, writing words down
- Take time to talk. Don’t rush the conversation
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- Allow time for what you've said to be understood
- Allow time to respond
- Talk in a quiet, calm environment
- Talking to one person is often easier than several at once
- Gain and maintain eye contact
- If it is difficult to think of the word, ask questions which only need a “yes” or “no” response
- Do activities that don’t rely on talking, e.g. looking at magazines / photographs, holiday postcards, hand massage / manicure, listening to music

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- You may have **difficulty communicating** after your stroke.

- There are **different ways** in which your communication could be affected.

- The Speech and language therapist will help you to learn **ways to cope** with your communication.

- The Speech and language therapist will help your **friends and family** learn ways to cope with your communication.

- The Speech and language therapist will help you work towards your **goals**.

- You may work on **other ways** of communicating.

- You may do **therapy exercises**.
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Physiotherapy

Following your stroke you may experience difficulty moving your body (see Physical effects of a stroke, Stroke Association Factsheet 33). A stroke may cause weakness, where the muscles are not receiving the messages from the brain. Your body may feel differently, your brain may not be interpreting the sensory messages correctly, making it more difficult to know where your body parts are, or causing difficulty when trying to distinguish between different shapes or textures.

You may experience problems with your posture and balance (Stroke Association, Factsheet 22) and your joints maybe more vulnerable to problems due to loss of supportive muscles. Sometimes a stroke can cause joints and muscles to feel stiff and you may develop muscle spasms or spasticity.

What is physiotherapy and how can it help?

Physiotherapy uses a combination of exercises, manipulation, massage, skills training and electrical treatment, to help heal and recover movement. The main focus is to help you learn to use both sides of your body again and regain as much strength and movement as possible. A physiotherapist will undertake an initial assessment and a treatment plan will be formulated which may include some or all of the following:

- Helping stroke nurses set up a plan of care to keep you as well as possible and avoid complications that may slow down your recovery, such as minimising joint stiffness or muscle tightness by providing appropriate movement and support, or offer advice on how to keep your lungs clear and reduce the risk of infection
- Advising on positioning in lying or sitting and how often you need to be moved
- Evaluate when you should get out of bed and start walking and what equipment (if any) is needed to move and support you
- Motivate you to be actively involved in sessions to help relearn normal patterns of movement
- Offer therapy to strengthen your limbs and teach you how to move again as independently as possible
- Work together with the rehab team and your carer, family or friends to support your recovery

It is important for you to be as active as possible as soon as you can; the team will encourage you to get up and about as much as you are able to, whether this is continuing your previous activity or just sitting in a chair.

In the early stages and for people with relatively mild problems, physiotherapy will focus on preventing complications and restoring your abilities to move and be active again, as time goes on, and for people with more severe problems, a full recovery is less likely so physiotherapy focuses on helping you to become more independent and do what is important to you, for example using equipment or doing things in a different way.

Therapy will begin soon after your admission to hospital. Initially this may be exercises in bed and moving around the ward or it may take place in rehabilitation areas, such as the gym. Physiotherapy will continue, if required, if you move wards, hospitals, or go on to a rehabilitation unit; and in the community, therapy may take place in your own home, or a clinic / outpatient setting. Whatever the setting your therapist will work with you to set a number of goals, which should be agreed with you and take into account your priorities,
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hopes and plans. These should be reviewed throughout your journey and this is intended to make sure your treatment is focused and working on the things that are important to you.

**Tips for recovery:**
- Practise the exercises your therapist set everyday
- Use a notebook to remind you, what you need to do and record your progress
- Involve and move your affected side as much as possible
- Be patient with yourself, aiming for long term rather than immediate results
- Resume sports and activities that you enjoy or try new activities that will help you to maintain or improve your recovery. Many people worry that being active might cause another stroke, this is very unlikely, but if you are concerned speak to a health professional (see Exercise and Stroke, Stroke Association resource sheet)

Information adapted from Stroke Association Factsheet 16, Physiotherapy after stroke (April 2012)

**Occupational Therapy**

Following a stroke, people may have problems with some aspects of daily living skills.

We help you to regain the ability to complete everyday tasks independently. This can include activities like getting dressed, cooking, getting about, or gardening. If appropriate, once home, we can support your return to a previous hobby, return to employment or return to driving.

Occupational therapy can also help you with thinking skills, memory and attention. We can also support you with any vision problems, anxiety or changes in your mood.

The practice of activities of daily living is likely to be ongoing in order to improve your independence which is often the end goal of therapy. Occupational Therapists work in the Hyper Acute, Acute and Community teams.

To help with your rehabilitation please have day clothes and toiletries available on the unit, if possible.

A treatment programme specific to your needs will be individually devised with you and your Occupational Therapist. This will be in conjunction with other members of the multi-disciplinary team such as physiotherapists, speech and language therapists, nursing, doctors, social worker and psychologist. All the team work closely together to meet your needs. In addition, clear therapy goals are set with you and updated as required.

A Home visit may be necessary as part of your in patient stay. Typically there are two types of home visit:

An Access visit is a visit carried out without you. The therapist will meet with your representative to assess the environment at your property to assess suitability and need for any adaptation or equipment to meet your needs.

A Home Assessment visit is a visit to your home with you. On the visit you will be able to experience the variety of tasks that you might normally need to perform on a typical day in your home (i.e. walking around your property, getting on / off bed, chair and toilet, making a hot drink, amongst other things). At the end of the visit, prior to returning to hospital, there will be a chance to discuss
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your progress and plan how your needs can be met ready for discharge from hospital.

On discharge from the acute stroke ward you may return home with / without support and with / without ongoing rehabilitation. You may be transferred to a hospital nearer your own home. You may be discharged to another rehabilitation facility for further rehabilitation if this is deemed appropriate by you and the team. These are all dependent on individual needs.

The occupational therapist will always liaise with the team who are going to be providing any ongoing therapy to ensure seamless care.

Concerns and Queries

If you have any concerns / queries about any of the services offered by the Trust, in the first instance, please speak to the person providing your care.

For Diana, Princess of Wales Hospital – you can contact the Patient Advice and Liaison Service (PALS) on (01472) 875403 or at the PALS office which is situated near the main entrance.

For Scunthorpe General Hospital – you can contact the Patient Advice and Liaison Service (PALS) on (01724) 290132 or at the PALS office which situated on C Floor.

Alternatively you can email: nlg-tr.PALS@nhs.net