

Parental agreement to investigation or treatment of a child who has leukaemia

Routine procedures under general anaesthetic for the whole course of leukaemia treatment

Authors: Paediatric Oncology Unit

- Lumbar puncture (to obtain samples of cerebrospinal fluid - CSF)
- Intrathecal chemotherapy (part of leukaemia treatment)
- Bone marrow aspirate and trephine (to sample the bone marrow using a smaller or larger needle)
- These procedures are usually carried out as day-case procedures in the Paediatric Day Unit at Addenbrooke's Hospital
- Please ask about anything you do not fully understand or wish to have explained in more detail.
- If you would like this information in another format or language or would like help completing the form, please ask a member of our staff.

Please bring this form with you to hospital

- You will be asked to read this form carefully and you and your doctor (or another appropriate health professional) will sign it with you to document your consent for one or more of the procedures, which form part of the treatment for leukaemia.
- All our consent forms are available on the Addenbrooke's website:
<http://www.addenbrookes.org.uk/consent>
- Remember, you can change your mind about having the procedure at any time.

For staff use:

Does the patient have any special requirements? (For example, requires an interpreter or other additional communication method)

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What is leukaemia?

Leukaemia is a type of blood cancer. Leukaemia cells are made in the bone marrow (the blood 'factory', where all blood cells are made) and are sometimes also found in the cerebrospinal fluid (CSF), which is the fluid surrounding the brain and spine. This is why we must look in both the bone marrow and CSF regularly to make sure the treatment is working. We also give medicines into the CSF (called intrathecal chemotherapy) to treat cells found in this area, even if there are no cells found there.

On the day before the planned procedure:

- Your child will need to have blood taken the day before the procedure (we will organise who does it for you). This is to make sure that their blood count is ok for both the procedure and the anaesthetic, and to let us order additional blood or platelets if needed.
- Please check with the Paediatric Day Unit (PDU) the afternoon before the procedure to see if we will be able to go ahead as planned (this will depend on the blood test results).
- Please also let us know if your child has a cold or other infectious illness.

On the day of the procedure

- Please remove any nail-varnish and/or make-up because they could hide important signs during the anaesthetic.
- The procedure will usually be done under a general anaesthetic (see below about anaesthetics). It is very important that your child does not eat anything for six hours before the general anaesthetic. Your child may drink water (not milk) but must not drink anything for three hours before the anaesthetic.
- Immediately before the procedure, your child will be weighed and have their temperature, pulse, blood-pressure and oxygen levels checked.
- You will also see a doctor and an anaesthetist (who is the doctor who will give the anaesthetic) to make sure your child is fit for both the procedure and the anaesthetic. It is important to tell our staff if your child has a cough/cold or any other minor illness on the day, because this might affect the anaesthetic. You will also be asked about any allergies, previous anaesthetics, loose teeth and when your child last ate or drank.
- Please ask us any questions you have about the procedure or anaesthetic at any time.

The procedure

- **The anaesthetic**

Your child will be asleep and will not be aware or feel anything during the procedure. The anaesthetic will be given via a mask (using gas), or into a vein.

- **Lumbar puncture and intrathecal chemotherapy**

During a lumbar puncture a small needle is inserted into your child's back to remove a sample of CSF, which is a clear liquid that surrounds the spine and brain. This sample is sent to the laboratory for testing. If required, medicines can then be injected through the same needle. The needle is then removed, and a small plaster put on the area. This plaster must be removed later the same day.

- **Bone marrow aspirate**

During this procedure, a needle is inserted into the back of the hip bone to sample the bone marrow. This sample is sent to the laboratory for testing. A small plaster will then be put on the area, which must be removed later that day.

Very occasionally an extra bone marrow sample may be taken, from the same place as the first, but with a slightly bigger needle (this is called a trephine). This is sent to a different laboratory for testing, and the results can take a week to come back.

