Oxford University Hospitals

Neurosurgery

After Cranial Surgery Information for patients



Introduction

This booklet was developed for people who have had cranial surgery, their families and carers. It provides information and guidance about what to expect after your discharge from hospital. It was developed with the help and support of Linda Daly, a patient who was treated at the Oxford Neurosurgical unit. On page 10 and 11 Linda shares some of her personal tips for coping when you go home.

Going home from the hospital after brain surgery can be both welcome and worrying. We will, of course, give you information and instructions that are specific to you when you are leaving hospital, but some experiences are similar for all people. The following general information will help you make a smooth transition from hospital to home.

Your operation is called

Craniotomy

Craniotomy is a surgical operation in which an opening is made in the skull to allow us to get to the brain or its blood vessels. Craniotomy is performed for a number of reasons including:

- removal of a lump or tumour, such as a meningioma
- removal of a blood clot or drainage of an abscess
- repair of fractures to the skull resulting from injury
- removal of pressure from the trigeminal nerve (also known as Microvascular Decompression)
- removal of pressure from the back of the brain (Foramen Magnum Decompression)

In a small number of cases it is used to carry out procedures on the blood vessels that supply the brain.

After your operation

Activity

People often ask, "How much am I able to do?" This is difficult to answer as it depends on the type of surgery you've had and how well you are recovering. You are likely to feel some tiredness for up to 6 weeks after surgery. This is a normal part of healing and is to be expected. You should become a little stronger every day.

Your nurse will have talked to you about the importance of doing regular exercises to help the circulation in your legs and reduce the risk of blood clots. It's also important to take time to do deep breathing exercises to reduce the chance of a chest infection, especially in the first few weeks after your surgery. You will be given individual instructions before you go home, but our general advice is:

- Increase your level of activity slowly.
- If you feel light headed or tired after activity, rest and reduce the amount of activity that you are doing. You may need to build up your tolerance to activity more slowly.
- **Do not drive** until you speak with your doctor. You will need to inform the DVLA of your surgery. (see 'Driving' on page 9)
- You can resume sexual activity when you feel ready.
- Avoid any activity that causes you to hold your breath and push, for example, lifting or moving heavy objects, or straining during bowel movements.
- Remember to rest when you feel tired. Listen to your body and avoid overexertion. Think about whether family or friends could help with childcare, housework, shopping and preparing meals.

Wound care

Keep your wound clean and dry. You will need to ask someone to check it every day for the first couple of weeks after surgery.

You can wash your hair but be careful to avoid knocking or rubbing off any scabs. Dry your hair nearest to your scalp by dabbing gently with a clean dry towel. Avoid direct heat from a hair-dryer for the first couple of weeks. Do not apply any lotions, ointments or other products to the wound and avoid hair dyes for up to 12 weeks. We will tell you when the stitches or clips need to be removed. You will need to make an appointment with your GP's nurse to have them removed.

Side effects

Surgery to the brain for any reason can cause certain symptoms and side effects, some of which are common and some of which are rare. The common symptoms in the first weeks following this type of surgery include:

Headaches

Having surgery to your head may cause two types of headache:

- The first is caused by the wound or cut on your head. This is usually described by people as being sore rather than painful. It can be controlled by taking painkillers you would normally have at home, such as paracetamol.
- The other type of headache is caused by pressure changes in your head. The brain is covered by layers of membranes which contain fluid that cushions the brain. During surgery this system is broken and the pressure can drop, causing a "low pressure" headache. The trauma of surgery can also cause swelling around the brain; this can cause raised pressure within the head, causing a "high pressure" headache. Pressure headaches do not usually respond to everyday painkillers. You should contact your GP or the nursing staff on the Neurosciences ward if you experience this type of headache.

Nausea and vomiting

Altered pressures in your head can make you sick or queasy. This sometimes occurs early on in your recovery. It can go on for longer in some people, especially if it's associated with the type of surgery they have had. It's important to tell your doctor or nurse if you feel nauseated or are sick, as there are lots of medications which can help to relieve these symptoms.

Poor balance

This can be a normal side-effect from certain types of surgery. It usually settles with time as the brain adjusts to the surgery. Again, speak to your doctor if you feel it becomes a problem.

Constipation

Constipation can be a problem due to you not being able to move around as much and also painkillers, which have a constipating effect. Drinking plenty of water or fresh juice, and eating plenty of fruit and vegetables will help. You may also be prescribed medicines that can help prevent constipation.

