Stroke patient handbook

This is a personalised document for:

Hospital number:

This booklet contains some useful information about stroke: What it is, some tests that you may undergo, and advice on how to reduce your risk of a further stroke in the future.

It also contains a section that will be completed on the ward with you before you are discharged. A member of the stroke team will fill in this section with you so that you can ask any questions. This booklet is confidential and there is space for you or your family to add further information.

Stroke Unit Team
What is a stroke?

A stroke occurs when the blood flow to the brain is cut off. This could be due to a blockage (clot) or bleed (haemorrhagic). This means that a particular area of the brain is permanently damaged. It can result in a number of different symptoms; commonly weakness of one side of the body e.g. arms or legs (or both), speech problems, loss of vision or poor balance. The symptoms are sudden and unexpected.

What tests have I had to diagnose my stroke?

You will have had a number of tests while you were in hospital. The standard tests are:

2. Blood tests – cholesterol and sugar which, if high, can increase risk of stroke.
3. Heart tracing (ECG) – to look for an irregular heart beat which can cause a stroke.
4. Brain scan – to see the stroke.

How am I being treated for my stroke?

If you have had a stroke due to a clot you are likely to be receiving:

1. Aspirin for 2 weeks – to thin the blood.
2. Clopidogrel after 2 weeks – to thin the blood.
3. A tablet to lower cholesterol e.g. statin.
4. Lansoprazole for 2 weeks – to protect the stomach from the effects of aspirin.
5. A tablet to lower blood pressure after 2 weeks.

If you have an irregular heart beat then you are likely to start warfarin – a different blood thinner.

If you have had a stroke due to a bleed you will not receive a blood thinning agent.
The biggest treatable risk factor for stroke is high blood pressure. Others include high cholesterol, diabetes, an irregular heart beat (atrial fibrillation), alcohol and smoking.

Risk factors that cannot be changed are increasing age, family history of stroke and ethnicity (Asian, African, African Caribbean). There are rare causes that you may be tested for if you do not have any obvious risk factors for stroke.

### Why did it happen?

### What caused my stroke?

**Which part of my brain has been affected**

Different areas of the brain are responsible for different functions, as shown below:

- **Parietal Lobe**
  - Sensation
  - Perception

- **Occipital Lobe**
  - Vision

- **Cerebellum**
  - Balance
  - Coordination

- **Brain Stem**
  - Vital Functions (e.g. respiration)

- **Frontal Lobe**
  - Problem Solving
  - Decision Making
  - Planning Behaviour

- **Temporal Lobe**
  - Hearing
  - Memory

Damage occurring on the left side of the brain presents symptoms throughout the right side of the body (and vice versa). When language is affected, the damage is almost always on the left side of the brain.
The following lifestyle changes help lower blood pressure, cholesterol and improve diabetic control:

1. Healthy diet – eat plenty of fruit, vegetables, fish and porridge, cut down on salt and fatty foods which are found in processed food products.
2. Reduce alcohol intake – less than 21 units for men and 14 for women.
3. Stop smoking.
4. Take regular exercise.

It is important to take your prescribed medications as advised by your doctor in order to reduce the risk of another stroke.
What happens when I am discharged from the ward?

Depending on your rehabilitation needs you may go to one of the following:

1 Stroke rehabilitation unit – for ongoing physiotherapy, speech therapy and social input.
2 Home - we may arrange some ongoing rehabilitation / support at home* if you require it.
3 Residential home/nursing home.

*This can include a rehabilitation team (Early Supported Discharge/Community Neuro Rehabilitation Team), carers, Meals on Wheels, Age Concern. You will also be seen by a stroke doctor in clinic after discharge to make sure you are managing well in the community.

When can I drive?

By law:

1 The DVLA specify that if you have a licence to drive a car or motorcycle (category B licence) you are not allowed to drive for at least one month after a stroke.
2 If you have a licence for a large goods vehicle or passenger-carrying vehicle, you are not allowed to drive vehicles under this licence for one year, and you will need to inform the DVLA.

For both of the above, you may return to driving after this period of time if your doctor says you have made a satisfactory recovery.

(p.11 for further details)

Fatigue

Fatigue is a common problem after any type of stroke, affecting up to 50% of stroke survivors. The symptoms you may experience can vary from relatively mild to severe. Fatigue can impact on your rehabilitation, your quality of life and relationships and can hinder you regaining your independence. There is no specific management for fatigue, but The Stroke Association (details p.9) has some very useful advice on tips to help you cope.
Is it safe for me to have sex?

