

Intrathecal cytarabine for children and young people

An information guide for parents, carers and young adult patients

The purpose of this guide is to give information about the use of intrathecal cytarabine to parents, carers and young people undergoing treatment for cancer.

Please read this guide carefully alongside any patient information provided by the manufacturer. We have written this guide to give you more information about the use of this medicine in children and young people. Keep it somewhere safe so you can read it again.

What is intrathecal cytarabine?

Cytarabine (also known as Ara C) is a chemotherapy medicine used to treat many different types of cancer. This information is about the use of cytarabine given into the fluid around the spinal cord during a lumbar puncture – this is called an ‘intrathecal injection’. Intrathecal cytarabine is used to treat or prevent leukaemia and some lymphomas in the central nervous system (CNS).

How is intrathecal cytarabine given?

The injection is given through a needle that is placed into a space between bones in the lower back. This procedure is known as a ‘lumbar puncture’ and is usually done under a general anaesthetic.

For a general anaesthetic, it is necessary to fast (not eat or drink) for a period of time before the procedure. Your medical team will tell you how long this will be for.

Any blood thinning medicines being taken may need to be stopped for a few doses before a lumbar puncture. Check with your medical team what you need to do.

It is necessary to lie flat for a period of time following an intrathecal injection to reduce the risk of headache. A dressing will be placed over the injection area. It is important to keep this dry for 24 hours and then remove the plaster.

Sometimes the injection is given into an implanted device in the head. This is called an ‘intraventricular injection’. The doctors will explain if a device is needed and how it will be used. This is mostly used for cancers affecting the brain or part of the CNS. It is not usually needed for patients with leukaemia or lymphoma.

If needed, as part of the treatment plan, other intrathecal medicines may be given at the same time as cytarabine. Your doctors will explain this to you.

Are there any side effects?

It is important to remember that everyone reacts differently to chemotherapy. Some will have very few side effects whilst others will have more. The side effects listed below will not affect everyone who is given intrathecal cytarabine and may be different if more than one chemotherapy drug is given.

What are the common side effects?

Intrathecal cytarabine itself does not often cause side effects, but the method of injection may lead to some discomfort for a few hours after the injection. Side effects may include:

- dizziness
- nausea (feeling sick)
- vomiting (being sick)
- loss of balance
- blurred vision

Anti-sickness medicine can be given, and lying down after the injection for a period of time and drinking plenty of fluids will help these effects to pass.

The place where the intrathecal needle has been placed may feel sore or slightly bruised. Pain relief can be given if needed.

What are the less common side effects?

Less common side effects may include:

- numbness or tingling in the arms and legs
- loss of coordination or movement, particularly in the lower half the body
- problems with vision
- sore eyes
- sensitivity to light

If any of these effects happen, tell your medical team straightaway. The doctors will be able to discuss any concerns with you.

Which tests/investigations may be needed?

A full blood count will be taken and blood tests to check kidney and liver function may also be done. Your medical team will do a general health check to make sure it is safe to have a general anaesthetic.

Giving consent

You will be asked to sign a form to give consent (permission) for the hospital staff to do the lumbar puncture and give the intrathecal cytarabine. Strict rules are in place to ensure that all hospital staff involved in preparing and giving intrathecal chemotherapy have training in this area, and there may be extra doctors or nurses in the room to carry out the safety checks.

If more than one intrathecal chemotherapy medicine is to be given on the same day, the injections will be given one after the other. You will give consent for all of the intrathecal medicines involved when signing the form.

Does intrathecal cytarabine interact with any other medicines?

Some medicines can affect how well intrathecal cytarabine works, so always tell the doctor about any other medication that is being taken. Check with your doctor or pharmacist before taking any other medicines. This includes supplements, herbal and complementary medicines.

Pregnancy

If a person is sexually active while taking anti-cancer medicines or drugs, it is important to use contraception such as condoms, the pill or coil to avoid pregnancy. A pregnancy test may be needed before taking this medicine. Contraception should continue for a while after treatment finishes. Your team will advise how long contraception should continue for.

Fertility

Depending on the type, dose and combination of medicines given during your treatment, it is possible that fertility may be affected. For girls, this means that it may be harder for them to become pregnant in the future. For boys, this may mean that their sperm is less fertile, which can affect their chance of having children in the future. If you would like more information about this please discuss with your medical team.

If you have any questions about intrathecal cytarabine, please contact your treating hospital. This guide only gives general information.

Always discuss individual treatment with your medical team. Do not rely on this guide alone for information about treatment.

Useful information

CCLG: The Children & Young People's Cancer

Association publishes a variety of free resources to order or download at www.cclg.org.uk/publications



Scan to order or download this factsheet or any other CCLG publications FREE of charge.

Young Lives vs Cancer provides practical support and advice for children and young people affected by cancer and their families.

www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer.

www.macmillan.org.uk

EMC (Electronic Medicines Compendium) offers up to date, approved and regulated information for licensed medicines.

www.medicines.org.uk



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We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

We make every effort to ensure that this information is accurate and up to date at the time of printing. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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