NHS
Oxford University Hospitals
NHS Foundation Trust

Kamran’s Ward: SECTION TWO

Supporting you and your child through treatment

This section contains key information about some very important topics. Please feel free to discuss these with a member of your child's medical or nursing team, if you need more information.

Contact the hospital if your child:

- has a temperature of 38°C or higher or below 35.5°C
- is lethargic (floppy) or seems 'unwell'
- is breathing differently (faster/slower/wheezing)
- is in pain
- is vomiting or has diarrhoea
- has any bruising, a bleeding nose or gums
- has a new rash
- has a persistent cough
- has not opened their bowels for two or more days
- is not eating or drinking
- has a red or sore Hickman line/Portacath site.

- **Please also call if you are unsure about their medicines.**

DO NOT HESITATE TO SEEK MEDICAL HELP IF YOU ARE CONCERNED ABOUT YOUR CHILD'S CONDITION

Types of treatment

There are several different types of treatment used for childhood cancer. These may include surgery, chemotherapy and radiotherapy. Often a combination of these treatments will be used. Some rarer cancers also need treatment with immunotherapy or stem cell transplantation.

Surgery

Your child may need an operation to remove a tumour. This would be carried out by our specialist surgical team.

Chemotherapy

Chemotherapy is the term used to describe the drugs that are given to kill the cancer cells. More information about this can be found on page 5.

Radiotherapy

Radiotherapy treats cancer by using high-energy rays (such as X-rays) to destroy the cancer cells in one area of the body, while doing as little harm as possible to healthy cells. More information will be provided if your child is to have radiotherapy.

Immunotherapy

Immunotherapy harnesses the power of your child’s own immune system to attack the cancer. This type of treatment is the focus of some clinical trials for specific types of cancer.

Stem cell transplantation

A stem cell transplant allows children to have much higher doses of chemotherapy than they could otherwise tolerate. Again, this is only used for children with a certain type of cancer and will be discussed with you if we think it is needed.

What is chemotherapy?

Chemotherapy is a type of treatment for cancer. It uses medicine which kills cancer cells. It kills the cancer cells by damaging them so they cannot reproduce and spread.

What are the risks?

The medications used in chemotherapy cannot tell the difference between fast growing cancer cells and other types of fast growing cells, like blood cells, skin cells, hair follicles and the cells inside the mouth and stomach.

This can lead to side effects, such as hair loss, vomiting and weight loss. It can also cause damage to vital cells within the blood. This can make your child more prone to infections, anaemia, bruising and bleeding. The "good cells" do recover after time.

Each of the chemotherapy drugs have specific side effects. You will be given written information about the drugs your child will receive. This will include details of side effects and what you will need to look out for at home.

We aim to avoid children feeling sick due to chemotherapy, with the use of anti-sickness medicines. These may need to be given for a few days after chemotherapy. We give each child their own plan for managing their nausea. If the nausea and/or vomiting is not controlled, please contact Kamran's Ward or your local hospital, or speak to your child's medical team for advice.

Medication

During your child's treatment they may need medication that has to be taken by mouth (orally) or given directly into their bloodstream through a vein (intravenously or 'IV').

Oral medication

For some children, taking tablets or liquid medicine can be really challenging. There is a Children Cancer and Leukaemia Group leaflet available called 'Tips to help your child to take medicine' and we are also very happy to support you and your child with this.

Some medication, such as oral chemotherapy, requires special precautions to protect you when giving it to your child. This might mean wearing gloves, for example. The nurse dispensing these medicines will explain this to you.

Steroids

Your child may receive steroids, such as dexamethasone, as part of their treatment. They may experience some of the following side effects:

- constant hunger and cravings
- aching/painful legs and joints
- mood swings
- difficulty sleeping
- weight gain, especially around the waist, thighs and face, leading to stretch marks
- indigestion
- muscle wasting (arms and legs)
- red face
- anxiety due to changed appearance
- tiredness.

What to do – tips for helping your child

These are a few suggestions – if you find other things that help, do let us know!