Signs to look out for

If you have any of the following symptoms they will need to be investigated urgently by your GP:

- feeling more unwell
- increasing drowsiness
- difficulty walking/weakness in your legs, arms or face
- confusion or memory problems
- double vision or blurred vision
- neck stiffness
- high temperature or fever
- severe sensitivity to light
- severe headache
- persistent vomiting or feeling sick after having a number of days of feeling well
- your surgical wound showing signs of redness, swelling, any leaking of fluid or feeling hot to touch
- productive cough with yellow or green sputum
- pain, swelling or redness in your calf or thigh
- any signs of fits or seizures, such as twitching or jerking movements or numbness and tingling in a part or several parts of your body

Page 6

What you should do if you have serious seizure

It is important that your family or friends know what to do if you have a seizure. Please share the following information with them:

DO move items which may cause injury to the person e.g. furniture.

DO cushion the person's head.

DO help breathing by turning their head to one side. Turn the person onto their side once the jerking has stopped.

DO stay with the person until fully recovered.

DON'T try to restrain the person.

DON'T put anything in their mouth.

DON'T try to move them unless in danger.

DON'T give anything to drink until fully recovered.

Most seizures stop by themselves. However, if the jerking part of a seizure goes on for longer than 5 minutes, or if the person is injured as a result of a seizure, call an ambulance by dialling 999.

If you are in any doubt about symptoms that you have and would like some advice, please telephone the hospital switchboard:

Tel: 01865 741 166

Ask the operator to bleep one of the Neurosurgical Advanced Nurse Practitioners (available from 9am until 4pm, Monday to Thursday).

After 4pm and on Fridays and at weekends, please ask the operator to bleep the Floor Co-ordinator for the Neurosciences ward on bleep **6556**.

Prescribed medication

- **Phenytoin** is a drug given to reduce the risk of fits or seizures after surgery. It is important to have the levels of this drug monitored by having regular blood tests. The first test should be two weeks after the day you started the medication. You can have the blood test taken at your doctor's surgery or by the district nurse. Your GP will then adjust the level of the drug if necessary.
- Paracetamol, codeine phosphate, tramadol and diclofenac are all painkillers.
- Lactulose and senna help to prevent constipation. It is important to drink plenty of water when you take these, to help the medication to work.
- **Dexamethasone** is a steroid similar to a hormone that is produced naturally in the body. As a drug, it is used to reduce swelling within the brain. Steroid tablets are always reduced slowly as it can be harmful if you suddenly stop taking them. Before you go home we will give you written information (on a blue card) about reducing the dose of steroids and advice on the possible side effects of taking steroids.

It is important to discuss your medication with your nurse or doctor before you are discharged. If you forget to take your medication or take too much please call the ward immediately for advice.

Advice and support

Rest, good nutrition and a positive attitude will aid your recovery, but it can take time and patience. You may find that talking to someone or going to a support group will help. On page 12 we have listed some organisations and associations that you or your family may find helpful. Previous neurosurgery patients have found the Headway Association an extremely valuable resource. The following information is taken from their website.

Driving

If you have had brain surgery it could affect your fitness to drive. You must inform the Drivers Medical Unit of the DVLA (Driver and Vehicle Licensing Authority). Your doctor will have access to the restriction details and will be able to advise you.

Drivers Medical Group

DVLA Swansea, SA99 ITU Website: www.gov.uk/dvla-medical-enquiries Tel: 0300 790 6806

Welfare benefits

Claiming benefits that you are entitled to can help to ease the pressure on family finances. But the benefit system is complex and can be confusing. It's important to get professional advice and to apply for benefits as soon as possible so that you don't lose money. The brain injury charity 'Headway' has information on its website which explains the benefits system clearly.

Website: www.headway.org.uk/Welfare-benefits.aspx

A description of all the benefits that may be available to you is shown on the Direct.gov website, along with a lot of other useful information. Your local Citizens Advice Bureau or Disability Information and Advice Line (DIAL) may also be able to help, either directly or by giving you details of a welfare rights officer in your area.

Sharing helpful information

If there is any information that you think will be useful to other people recovering from brain surgery please contact the:

Advanced Nurse Practitioners

Neurosciences Outpatient Department West Wing John Radcliffe Hospital Headington Oxford OX3 9DU

Direct line: **01865 234 975** (Monday to Thursday, 9am to 4pm)

Linda's helpful hints

Linda is a former Neurosurgical patient. She has put together a list of tips which you may find helpful after you go home.

