Patient information and consent to lumbar infusion study

Key messages for patients

- Please read your admission letter carefully. It is important to follow the instructions we give you about not eating or drinking or we may have to postpone or cancel your operation.

- Please read this information carefully, you and your health professional will sign it to document your consent.

- It is important that you bring the consent form with you when you are admitted for surgery. You will have an opportunity to ask any questions from the surgeon or anaesthetist when you are admitted. You may sign the consent form either before you come or when you are admitted.

- Please bring with you all of your medications and its packaging (including inhalers, injections, creams, eye drops, patches, insulin and herbal remedies), a current repeat prescription from your GP, any cards about your treatment and any information that you have been given relevant to your care in hospital, such as x rays or test results.

- Laxatives and painkillers may be required after your hospital stay; please ensure you have appropriate supplies at home.

- Take your medications as normal on the day of the procedure unless you have been specifically told not to take a drug or drugs before or on the day by a member of your medical team. If you have diabetes please ask for specific individual advice to be given on your medication at your pre-operative assessment appointment.

- Please call the Clinical Nurse Practitioner on telephone number 01223 245151 ask operator for bleep 152 423 if you have any questions or concerns about this procedure or your appointment.

After the procedure we will file the consent form in your medical notes and you may take this information leaflet home with you.

Important things you need to know

Patient choice is an important part of your care. You have the right to change your mind at any time, even after you have given consent and the procedure has started (as long as it is safe and practical to do so). If you are having an anaesthetic you will have the opportunity to discuss this with the anaesthetist, unless the urgency of your treatment prevents this.

We will also only carry out the procedure on your consent form unless, in the opinion of the health professional responsible for your care, a further procedure is needed in order to save your life or prevent serious harm to your health. However, there may be procedures you do not wish us to carry out and these can be recorded on the consent form. We are unable to guarantee that a particular person will perform the procedure. However the person undertaking the procedure will have the relevant experience.

All information we hold about you is stored according to the Data Protection Act 1998.
About the infusion study

Cerebrospinal fluid (CSF) is produced in the fluid spaces in your brain. It then circulates through these spaces to the spinal canal and back up again to the brain in a loop. Fluid is then reabsorbed in the brain. This cycle normally takes place three times a day. Many things can affect this loop:

- There may be too much fluid produced.
- There could be a blockage in part of the loop.
- Even if the loop is working, it may be inefficient for some reason.

Your doctor will discuss this with you.

The first step of the test is a lumbar puncture. This involves inserting a needle into the fluid spaces in your spinal canal in the lower back. The infusion study involves the injection of saline fluid (which is made of water and salts) into this fluid space. This fluid column is connected to monitoring devices which allow us to make pressure measurements. In this way, we can tell how efficiently your CSF loop is working.

This test is done under local anaesthesia. The test takes about half an hour to forty-five minutes. You will then have to rest by lying down on a bed for three to four hours. You will be asked to drink to replenish any fluids you have lost during the test. You will usually be able to go home on the same day.

Intended benefits

To assess if you have hydrocephalus (fluid pressure on the brain), which can be improved with a shunt operation.

Who will perform my procedure?

This procedure will be performed by doctor or specialist nurse practitioner as well as a member of the infusion study team.

Before your procedure

When you are seen in the outpatient clinic, we may offer this test to you if it is appropriate. You will then have a separate appointment to come in for the test. At this clinic, we will ask for details of your medical history and carry out any necessary clinical examinations and investigations. Please ask us any questions about the procedure, and feel free to discuss any concerns you might have at any time.

We will ask if you take any tablets or use any other types of medication either prescribed by a doctor or bought over the counter in a pharmacy. Please bring all your medications and any packaging (if available) with you. Please tell the ward staff about all of the medicines you use. If you wish to take your medication yourself (self-medicate), please ask your nurse. Pharmacists visit the wards regularly and can help with any medicine queries.
Patient Information

Please bring your tablets and continue to take them when you are in hospital for the day. However, if you are on Warfarin, Aspirin, Clopidogrel or Di-Pyridamole please let us know. These will need to be stopped seven to ten days before the test, if it is safe to do so.