- Encourage them to eat small and frequent meals.
- Give them their steroids with or after food.
- Ask your doctor or nurse for indigestion medicine, if this is a problem.
- Warn friends and family about potential mood swings.
- Find distractions to help them deal with the mood swings – keep them busy!
- When your child is struggling to sleep, try audio stories, music or putting thoughts on paper (writing a journal). Sometimes taking the last daily dose of steroids a little earlier in the evening can help as well.
- Reassure your child that, the weight and other side effects will go away after the steroids stop.
- Use moisturiser gently over thei r skin, especially the stretch marks.
- Encourage them to take gentle, regular exercise, if they are able.
- Make sure they take regular rest periods.
- Talk to the doctors if the side effects are particularly severe. You or your child may need to keep a diary of the things that seem worrying.
- If the side effects include on-going sleep difficulties, high levels of anxiety or significant behavioural changes that are concerning you, you may want to speak with the psychologists. Their contact details can be found in the 'Welcome to Kamran's Ward' booklet. Alternatively, you can speak to your child's doctor or nurse.

Remember, young children in particular benefit from consistency in their lives. As far as you are able, try to keep routines and family rules in place. Children feel safer and more secure knowing that as much as possible remains the same, such as mealtimes, bedtimes and expectations around behaviour, be it good or bad.

Please also ask for the Children Cancer and Leukaemia Group (CCLG) leaflet 'Dexamethasone – A self help guide for parents'.

Intravenous (IV) medication

IV medication can be given through a temporary cannula or a permanent indwelling line.

Some IV medication is given over a period of a few minutes, which is called a bolus or push. Other medications are given over several hours, using an infusion pump.

Cannula

A cannula is a small flexible tube which is placed under the skin, often in the back of the hand. It is used to give medication or fluid directly into the bloodstream.

Permanent indwelling lines

If your child needs long term IV medication, a permanent indwelling

line may be recommended. It is safer to give chemotherapy into a permanent indwelling line, as they sit in big veins which are less likely to be damaged by the medication. It also reduces the need for lots of needles for cannulas and blood tests.

The options for different types of indwelling lines, such as Hickman lines or Portacaths, will be discussed with you. We also have information sheets available, which will tell you more about how they are inserted and how to care for them.

Risks of IV medication

If your child complains of any stinging or burning while the medication or fluid is being given, or there is any redness or leakage of fluid from a cannula or permanent indwelling line, tell the doctor or nurse immediately. If medicines leak into the tissue this can cause damage.

Common side effects of treatment

Each specific treatment option carries the risk of a variety of side effects. Before any treatment the specific side effects will be discussed with you.

The degree to which your child experiences side effects will vary, depending on many factors. This could be the intensity of their treatment, their age and the specific type of chemotherapy they are receiving.

Some of the more common side effects are shown below:

- damage to the bone marrow function and blood counts
- increased risk of infections – 'immunosuppression'
- fever and/or potential infection
- sore mouth
- constipation.

Chemotherapy supresses the work of the bone marrow, which produces a variety of blood cells. This is measured as the 'blood count'.

Red blood cells

These contain haemoglobin, which carries oxygen around the body to all cells.

A normal level of haemoglobin (Hb) is 115-155g/L (grams per litre), but this varies with age. This level can fall as a result of chemotherapy or radiotherapy. A low level of haemoglobin is called anaemia.

If the Hb falls below 80 g/L a blood transfusion may be required. Symptoms of anaemia include tiredness, headaches and breathlessness. Older children and teenagers may find that they have symptoms of anaemia before their Hb drops to 80 and may need a blood transfusion earlier.

White blood cells

These cells fight bacterial, viral and fungal infections. There are many types of white cells. One of the most important are the neutrophils, which fight bacterial infections. The normal white cell count is 5-15 x109/L (parts per billion in a litre) and a normal neutrophil count is 1.5-8 x109/L. However, these ranges vary with age. Neutropenia or being 'neutropenic' is the term we use when the neutrophil count falls below 0.75 x109/L.

The neutrophil count is generally at its lowest 7 to 10 days after chemotherapy. When your child is neutropenic they are at greater risk of developing infections and they will find it harder to fight infections. During these periods of neutropenia it is extremely important you contact us if your child is unwell.