- If someone offers help take it.
- Rest means rest. Don't worry if you don't sleep. Give your body time to adjust to the trauma it has been through.
- Pay attention to your body. Say NO to activity if you don't feel up to it. You'll get the hang of it (side-effects of headaches and fatigue will be a handy reminder).
- Get someone to do your talking for you if you are not feeling up to it.
- Try and get lots of fresh air and drink plenty of water.
- Be in bed by 8pm for the first couple of weeks. It doesn't matter if you don't sleep.
- Sit down as much as possible when doing jobs. For example, buy a seat/kneeling pad for gentle gardening or a fold up chair that is easy to carry round for sorting/cleaning, etc.

Page 10

- Try to manage your headache as much as possible and as your pain threshold will allow. Try ice packs, get fresh air and learn from your experiences. An activity may be responsible for the headache rather than the surgery.
- When cooking choose easily prepared food that does not need a lot of attention (slow cookers are great for this). Cook more than you need so that you can freeze the extra portions for a day when you don't feel like cooking.
- Don't be shy about talking about your experiences. You'll be surprised how many people know someone who has had a similar experience.

Memory aids

- Make a medicine chart so you know when you have/haven't taken your medication. MAKE A NOTE EVERY TIME you take your medication in the early days. Over or under medication can be serious.
- Keep a little pad and pen ready by the phone and/or in your pocket.
- Buy yourself a timer. Set the time for when you need to remember something or when you want to do a task. Leave a "post it note" by the timer, to remind you what you want to do or what you want to remember.
- Use a diary and the reminder function on your mobile.
- Use "post-it notes" around the house if you want to remember something, or if you are out and about send yourself a text. Whiteboards are also useful to aid your memory.
- You will surprise yourself in how far you have come. People will start to ask you about your strategies.

Useful organisations

Headway UK

Headway is a charity that was started in 1979 to support people affected by a brain injury. They help people understand about brain injury, offer support and run a free information helpline. They operate a network of local groups and branches across the UK. They offer a wide range of services including support networks, community based services, outreach services and respite care.

Helpline: 0808 800 2244 (Freephone) Website: www.headway.org.uk Email: helpline@headway.org.uk

Headway Oxford

Headway House 4 Bagley Wood Road Kennington Oxford OX1 5LY, UK Tel: 01865 326 263 Website: www.headwayoxford.org.uk Email: admin@headway-oxford.org.uk

Headway Ireland

Blackhall Green, Off Blackhall Place, Dublin 7, Ireland Chy No: 7417 Tel: +353 (0) 160 40 800 Fax: +353 (0) 160 41 700 Email: services@headwayireland.ie Website: www.headway.ie/

Brain and Spine Foundation

Research, education and information. Booklets on a wide range of neurological conditions and symptoms. An online discussion forum. Helpline is staffed by Neuroscience nurses.

Tel: 0207 793 5900 Fax: 0207 793 5939 Helpline: 0808 808 1000 Website: www.brainandspine.org.uk/ Email: info@brainandspine.org.uk

Brain and Spinal Injury Charity (BASIC)

Tel: 0161 707 6441 National Helpline 0870 750 0000 Website: www.basiccharity.org.uk

British Acoustic Neuroma Association (BANA UK)

Freephone number: 0800 652 3143 Tel: 01246 550 011 Website: www.bana-uk.com/ Email: admin@bana-uk.com

Carers UK

Carers UK is the voice of carers and the leading campaigning, policy and information organisation for carers. Website: www.carersuk.org

Citizens Advice Bureau

Website: www.citizensadvice.org.uk/

Direct.gov

For general public service information on practical issues, you might like to search the Direct.gov website Website: https://www.gov.uk/

Motability

A national charity, set up on the initiative of the Government in 1977, to assist disabled people with their mobility needs. Website: http://www.motability.co.uk/

Speakability

Advice line for people with dysphasia (loss of language following stroke or head injury), their families, and professionals. Advice on accessing services, benefits, holidays, equipment and computer technology. Also gives advice on self-help groups and speech therapy.

Helpline: 0808 808 9572 Tel: 020 7261 9572 Fax: 020 7928 9542 Website: www.speakability.org.uk Email: speakability@speakability.org.uk

Questions

If you have any questions or concerns about the information in this booklet, please contact the:

Advanced Nurse Practitioner

Neurosciences Outpatient Department West Wing John Radcliffe Hospital Oxford, OX3 9DU

Direct line: **01865 234 975** (Monday to Thursday, 9am until 4pm) Acknowledgements to Maggie Tristram, Epilepsy Advanced Nurse Practitioner

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

Gillian Hemmings Advanced Nurse Practitioner, Neurosurgery February 2015 Review: February 2018 Oxford University Hospitals NHS Trust Oxford OX3 9DU www.ouh.nhs.uk/information



OMI 11585P