There are no restrictions regarding sex following a stroke. The common fear is that during sex your blood pressure rises; however there is no evidence that you’re more likely to have a stroke whilst having sex.

Things that may affect sexual function include physical weakness, fatigue, incontinence, medications and changes in mood. If you experience any problems you should seek advice from your doctor (GP/stroke doctor).

Is it common to feel depressed after a stroke?

Lots of people feel depressed or frustrated after a stroke for many different reasons. It is estimated that nearly half of patients who have suffered a stroke will feel depressed at some time in the years after a stroke.

If you are suffering with low mood then there are many resources available to help you. See back page for useful numbers and website addresses.

What support is available in the community?

1. GP – for general advice, medications and health and psychological needs.
2. Early Supportive Discharge (ESD) or Community Neuro Rehabilitation Therapy (CNRT) – for physiotherapy, speech therapy, occupational therapy and psychological support.
3. Social services – to provide extra practical support in the home e.g. carers.
4. Meals on Wheels.
5. Carer support groups.
6. Local support groups.
Useful contacts

Primary Care Trust (PCT), Hospital and Patient Advice and Liaison Service (PALS)

Brighton and Sussex University Hospitals NHS Trust
www.bsuh.nhs.uk

Royal Sussex County Hospital
Telephone: 01273 696955

Stroke Unit
Telephone: 01273 696955 Ext.4006

Patient Advice and Liaison Service
Telephone: 01273 696955 Ext.4029 or 4588

Princess Royal Hospital (Stroke Unit)
Telephone: 01444 441881 Ext.8283

Sussex Rehabilitation Centre
Telephone: 01444 441881 Ext.5727

Patient Advice and Liaison Service
Telephone: 01444 441881 Ext.5909

Community Rehabilitation Teams

Some people may be referred to a community rehabilitation team once they have been discharged home from hospital. This service offers therapy in your home to help you to resume your daily activities following a stroke.

Community Neuro Rehab Team
Telephone: 01273 242271

Community Short Term Service
Telephone: 01273 242042
Expert Patient Programme

Six week self management programme for people with any long term health condition aims to equip people with the tools and skills to better manage their health & wellbeing and improve quality of life.

Brighton and Hove: 01273 574647

West Sussex: 01403 227000 Ext.7547       Email: sc-tr.epp@nhs.net

Social Services and Department for Work and Pensions

Social Services

Brighton and Hove
Telephone: 01273 295555
Email: accesspoint@brighton-hove.gov.uk

Haywards Heath
Telephone: 01243 642121

Department for Work and Pensions

Benefits Enquiry Helpline for people with disabilities
Telephone: 08008 82200
www.direct.gov.uk

Job Centre Plus call centre – find work or claim benefits
Telephone: 08456 073051
www.jobcentreplus.gov.uk

Pension Credit Helpline
Telephone: 08456 060265
www.direct.gov.uk

Information and claim enquiries for Personal Independence Payment/Attendance allowance
Telephone: 08457 123567
www.direct.gov.uk
Support when you get home

**Stroke Association:** Supporting people with stroke and aphasia
Telephone: 0303 303 3100
www.stroke.org.uk
www.stroke.org.uk/talkstroke – online community offering help and support

**Family and carer support:**

**Mid Sussex:** Anne Jones, Tel: 01444 847420 mob: 07957 127404
Email: Anne.jones@stroke.org.uk

**Horsham and Crawley:** Lisa Burstow, Tel: 07985 131268
Email: Lisa.burstow@stroke.org.uk

**East Sussex:** Jayne Fenner, Tel: 01323 886920 mob: 07799 436053
Email: Jayne.fenner@stroke.org.uk

**Different Strokes** (support for younger people with stroke)
www.differentstrokes.co.uk

**Connect** (aphasia support): Telephone: 020 7367 0840
www.ukconnect.org

**Friends of Hove Stroke Club**
Organiser: Janet Seymour
Bishop Hannington Church Centre, Neville Avenue, Hove BN3 7NB
Telephone: 01273 724960 Friday 2pm to 4pm

**Four Deans Stroke Club**
Organiser: Caroline Hancock
St Patrick’s Church Hall, Broad Green, Woodingdean BN2 6TB
Telephone: 01273 306215 Meet Fridays 11.30am to 3pm