This procedure involves the use of local anaesthesia. We explain about the different types of anaesthesia or sedation we may use at the end of this leaflet. You will see an anaesthetist before your procedure.

This test is done as a ‘day admission’, meaning you can go home on the same day.

**During the procedure**
- Your doctor will explain what is happening. You will also meet a member of our specialist infusion study team, who will be performing the measurements.
- The procedure is done under local anaesthetic.
- You will need to lie on your side, with your legs curled up to your chest. We will help you position yourself into a comfortable position.
- During the procedure, you will be able to talk to us and find out what is happening.

**After the procedure**
The test takes about half an hour to forty-five minutes. You will then have to rest by lying down on a bed for three to four hours. You will be asked to drink to replenish any fluids you have lost during the test. You will usually be able to go home on the same day.

**Eating and drinking.** After this procedure, you will need to drink plenty of fluids to replenish the fluids you lost in the procedure. You should be able to eat and drink as normal.

**Getting about after the procedure.** You will need to lie down for three to four hours. We will then help you to become mobile.

**Leaving hospital.** You will be able to go home on the same day. If you feel quite unwell, you may have to stay overnight but this is very unlikely.

**Resuming normal activities including work.** You will be able to resume your normal activities the next day.

**Special measures after the procedure:** You will need to drink plenty of fluids over the next 24 hours to prevent problems due to the fluid loss. You will also be given information about things to watch out for that might be early signs of problems (for example, infection).
Check-ups and results: When the test results have been analysed, you will be given an appointment to see your neurosurgeon in the outpatient clinic to discuss the results.

Significant, unavoidable or frequently occurring risks of this procedure

- **Nerve damage** – it is rare to cause nerve damage by doing a lumbar puncture in the lower spine. At this level, the nerve rootlets float freely in a sac of fluid. However, if you know that you have a spinal abnormality, please let us know about this.

- **Bleeding** – sometimes the lumbar puncture may cause bleeding from veins in the spinal canal. This rarely causes a severe problem unless you are on blood-thinning medication, such as warfarin. Please advise us of this and stop your medication seven days before the test to be safe.

- **Infection** – an infection can occur related to any puncture of the skin.

- **Discomfort** – sometimes a lumbar puncture can be uncomfortable. This is alleviated by giving local anaesthesia. You will also be able to talk to us during the procedure.

- **Headaches** – we drain fluid as part of the test and encourage you to drink fluids to replenish this loss afterwards. However, you may experience a headache due to loss of fluid. This usually improves over the next day or so as your body produces more fluid.

- **Inconclusive test results** – sometimes even if the test goes smoothly, the results may be inconclusive. We will discuss the implications of the test with you at your next clinic appointment.

Alternative procedures that are available

- Some patients are not able to have a lumbar puncture test. Another way of doing an infusion study test is to insert a tube into the fluid spaces in the brain. This is connected to a reservoir through which the infusion study is done in the usual way. This type of infusion study test is done under general anaesthesia. Only certain patients will need this type of test. Please discuss this with your doctor.

- Some patients have a type of hydrocephalus which is not life-threatening. They may have symptoms of walking or balance problems, incontinence or memory problems. In this situation, a shunt operation may help. If you have this condition but do not wish to proceed to have surgery, there is no need for you to have any type of infusion study at all. Please discuss this with your doctor.

Information and support

You might be given some additional patient information before or after the procedure, for example, leaflets that explain what to do after the procedure and what problems to look out for. If you have any questions or anxieties, please feel free to ask a member of staff.
Local anaesthesia

In local anaesthesia the local anaesthetic drug is injected into the skin and tissues at the site of the operation. The area of numbness will be restricted. Some sensation of pressure may be present, but there should be no pain. Local anaesthesia is used for minor operations such as stitching a cut, but may also be injected around the surgical site to help with pain relief. Usually a local anaesthetic will be given by the doctor doing the operation.