Platelets

The normal platelet count is 150-400 x109/L. A platelet count of below 10 will require a transfusion of platelets, to reduce the risk of bleeding.

If your child has unexplained bruising and/or bleeding from their nose or gums, they may be given a platelet transfusion, even if their count is higher than 10. If your child has an infection we may also give them a platelet transfusion, if their platelet count is low.

Watching for infections

After chemotherapy, we recommend you take your child's temperature twice a day and at any other time you think your child is unwell. Normal body temperature is 36-37.5°C.

A raised temperature is a sign of infection.

If your child has a temperature of 38°C or above, contact Kamran's Ward or your local hospital immediately and take your child to the hospital straight away.

Some children feel very cold when they have a high temperature and might shiver, making you think they are cold, but this can be a sign of severe infection. If this happens, check their temperature and contact the hospital immediately.

A low temperature (less than 35.5°C) may also mean your child is becoming unwell. Always contact the hospital if you are concerned about your child's temperature.

If at any time, but particularly during periods of neutropenia, your child is unwell or in pain, even if they don't have a temperature, they will need to be reviewed by a doctor or nurse.

Most infections children develop come from bacteria within their own body or on their skin, rather than from contact with other people. However, there are some sensible rules to follow to reduce the risk of infection (please see page 15). This is particularly important during periods of neutropenia.

Pain

Your child may experience pain due to their illness or treatment. It is very important that we help to control any pain they might have.

If your child is in pain and unwell or the pain is new or unexplained, call the hospital and tell us immediately.

Paracetamol is a great painkiller. However, it also lowers the body's temperature and reduces fevers. This could mean treatment for a serious infection could be delayed, as a fever could be masked by the effect of the paracetamol.

Although it must be used with caution, paracetamol may be an appropriate painkiller, depending on the situation. This is particularly true if the reason for the pain is explained, such as following a procedure and if your child is otherwise well.

However, if you are unsure, check your child's temperature first and call your local nursing or medical team to discuss the situation. They can advise you on the best way forward to manage your child's pain. Paracetamol should not be given regularly (multiple doses) unless advised by the nursing or medical team.

Ibrupofen **cannot** be used as a painkiller until your child has completed all of their treatment, as it can have an impact on your childs platelet count. We may recommend a small dose of oral morphine, as this can be a safe and effective way to help your child to become pain free.

Mouth care

Chemotherapy can cause damage to the lining of the mouth, called the mucosa. This can be painful and make both eating and drinking very difficult. Ulcers may develop and add to the problem. We can prescribe medicines to help with this side effect; these may include painkillers or mouthwashes.

Ideally your child should see a dentist soon after diagnosis, to identify any potential infection risks that may be caused by poor oral health . During treatment it is recommended that they are seen by a dentist every 3-4 months.

We do not recommend that any invasive dental treatment, such as fillings, are carried out during chemotherapy treatment, as bacteria in the mouth can pose a risk to children with lowered immune systems. Please discuss any dental treatment you child might need with the doctors on Kamran’s Ward, or with your local team.

Your child’s teeth should be cleaned twice a day with a soft, small-headed toothbrush and a pea-sized blob of toothpaste. Use small gentle strokes to protect the gums, ensuring that every surface of each tooth is cleaned. Check their mouth daily for redness, inflammation, ulcers or bleeding and contact us if you have any concerns.

Constipation

Constipation can be a problem for children with cancer because of the disease itself, or as a side effect of the chemotherapy or other medicines. It can be a serious issue that can delay on-going chemotherapy, as some medications cannot be given if the child is constipated.

It is very important to keep a close eye on the frequency and consistency of your child's bowel movements. The medical team can use this information to advise you on the best way of making sure your child maintains healthy bowel habits.

If it becomes difficult for your child to open their bowels, please let the hospital know. Early use of laxatives can be very helpful to avoid significant discomfort and problems.

Try to encourage your child to eat a good, healthy diet, including fruit, vegetables and wholegrain cereals, along with plenty of fluids like water and fruit juices.

Managing life when on treatment

This section contains a selection of information to provide you with some tips for managing everyday life whilst your child is having treatment.