**Southwick**
Organiser: Stan Ford
Telephone: 01273 453760

**Silverline:** 24hr confidential helpline for older people
Telephone: 08004 708090
Samaritans: 24hr confidential support
Telephone: 08457 909090
Local branches:
Brighton, Hove and District: Dubarry House, Newton Rd, Hove, BN3 6AE
Telephone: 01273 772277
Worthing: 2 Lennox Road, Worthing, BN11 1DA
Telephone: 01903 205555
Eastbourne and District:
The Haven, 13 Bolton Road, Eastbourne, East Sussex, BN21 3JT
Telephone: 01323 735555

Age UK
Advice line: 0800 169 6565  www.ageuk.org.uk
Local branch: 29-31 Prestonville Rd, Brighton, BN1 3TJ
Telephone: 01273 720603

Alzheimer’s Society
Helpline: 0300 222 11 22  www.alzheimers.org.uk
Local branch: Annexe, Ireland Lodge, Lockwood Crescent, Brighton, BN2 6UH
Telephone: 01273 726233
for information of services provided in local area

Carers UK
Advice line: 0808 808 7777  www.carersuk.org

Citizens Advice Bureau
Brighton and Hove: 1 Tisbury Rd, Hove, BN3 4AH
Telephone: 01273 223951
Haywards Heath: Oaklands, Paddockhall Rd, Haywards Heath, RH16 1HG
Telephone: 03444 771171
www.citizensadvice.org.uk

Money Advice and Community Support
Local branch: 24 Old Steine, Brighton, BN1 1EL
Advice line: 01273 664040  www.macss.org.uk
Activities of daily living

Meals on Wheels
Telephone: 01273 410117

Easylink Shopping Bus Service: Brighton and Hove
Telephone: 01273 677559

Wiltshire Farm Foods
Telephone: 0800 773773 www.wiltshirefarmfoods.com

Oakhouse Foods
Telephone: 0845 6432009 www.oakhousefoods.co.uk

It’s Local Actually: Database to find local activities
www.thededonline.org.uk/services/out-and-about/its-local-actually

Travel

Specialist driving assessment centre
South East DriveAbility
20/20 Business Park, St Laurence Avenue
Allington, Maidstone, Kent ME16 0LL
Telephone: 01622 606900 Email: wk-pct.sedriveability@nhs.net
www.kentcht.nhs.uk/our-services/specialist-clinical-services/south-east-drive-ability

Taxi Vouchers
If you are unable to use your bus pass due to a disability you may be eligible to exchange your pass for £70 worth of taxi vouchers.
Brighton and Hove City Council: 01273 290000
West Sussex: 01444 477304

Community Transport: Brighton and Hove
Offer a range of services for disabled people who cannot use public transport.
Telephone: 01273 677559
Stroke Diagnosis:

**Medication on discharge**

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If you have any concerns or questions regarding your medication please contact the ward, your GP or the BSUH Medicines Helpline Tel: 01444 454388.

‘Return any unwanted/out-of-date medicines to the supplying pharmacist for safe disposal’

**Target blood pressure <130/85**
**Target total Cholesterol <4.0 mmol/l**
**Target LDL Cholesterol <2.0mmol/l**

**Blood pressure (BP) on discharge**

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Goals on discharge

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Key contact and telephone number

Therapist Names:
Physiotherapist
Occupational Therapist
Speech and Language Therapist
Nurse
Stroke Coordinator
Social Worker

Early supported discharge: Yes / No
Community Neuro Rehabilitation therapy: Yes / No
Package of care: Yes / No
Details of care package:

Contact number re care package:

Other:
Your thoughts, your experience

Come and join us for tea and cake

We would like to understand more from the patient’s perspective. Please come and share with us your stroke experience from your hospital stay to the support you received thereafter. We hope that by listening to you, we may improve our service and give patients exactly the right support.

We’ll have members of the whole team including social worker, doctor, nurse and therapists there to listen to you.

You will also be contacted by a member of the stroke team (by phone) 6 months after your stroke to see how you are getting on.
Please join us on

From

Opposite the main entrance of the Royal Sussex County Hospital in the **Audrey Emerton Building** (follow signs in reception) Family/carers/next of kin welcome

We really value your ideas

Please contact Danielle Swaithe (Occupational Therapist) on the Stroke unit for further information on 01273 696955 Ext. 4590
Other relevant information

Your medication has been prescribed for a reason. If you have concerns about your tablets please consult your General Practitioner or the Stroke Unit team before making any changes.