Information about important questions on the consent form

1 Creutzfeldt Jakob Disease (‘CJD’)

We must take special measures with hospital instruments if there is a possibility you have been at risk of CJD or variant CJD disease. We therefore ask all patients undergoing any surgical procedure if they have been told that they are at increased risk of either of these forms of CJD. This helps prevent the spread of CJD to the wider public. A positive answer will not stop your procedure taking place, but enables us to plan your operation to minimise any risk of transmission to other patients.

2 Photography, Audio or Visual Recordings

As a leading teaching hospital we take great pride in our research and staff training. We ask for your permission to use images and recordings for your diagnosis and treatment, they will form part of your medical record. We also ask for your permission to use these images for audit and in training medical and other healthcare staff and UK medical students; you do not have to agree and if you prefer not to, this will not affect the care and treatment we provide. We will ask for your separate written permission to use any images or recordings in publications or research.

3 Students in training

Training doctors and other health professionals is essential to the NHS. Your treatment may provide an important opportunity for such training, where necessary under the careful supervision of a registered professional. You may, however, prefer not to take part in the formal training of medical and other students without this affecting your care and treatment.

4 Use of Tissue

As a leading bio-medical research centre and teaching hospital, we may be able to use tissue not needed for your treatment or diagnosis to carry out research, for quality control or to train medical staff for the future. Any such research, or storage or disposal of tissue, will be carried out in accordance with ethical, legal and professional standards. In order to carry out such research we need your consent. Any research will only be carried out if it has received ethical approval from a Research Ethics Committee. You do not have to agree and if you prefer not to, this will not in any way affect the care and treatment we provide.
The leaflet ‘Donating tissue or cells for research’ gives more detailed information. Please ask for a copy.

If you wish to withdraw your consent on the use of tissue (including blood) for research, please contact our Patient Advice and Liaison Service (PALS), on 01223 216756.

Privacy & dignity

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and/or specialist one to one care is required.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team:

patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history

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Lumbar infusion study, CF394, Version 4, May 2017
Consent Form

Patient agreement to investigation or treatment for neurosurgery, spinal surgery or vitreoretinal surgery

Please use ‘Procedure completed’ stamp below on completion:

Interpreter’s statement (if appropriate)

I have interpreted the information to the best of my ability, and in a way in which I believe the patient can understand:

Signed (Interpreter): .................................................. Date: .......................... D D J M M M Y Y Y Y

Name (PRINT): ........................................................................

Or, please note the language line reference ID number: .................................................................

Patient safety – at the heart of all we do

Addenbrooke’s Hospital | Rosie Hospital
Patient Information

To assess if you have hydrocephalus (fluid pressure on the brain), which can be improved with a shunt operation.

A Name of proposed procedure or course of treatment

(include brief explanation if medical term not clear)  

Lumbar infusion study

B Statement of health professional (details of treatment, risks and benefits)

1 I confirm I am a health professional with an appropriate knowledge of the proposed procedure, as specified in the hospital’s consent policy. I have explained the procedure to the patient. In particular, I have explained:

   a) the intended benefits of the procedure (please state)

   To assess if you have hydrocephalus (fluid pressure on the brain), which can be improved with a shunt operation.

   b) the possible risks involved. Addenbrooke’s always ensures any risks are minimised. However all procedures carry some risk and I have set out below any significant, unavoidable or frequently occurring risks including those specific to the patient

   Nerve damage; Bleeding; Infection; Discomfort; Headaches; Inconclusive test results

   c) what the treatment or procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient:

   d) any extra procedures that might become necessary during the procedure such as:

   Blood transfusion  Other procedure (please state)

   e) Was the patient born after 1 January 1997?  

2 The following information leaflet has been provided:

   Lumbar infusion study

   Version reference and date: CF394 version 4 May 2017

   or  I have offered the patient information about the procedure but this has been declined.

3 This procedure will involve:

   General and/or regional anaesthesia  Local anaesthesia  Sedation  None

Signed (Health professional):  

Date: D M Y  

Name (PRINT):  

Time (24hr): H H : M M

Designation:  

Contact/bleep no:  

CF394 Lumbar infusion studies V4 May 2017
## Consent of patient/person with parental responsibility

I confirm that the risks, benefits and alternatives of this procedure have been discussed with me and that my questions have been answered to my satisfaction and understanding.