Avoiding infection

Children who are having treatment for cancer are at increased risk of developing infections. It is important to strike a balance between reducing the risk of infection and keeping life as 'normal' as possible. If you have any questions about how to do this, please speak with your child's medical team.

Whilst your child is neutropenic, try to avoid crowded places such as cinemas, theatres and supermarkets, to reduce their risk of exposure to viral or bacterial infections found within the general public.

Food hygiene

Getting the right nutition during treatment is extremely important but can be a challenge, as your childs appetite may vary and their tastes may change.

However, good food hygiene is essential at all times, to avoid foodborne infections. For more information visit:

www.nhs.uk/LiveWell/Homehygiene/Pages/Homehygienehub.aspx

School

It is recommended that when children are feeling well they should attend school. This allows them to continue with education and to spend time with their friends. However, the school must inform you of any significant infections amongst pupils. Support to help your child attend school whilst on treatment can be provided by your community outreach nursing teams.

Pets

Pets are a huge part of family life and very important to children, but they can harbour bacteria. Please ask us for the Children Cancer and Leukaemia Group leaflet 'Children with Cancer and Pets'. This gives more advice if this is relevant to your family.

Chickenpox and shingles

If your child develops any sign of a rash, contact Kamran's Ward or your local hospital.

Contracting chicken pox can be dangerous for children undergoing chemotherapy and/or radiotherapy. All children have their immunity checked for childhood illnesses, such as chicken pox, before their first course of chemotherapy. If they are immune to chicken pox at the time of their diagnosis then they are protected.

However if your child is not immune to chicken pox and is exposed to someone with chicken pox or someone who then develops chicken pox or shingles, you will need to contact the hospital, even if they have completed their treatment. We will discuss this with you and decide on the next steps. This may involve giving them an injection called Zoster Immune Globulin (ZIG).

This injection may help prevent your child from developing chickenpox or reduce the severity of the illness if it does develop.

Shingles develops from the same virus as chickenpox (varicella zoster virus). You can only get shingles if you have had chicken pox in the past. However, if you are not immune to chicken pox you can contract this from a person with shingles.

Holidays

Before booking a holiday, whether in this country or abroad, please speak to your child's doctor or nurse. We can make sure that the timing is appropriate and fits in with planned treatment.

If your child needs a blood count while you are away, it may be possible for this to be carried out at a hospital close to where you are on holiday. It is recommended that you take a medical letter outlining your child's diagnosis and treatment on holiday with you. Please ask your doctor or nurse for this a few weeks before you travel.

We would always recommend taking out travel insurance if travelling abroad. There are some leaflets about holidays for children receiving hospital treatment available on Kamran's Ward. For advice about travel insurance, speak to a CLIC Sargent social worker or nurse.

Vaccinations

When your child is receiving chemotherapy or radiotherapy they should not be given any vaccinations or immunisations, unless advised by their consultant.

The only exception to this rule is the 'flu jab. It is recommended that your family and your child receive the 'flu vaccination as early as possible in the autumn each year and during the 6 months following the end of treatment. You will receive a letter every year about this vaccination.

Once chemotherapy is finished, it will take your child about 6-12 months for their immune system to recover fully. When your child has been off treatment for 6-12 months they should be given boosters of the vaccinations they had received before the start of treatment. This will be arranged by their consultant and GP.

We recommend that the siblings of children who are not immune to chickenpox, who have not had chickenpox themselves, receive the chickenpox vaccination. This will help to protect their sibling who is undergoing treatment. We will give you a letter to take to your GP to arrange this.

Useful websites

The internet can be an extremely useful source of information and support during treatment. However, it is important to remember that not all information that you can find on the internet is accurate or helpful. The websites below are reliable sources of information and easy to navigate.

If an internet search brings up any information that concerns you or leaves you with questions, please do discuss this with your child's medical team.

Young Lives vs Cancer

www.younglivesvscancer.org.uk

Children's Cancer and Leukaemia Group

www.cclg.org.uk

Cancer Research UK

www.cruk.org.uk

Macmillan Cancer Support

www.macmillan.org.uk/cancerinformation

Teenage Cancer Trust

www.teenagecancertrust.org

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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