After the procedure

- After the procedure, your child will stay in the treatment room until the anaesthetist is happy that they have woken up enough to go back to the ward area. They may sleep for a while afterwards and might need to have some extra oxygen using a face mask.
- After a lumbar puncture, if possible, your child should lie flat for an hour, because this will help to prevent headaches in the first few hours. Your child may have slight bruising around the sites of both a lumbar puncture and bone marrow aspirate/trephination, and this area might be a little tender. Taking Calpol (a type of paracetamol) can help this, so if your child is sore please ask a member of staff for some.
- Once your child is awake, has had something to eat and drink, and the nurses and you are happy, you will be discharged home (provided no further treatment is needed that day).

Who will perform my child's procedure?

This procedure will be performed by experienced doctors from the Paediatric Oncology Unit.

Alternative procedures that are available

As treatment progresses, some children decide that they would prefer to have their procedures carried out under a local anaesthetic. This means that they can be awake while the procedure is carried out. We will talk to you about this if you would like to know more.

Serious or frequently occurring risks

- There is a small chance of bruising around or bleeding from procedure sites. If there is bleeding, press on the area until it stops. Paracetamol can be given if there is any pain.
- It is also possible for these sites to become infected, as with any break in the skin. This is more of a risk if your child has neutropenia (low neutrophils). Removing the plaster later the same day can reduce this risk. Please watch for signs of infection, which are redness, pain or swelling.
- Serious complications with anaesthetics are very rare. Any increased risk due to your child's personal health and circumstances will be discussed with you on the day of the procedure. The anaesthetist will care for all aspects of your child's health and safety over the period of their procedure and immediately after.

Information and support

Additional information will be given to you in the form of patient information leaflets. Please speak to a member of staff if you have any questions or anxieties.

- PDU (Day Unit) 01223 217234 or 257157
- Ward C2 01223 217231 or 217534

Further information

Training doctors and other health professionals is essential for the continuation of the health service and improving the quality of care. Your child's treatment may provide an important opportunity for such training, where necessary under the careful supervision of a senior doctor. When new doctors join the team and during their training, they will always be supervised by a senior doctor.

Glossary of terms

ALL	Acute lymphoblastic leukaemia
AML	Acute myeloid leukaemia
Anaesthetist	The doctor who will give the anaesthetic for the procedure and monitor your child's condition during procedures and in recovery
Bone marrow	The blood 'factory' where the blood cells are made This is found in the centre of many bones
Bone marrow aspirate	A small amount of bone marrow taken with a needle and syringe
Central line	A tube through which blood can be taken and medicines given
Chemotherapy	Drug treatment for leukaemia or other forms of cancer
CNS	Central nervous system, the brain and spine
CSF	Cerebrospinal fluid, the fluid around the brain and spine
General anaesthetic	A special sleep, which will mean your child will be not be aware or feel anything during the procedure
Intrathecal	Medicines given into the CSF
Intravenous	Medicines given into the veins or blood stream
Lumbar puncture	A needle is inserted into the lower back and fluid is taken off
Oncology	Care of people with cancer
Neutropenia	Low neutrophils, meaning your child is at risk of infection
Neutrophil	A type of white cell, which fights infection
Paediatric	Children's
Remission	There is no leukaemia seen in the bone marrow
Trephine	An extra bone marrow sample taken with a slightly larger needle. This is only taken occasionally and is sent to a different laboratory for testing. It is a different way of looking at the bone marrow, and it takes a week for the results to be ready



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

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

Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or

patient.information@addenbrookes.nhs.uk



Document history

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Consent Form 2
 Parental agreement to
 investigation or treatment

For staff use only:
Surname:
First names:
Date of birth:
Hospital no:
Male/Female:
(Use hospital identification label)

Responsible health professional/job title

Special requirements.....
 (For example, other language/other communication method)

Name of proposed procedure or course of treatment

Consent for routine procedures during Leukaemia treatment:

- Lumbar Punctures
- Intrathecal Chemotherapy
- Bone Marrow Aspirates (+/- trephine)

Statement of health professional

(To be filled in by a doctor experienced in the care of children with leukaemia, as specified in the Hospital's consent policy)

I have explained the procedure to the child and his/her parent(s). In particular, I have explained how it will be performed, the intended benefits of the procedure, any serious or frequently occurring risks including those specific to the patient

- Any extra procedures that might become necessary during the procedure
- I have discussed the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient and his/her parent(s).