**Important:** please read the patient information on ‘Consent’ and then put a tick in the relevant boxes for the following questions:

### 1 Creutzfeldt Jakob disease (CJD)

**a)** Have you ever been notified that you are at risk of CJD or variant CJD for public health purposes? If yes, please inform your health professional.  
☐ Yes ☐ No

**b)** Have you had a history of CJD or other prion disease in your family?  
☐ Yes ☐ No

**c)** Have you ever received growth hormone or gonadotrophin treatment?  
If yes, please give details below:  
Please specify:  
(i) whether the hormone was derived from human pituitary glands  
☐ Yes ☐ No

(ii) the year of treatment  

(iii) whether the treatment was received in the UK or another country  
☐ UK ☐ Other

**d)** Have you ever had surgery on your brain, eye or spinal cord?  
If yes, please give details below:

**e)** Since 1980, have you had any transfusions of blood or blood components (red cells, plasma, cryoprecipitate or platelets)?  
If yes, please answer questions below:  
Have you either:  
(i) received more than 50 units of blood or blood components,  
☐ Yes ☐ No

or  
(ii) received blood or blood components on more than 20 occasions  
☐ Yes ☐ No

Where possible, please provide the names of all the hospitals where you received blood or blood components:

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In the case of a positive reply to any CJD question, staff should immediately inform Infection Control on ext 3497 (bleep numbers 152-198 or 151-803) and the theatre co-ordinator (24 hour bleep number 152-585); out of hours contact the on call medical microbiologist via the hospital contact centre.

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## 2 Photography, Audio or Visual Recording

**a)** I agree to the use of any of the above type of recordings for the purpose of diagnosis and treatment.  
☐ Yes ☐ No

**b)** I agree to unidentified versions of any of the above recordings being used for audit and medical teaching in a healthcare setting.  
☐ Yes ☐ No

## 3 Medical Training

I agree to the involvement of medical and other students as part of their formal training.  
☐ Yes ☐ No
Use of Tissue

a) I agree that tissue (including blood) not needed for my own diagnosis or treatment can be used and stored for ethically approved research which may include ethically approved genetic research. □ Yes □ No

b) Where additional clinical information is needed for the purposes of ethically approved research, I agree that relevant sections of my medical record may be looked at by researchers or by relevant regulatory authorities. I give permission for these individuals to have access to my records. □ Yes □ No

I have listed below any procedures that I do not wish to be carried out without further discussion.

I have read and understood the Patient Information entitled Consent and the above additional information. I agree to the procedure or treatment.

Signed (Patient): ............................ Date: ...D.D./M.M./Y.Y.Y.Y....
Name of patient (PRINT):

If signing for a child or young person; delete if not applicable.
I confirm I am a person with parental responsibility for the patient named on this form.

Signed: ........................................ Date: ...D.D./M.M./Y.Y.Y.Y....
Relationship to patient:

If the patient is unable to sign but has indicated his/her consent, a witness should sign below.

Signed (Witness): ................................ Date: ...D.D./M.M./Y.Y.Y.Y....
Name of witness (PRINT):
Address:

Confirmation of consent

Confirmation of consent (where the treatment/procedure has been discussed in advance)
On behalf of the team treating the patient, I have confirmed with the patient that she/he has no further questions and wishes the treatment/procedure to go ahead.

Signed (Health professional): ............................ Date: ...D.D./M.M./Y.Y.Y.Y....
Name (PRINT): ........................................ Job title:

Please initial to confirm all sections have been completed:

Withdrawal of patient consent

□ The patient has withdrawn consent (ask patient to sign and date here)

Signed (Patient): .................................... Date: ...D.D./M.M./Y.Y.Y.Y....

Signed (Health professional): ............................ Date: ...D.D./M.M./Y.Y.Y.Y....
Name (PRINT): ........................................ Job title: