

Kamran's Ward: SECTION ONE

Kamran's Ward and our Team



Kamran's Ward

Kamran's Ward cares for children and young people with haematology (blood) and oncology (cancer) conditions.

The ward treats children from all over the Thames Valley and is one of the principal treatment centres (PTCs) in the United Kingdom for children with cancer and leukaemia. The ward has nine beds; four in a communal bay and five single cubicles. We also have a separate Day Care unit.

Staying on Kamran's Ward

When your child is admitted you will be shown around the ward. The ward has security swipe access and you will be allocated a swipe card. Please return the card to the nurse when your child is discharged.

There are no set visiting hours, but only one parent can stay overnight, due to limited space. There are sofa beds available in the cubicles and camp beds for bays. We provide the sheets and pillows. We also have a house off-site where parents of children on the ward can stay (see page 8 for further information). Please let us know if you think this might be helpful.

If you are bringing in other children under the age of sixteen you must not leave them unsupervised on the ward at any time.

There is a beverage room to make drinks and toast and to microwave food. Hot drinks are not permitted on the ward, due to the risk of spillages and burns, but if your child is in a cubicle you can make a hot drink and take it to the cubicle in the thermos flask provided. There is also a parents' room just outside Kamran's Ward where you can go for a break and hot drink.

In each cubicle there is a fridge which you can use. If your child is in a bay, you will be allocated a shelf in the fridge on the ward.

A breakfast trolley comes to the ward at 7.30am, but you can prepare breakfast for your child from the beverage room at any time. Menus are provided for your child for lunch (12.00 midday) and supper (5.00pm to 6.00pm). There is also a snack box and Light Bite menu available throughout the day. Please ask the nurse looking after you for details.

Please ring the ward on the day of your child's admission to confirm that your child can go ahead with their treatment and there is a bed available. Although a specific date will be given for your child's chemotherapy, sometimes treatment is delayed due to a low blood count or if your child is unwell.

Please wash or gel your hands when entering the ward. This helps to reduce the risk of infection. If you or your child are unwell please speak to a nurse.

You may want to take photographs during your time on the ward, but to respect the privacy of other children, families and staff on the ward, please make sure you only take photographs of your own children.

What to bring into hospital:

- pyjamas for you and your child
- mobile phone, electronic devices (tablet/handheld game console) and charger
- toiletries for you and your child
- favourite teddies or blankets/pillows
- comfy clothes for you and your child
- food for yourself and your child's favourite snacks.

Teenage room

On Kamran's Ward there is a teenage room, for children 12 years and over and their families. This room has drink making facilities, an X-box, i-Pod docking station, DVDs and comfy chairs. This room can be used if your child is an inpatient or if they are coming to Kamran's Day Care.

Kamran's Day Care

This is a separate area of the ward which children come to for any procedure or treatment that does not require an overnight stay.

This includes:

- chemotherapy
- investigations, procedures or scans
- blood and platelet transfusions
- medical reviews.

Kamran's Day Care is open and staffed by our nursing team from Monday to Friday (7.30am to 8.00pm). The medical team (doctors and Advanced Nurse Practitioner) are available during working hours. You will be given a specific time to come to Kamran's Day Care. Please keep to this time, as this helps the doctors and nurses to organise treatment for your child and other children.

Allow plenty of time for travelling and parking, as the hospital can get very busy.

The Kamran's Day Care email address can be used to order repeat prescriptions for your child, before an arranged appointment, or to ask non-urgent questions. Please allow two to three working days for repeat prescription requests. If you have more urgent questions, please telephone the number below.

Kamran's Day Care

Tel: **01865 234 061**

Email: **kamransdaycare@ouh.nhs.uk**

Paediatric Oncology Shared Care Units (POSCUs)

If you do not live in Oxfordshire, you can get further support from your local hospital or Paediatric Oncology Shared Care Unit (POSCU). This means that some parts of your child's treatment and any supportive care required can be delivered closer to your home. This system is known as 'Shared Care'.

When your child is ready to go home for the first time from Kamran's Ward, you will be given more information about your POSCU, including their contact details. You will either be given an appointment to meet the team, or a date for a home visit from your local community nurse.

For more information about your own POSCU, please see the leaflet provided. If you haven't received a leaflet, please ask us for a copy.

Professionals you may meet (A-Z)

Throughout your child's diagnosis and treatment you will meet many new people. They are on hand to provide you with a wide range of support. Here is an A-Z of some of the people you may meet.

Advanced Nurse Practitioner (ANP)

The Advanced Nurse Practitioner works alongside both the medical and nursing team on Kamran's Day Care. Their role involves tasks such as assessing your child prior to treatment or procedures, carrying out medical reviews, or the prescription of medication and chemotherapy.

Young Lives vs Cancer Social Worker

Young Lives vs Cancer is the UK's leading cancer charity for children, young people and their families. They provide clinical, practical, financial and emotional support, to help children and families wherever possible. They can be there from diagnosis onwards and aim to help the whole family deal with the impact of cancer and its treatment.

We try to make sure that a Young Lives vs Cancer social worker meets every family as soon as possible after diagnosis. If we haven't seen you and you feel this would be helpful, please ask the ward staff to contact the Young Lives vs Cancer team.

We have a team of Young Lives vs Cancer Social Workers based at the Children's Hospital. Each social worker has a specific geographical area to cover and also links with the relevant POSCU. They will see you and your child at the hospital and can visit you at home, if you would find this helpful. They can offer emotional and practical support, financial advice and guidance around benefits via the Young Lives vs Cancer specialist Welfare Advice Line:

Tel: 0300 330 0803

They can also help with accessing a family break or holiday.

Young Lives vs Cancer also provides accommodation for families with a child receiving treatment in Oxford. Their house, CLIC Court, is situated very close to the hospital (87 Jack Straw's Lane, Oxford) and can accommodate up to five families at a time. It is no more than a 10 minute walk from the hospital.

Some families use the house if they are travelling a long distance, have very early appointments in the hospital or are frequently returning, e.g. for radiotherapy treatment. Whatever your reason, you are most welcome to make use of the house.

The house and facilities are free of charge and all bed linen and towels are provided. If you would like more details about the house or would like to book a room (via Kamran's Ward), please speak to a member of staff on the ward, or your Young Lives vs Cancer social worker.

Young Lives vs Cancer social workers:

Oxford.ServicesTeam@younglivesvscancer.org.uk

Dietitian

During your child's treatment it is important that they eat well. Being well nourished throughout treatment will help their body to:

- fight infection and reduce the risk of other complications from treatment
- build and repair healthy tissues that have been damaged during treatment
- continue to grow and develop.

All children react differently to their cancer treatment. Some children experience no difficulties with their appetite, which helps them to continue to eat healthily. However, it is likely that there will be times during their treatment when your child's appetite and taste will change. If this happens, your child may need to be referred to a dietitian.

The role of a dietitian is to provide advice and support to make sure your child is properly nourished during treatment. There are different ways of achieving this, depending on the symptoms your child has.

Their input may include:

- Providing information on eating problems associated with your child's treatment, such as change in taste or sore mouth.
- Providing information on ways to increase the nutritional value of meals and snacks.
- Providing nutritional drinks to supplement diet.
- Support with other forms of feeding, such as through a nasogastric tube.

If you have any concerns about your child's appetite, please ask to be seen by a dietitian. For more information and tips, please ask for the Children and Cancer Leukaemia Group booklet called 'Helping your child to eat'.

Doctors

Every child has their individualised care lead by a consultant in haematology or oncology, depending on their diagnosis. Their consultant will oversee all aspects of your child's treatment. They will meet with you regularly, particularly at key points such as diagnosis, or to discuss any changes to your child's treatment.

You will also meet a selection of junior doctors and speciality doctors, both on Kamran's Ward and Kamran's Day Care. They have a wide variety of knowledge and experience of caring for children during cancer treatment.

Consultant Paediatric Oncology Secretary: **01865 234 196**

Consultant Paediatric Haematology Secretary: **01865 226 654**

Hospital School Teachers

The teaching staff work on the wards every weekday during term-time. They will make contact with you if your child needs to continue their schooling whilst they are on the ward. The Hospital School welcomes and provides education for all school age pupils (and occasionally siblings when necessary).

One to one teaching and group sessions are tailored to individual needs and cover most areas of the curriculum. Teaching takes place in the classrooms when possible, or at bedsides if this is more appropriate. The classrooms are on Level 0 of the Children's Hospital, next to Melanie's Ward, and also on Level 1 on Tom's Ward.

The Hospital School allows pupils to continue with their education whilst they are still in hospital. Your child will be allocated a key teacher from the Hospital School. They will work closely with you, the medical staff and your child's actual school.

We encourage pupils to continue with work set by their usual school (when appropriate). The Hospital School also offers a range of educational activities, which help pupils engage and achieve. This enables them to learn new skills and raise their self-esteem.

When your child leaves hospital, we will advise and support their school with getting them back into their usual education.

Hospital School Team

Tel: **01865 234 999**

Available during school term time, Monday to Friday, 9.00am to 5.00pm.



Paediatric Oncology Outreach Nurse Specialists (POONS)

There is a team of Outreach Nurses based within the Kamran's Team. They are a team of experienced children's cancer nurses and provide a link between the hospital and home for children who have cancer or leukaemia. You may also hear them referred to as POONS or Key Worker Nurses.

An Outreach Nurse can help you to understand your child's diagnosis and treatment. They will make sure you have the right information at all times. They will help to co-ordinate your child's treatment and care and provide a smooth transition from hospital to home. They can also deliver some aspects of care at home or school, to try to reduce the need for visits to the hospital.

If you live outside Oxfordshire, you will have a local Key Worker Nurse who works closely with your Paediatric Oncology Shared Care Unit (POSCU).

Paediatric Oncology Outreach Nurse Specialists

Tel: **01865 234 988**

Pharmacists

Kamran's Ward has a dedicated team of specialist clinical paediatric pharmacists, as well as a close relationship with the Oxford University Hospitals clinical trials pharmacy team.

The pharmacists work together to make sure that all the medications used are available, safe and prescribed appropriately for your child.

They work with the specialist doctors and nurses to help choose the most appropriate medicines, advise on the dose used and the correct way to administer it, whether that be in hospital, by a community nurse or by family at home.

From Monday to Friday the pharmacy team visits Kamran's Ward. There is an on-call pharmacist who can help out of hours. They will check your child's medication charts, review chemotherapy treatments, and discuss any new medication issues.

When possible, they will prepare medications ahead of visits. Repeat prescription requests from families ahead of time are particularly helpful, as this means that they have time to order medication supplies. They also liaise with the pharmacists at each of our POSCUs.

They can advise both you and the medical team on a range of issues:

- chemotherapy (drug choice, dose, monitoring, side effects, drug interactions, preparations)
- supportive treatments needed during chemotherapy, such as anti sickness medications, prophylactic (preventative) antibiotics, intravenous fluids
- antibiotics for infection
- clinical trials medications
- natural therapies (their safety and the potential for any interactions with prescribed medicines).

The pharmacists are here to help you whenever you have concerns about the medications your child is prescribed. Please ask the ward staff to contact them – they are happy to talk with you over the phone or face to face, if possible.

Physiotherapists

During your child's treatment they may see a physiotherapist. They can help with the side effects of treatment that impact on your child's movement and mobility. Younger children may need help to maintain their milestones, such as sitting, crawling and walking, as a result of being unwell. Children should be able to remain active throughout their treatment and the physiotherapist can help with this.

For more information about mobility and exercise advice, please ask to see a physiotherapist. The Children and Cancer Leukaemia Group leaflets below may also be good sources of information. They are available on Kamran's Ward:

- *"How physiotherapy can help your child"*
- *"Sport and exercise for children and young people with cancer: a parent guide".*

Play Specialists

Being in hospital and the treatments involved can affect children in different ways. This depends on their age, level of understanding and coping skills.

We strongly believe that play and activity creates a more normal environment for children, especially in times of stress and uncertainty. It can allow your child to come to terms with and work through strange experiences or surroundings, separation, anxieties, pain and discomfort.

There is a playroom in the centre of Kamran's Ward for younger children and a large covered play terrace outside the Level 0 classroom. There is a teenage room for young people of secondary school age, which also has an outside terrace.

The playroom and teenage room can be used at all times (including evenings and weekends).

The Play Specialist can bridge the gap between hospital and home, by providing normalising play. This can be useful both at home and in hospital.

The Play Specialists on Kamran's work during the week and can provide a large range of activities, both in the play areas and by the bedside. This can help to relieve boredom, release energy and help your child to socialise and become more familiar with the hospital environment.

An important part of the Play Specialist's role is to support you and your child throughout their treatment. By using age appropriate information and resources they can help your child cope with the tests and procedures they have to go through.

They can:

- provide distraction and relaxation techniques during blood tests and cannulation
- prepare your child for surgical procedures and other procedures which need a general anaesthetic
- use specially adapted dolls to prepare your child for the insertion of a central indwelling line
- give information and support to help your child prepare for specialised scans and radiotherapy.

Involving your child with preparing for the procedure can help them to understand what is going to happen to them.

Play Specialists can also give advice about coping strategies relating to behaviour and other effects of treatment and hospitalisation. They can also provide support for siblings who may be affected by their brother or sister's diagnosis and treatment.

The Play Team in the Children's Hospital wear red polo tops. Please do ask for their support whenever you need to.

Psychological support

Our Department of Paediatric Psychology can offer support for children and young people who have been diagnosed with cancer, as well as their family. Diagnosis and treatment of cancer affects everyone in the family and it can be a very challenging time. The Psychology Service offers confidential psychological and emotional support, from diagnosis, through treatment, and afterwards.

They can provide support in a number of ways, including:

- space to share feelings and explore ways of managing them (common feelings include anxiety, uncertainty and fears about the future, anger, distress, depression, guilt)
- support with managing changes in behaviour, feeding and sleep
- coping with treatment procedures, side effects and being in hospital
- coping with the many ways in which life changes (for all the family) as a result of diagnosis and treatment
- talking with the medical and multi-disciplinary team
- talking with others about the diagnosis and treatment
- accessing support from family, friends and the community
- support with the impact that the diagnosis and treatment can have on friendships, self-esteem, body image, identity, independence and education.

Support is available either on an individual or family basis. Please contact the team whenever you need to.

Clinical Psychology Secretary

Tel: **01865 234 714**

Neuropsychology Team

Tel: **01865 234 264**

Occupational Therapy

Your child may see an Occupational Therapist (OT) during their treatment. Occupational Therapy aims to help your child to continue with everyday life as much as possible, within the limits of their illness, treatment and the hospital environment. The therapists work closely with all members of your child's hospital team and often jointly with physiotherapy.

Occupational Therapy can help and support your child with:

- staying independent with activities of daily living; washing, dressing, feeding and play
- advice for returning to or staying at school
- advice on managing tiredness
- developing play plans (alongside the physiotherapist and play specialist)
- manual handling equipment – for example, slide boards if your child is struggling to get out of bed
- wheelchairs, if your child has difficulties walking – this could be due to on-going tiredness and pain
- referrals to community Occupational Therapy and wheelchair services.

Oncologists and Radiotherapists

Radiotherapy uses high-energy beams, such as X-rays, to treat cancer (and some other diseases). It can be given as a treatment by itself or it can be given after surgery. It may also be given in combination with or after a course of chemotherapy.