- Blood transfusion
- Other procedure (please specify)

I have discussed what the treatment / procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient and his/her parent(s).

- The following information leaflet has been provided:
 - Information sheet for parents of children with leukaemia –
 - Leukaemia protocol parent information document

..... Version/Date/Ref: 5/January 2011/CF280.....

This procedure will involve:

- General and/or regional anaesthesia or Local anaesthesia if this is preferred by the child after full discussion of what is involved.

Health professional's signature Date:

Name (PRINT): Job title:

Contact details (if patient/parent wishes to discuss details later)

PDU (Day Unit) - 01223 217 234 or 257 157
 Ward C2 - 01223 217 231 or 217 534

I have offered the parent information about the procedure but s/he has declined information.

Important notes: (tick if applicable)

- The parent has withdrawn consent (ask parent to sign/date here)
- See also advance directive/living will

Statement of the interpreter (if appropriate)

I have interpreted the information to the child and his/her parent(s) to the best of my ability, and in a way in which I believe they can understand:

Interpreter's signature Date:

Name (PRINT):

For staff use only:
Surname:
First names:
Date of birth:
Hospital no:
Male/Female:
(Use hospital identification label)

Statement of parent

Please read this form carefully. If your treatment has been planned in advance, you should already have your own copy, which describes the benefits and risks of the proposed treatment. If not, you will be offered a copy now. Do ask if you have any further questions. The staff at Addenbrooke's are here to help you and your child. **You have the right to change your mind at any time before the procedure is undertaken, including after you have signed this form.**

Training doctors and other health professionals is essential to the continuation of the Health Service and improving the quality of care. Your child's treatment may provide an important opportunity for such training, where necessary under the careful supervision of a senior doctor. You may, however, decline your child's involvement in the formal training of medical and other students without this adversely affecting your care and treatment.

Please read the following:

- I understand** that my child and I will have the opportunity to discuss the details of anaesthesia with an anaesthetist before the procedure, unless the urgency of the situation prevents this. (This only applies to children having general or regional anaesthesia.)
- I understand** that you cannot give me a guarantee that a particular person will perform the procedure. The person undertaking the procedure will, however, have appropriate experience.
- I understand** that any procedure in addition to those described on this form will only be carried out if it is necessary to save my child's life or to prevent serious harm to his/her health.
- I have been told** about additional procedures which may become necessary during my child's treatment. I have listed below any procedures that **I do not wish, without further discussion, to be carried out.**

- I understand** that any tissue (including blood) removed as part of the procedure or treatment will be anonymised and may be used for teaching or quality control, and stored or disposed of in a manner regulated by appropriate, ethical, legal and professional standards.
- I understand** that all research will be approved by a research ethics committee and undertaken in accordance with appropriate ethical, legal and professional standards.
- I understand** that the research may be conducted within a hospital, university, not for profit organisation or a company laboratory.

Please tick boxes to indicate you either agree/disagree to the three points below. Yes No

- I agree** that tissue (including blood) not needed for my child's diagnosis or treatment can be used for **research which may include genetic research. If you wish** to withdraw your consent for the use of your tissue (including blood) for research, please contact the Patient Advice and Liaison Service at Addenbrooke's Hospital.
- I agree** to the use of photography for the purpose of diagnosis and treatment.
- I agree** to anonymised photographs being used for medical teaching.
- I confirm** that the risks, benefits and alternatives of this procedure have been discussed with me and my child and I have read and understood the above and agree to the procedure (or course of treatment) on this form.

Parent's signature: **Date:**

Name (PRINT):

Child's agreement to treatment (if child wishes to sign)

I agree to have the treatment I have been told about.

Signature: Date:

Name (PRINT):

Confirmation of consent (to be completed by a health professional when the child is admitted for the procedure, if the parent/child have signed the form in advance)

On behalf of the team treating the patient, I have confirmed with the child and his/her parent(s) that they have no further questions and wish the procedure to go ahead.

Signature: Date:

Name (PRINT): Job Title:

Copy accepted by parent: yes / no (please circle)