There are two Clinical Oncologists in Oxford who treat children. If your child is to have radiotherapy, you will meet them a few weeks before the treatment is due to begin.

Usually there is quite a bit of preparation required (called 'planning') before the treatment can start. The planning involves special CT scans. Your child may also have a special mould made, to help make sure they lie in exactly the same position each time they are treated.

If your child is very young they will need to have a general anaesthetic for each radiotherapy treatment. This stops them from

moving during the treatment, which needs to be delivered to a very specific area. This anaesthetic is very brief and your child will be treated first thing in the morning, so they can go home once they have woken up.

You will also meet the Radiographers, who will give the radiotherapy. The Paediatric Radiographer specialises in looking after children and will co-ordinate the treatment. The Radiologists work closely with the Play Specialists, to make sure children are well prepared for their treatment.

The Radiotherapy Department is on the Churchill Hospital site in Headington, about two miles from the Children's Hospital.

Research Nurses – Clinical Trials

Most of the advances that have been made in treating children's cancer have been discovered through research studies and clinical trials. A clinical trial is a way of comparing a new treatment for a particular cancer with the best available treatment, known as the 'standard treatment' for that cancer. The new treatment may be a new drug or a new way of giving an existing drug. It is hoped that the new treatment will be better than the medication already used, but this can't be confirmed without a clinical trial.

Within Kamran's Team there is a specialised Paediatric Haematology/Oncology Research Team. You will meet with the Research Nurses, who can go through the information sheets.

Please do ask any questions you have, if there is anything about the trial or any treatment that you do not understand. Please ask a nurse on Kamran's Ward if you wish to speak to a Research Nurse.

If you or your child is invited to take part in a clinical trial you will be given parent/patient information sheets, which you must read very carefully. Your child's consultant should discuss the trial with you and answer any questions you may have. To be able to give your permission for your child to be included in the trial you need to understand what the trial is looking at, how it works and what samples may need to be taken.

If you/your child agree to participate, you will be asked to sign a consent form; this will be specific to the trial. Once this has been signed you/your child will be entered into the clinical trial.

If you do not wish for your child to enter a clinical trial, their consultant will go through the other available treatment options.

If you have given consent but change your mind during the treatment or trial, you and your child may withdraw at any time – please discuss this with their consultant. Your child will not be entered into a trial without your permission.

Surgeons

As part of your child's treatment they may require an operation. This will depend on the type and the site of their tumour. A specialist team of paediatric oncology surgeons, paediatric orthopaedic surgeons or paediatric neurosurgeons carry out these operations. They work closely with your child's lead consultant and will also discuss the surgical options with you.

Before any procedure you will meet these teams to discuss the operation in detail. Immediately after the operation your child may be cared for on a specialist surgical ward, such as Tom's Ward or Robin's Ward.

Paediatric Oncology Surgeons' Secretary

Tel: **01865 231 307**

Paediatric Neurosurgeons' Secretary

Tel: **01865 231 507**

Paediatric Orthopaedic Surgeons' Secretary

Tel: **01865 238 026**

Ward nurses

The Kamran's nursing team is led by an experienced Sister, who oversees both Kamran's Ward and Kamran's Day Care.

Our nurses have specific children's cancer and chemotherapy training, as well as a lot of experience of caring for children during treatment. They can be a great source of support and advice. The nurses that will be looking after your child will introduce themselves at the beginning of each shift.

Ward clerk

The ward clerk is available from 9.00am to 5.00pm. They can arrange swipe access cards, car park permits, travel expense forms, transport requests and bookings for CLIC House.

Other people you may meet...

The list in this leaflet will certainly not cover all the people who may be involved in the care of your child. You can use this area to note down names or contact details of any other professionals you may meet.

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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Oxford University Hospitals NHS Foundation Trust

www.ouh.nhs.uk/information



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