

# Paediatric Haematology and Oncology Service

#### Introduction

This leaflet gives you information about the Paediatric Haematology and Oncology Service based at the Children's Centre, Gloucestershire Royal Hospital. It also includes details about the team members, requesting medication and parking.

## About the Paediatric Haematology and Oncology Service

We are a shared care centre and part of the South West regional Paediatric Haematology and Oncology Service. We work closely with our colleagues in the Principal Treatment Centre at Bristol Royal Hospital for Children.

The majority of our children are referred to Bristol Royal Hospital for Children for diagnosis and treatment planning. The management and delivery of care is then agreed and shared between services at Bristol Royal and Gloucestershire Royal Hospitals, dependent on your child's diagnosis, age and treatment.

The Paediatric Haematology and Oncology team at Gloucestershire Royal Hospital regularly liaise with the Bristol team about each child's care.

#### The team

During your child's treatment, you will meet many professionals who are working together in the best interests of your child, to meet their needs and provide a high standard of care:

#### **Medical staff**

 Consultant paediatrician (Head of Service) is responsible for the planned treatment, medical management and longterm follow up care of paediatric haematology patients. They are also responsible for the overall management of the Paediatric Haematology and Oncology Service.

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Department

Paediatric Oncology

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 Consultant paediatrician is responsible for the planned treatment, medical management and long-term follow up care of the paediatric oncology patients.

If your child is unwell and attends the Emily Kent Unit (EKU), they will be seen by a ward doctor. All ward doctors are able to care for your child and will contact your child's consultant or the team in Bristol, if necessary.

#### **Nursing staff**

- Lou Alexander, Lead Paediatric Oncology / Haematology Clinical Nurse Specialist (CNS)
- Kelly Prosser, Paediatric Oncology Clinical Nurse Specialist (CNS)

The CNS team are mainly community-focused and are responsible for the nursing aspects of your child's care at home. They will also provide advice and support.

When possible, the CNS will visit your child at home to reduce the time spent in hospital.

The CNS will be your child's key worker; linking home and hospital. They will be your point of contact for any queries you may have.

If needed, the CNS team will liaise with the Primary Health Care Team (PHCT), the Children's Community Nursing Team (CCNT), Acorn's Hospice, nurseries and schools.

Family Support Worker
 Hannah Bressington, The Family Support Worker
 provides both emotional and practical support to our
 paediatric oncology patients and their families. The support
 may be advice, referral or signposting to the most
 appropriate community and social resources. The Family
 Support Worker also arranges support groups and
 associated events.



 Emily Kent Unit (EKU)
 Hannah Hulcup, Ward Manager and Paediatric Matron is responsible for the overall running of the unit.

#### The EKU nursing team

There are a number of nurses working on the EKU, who you will get to know well. They are responsible for day case treatments and inpatient nursing. This includes administering chemotherapy and providing medical care to your child.

Teenage and Young Adults (TYA)
 Meg Wilsher, Specialist Nurse works with young people aged 16 to 24 years to provide continuity of care and support into young adulthood.

#### Wider team members

Hospital Play Specialists and assistants

The play specialists and assistants play with the children in the playroom and at their bedside and are skilled at meeting your child's needs. They will work with the children and parents to find ways in which to support them during difficult procedures.

The play specialists and assistants are also responsible for making sure that all children are provided with the opportunity to join the 'Beads of courage' scheme. They will ensure collection of your child's beads during treatment.

#### School teacher

Children from Reception class up to Year 11 will continue to receive education while in hospital. The school teacher will liaise directly with your child's school. A referral may also be made to the education outreach team to provide lessons at home. If you have any questions about your child's education, please discuss this with one of the teaching staff.

 Young Lives vs Cancer Social Worker provides support, help and advice, benefit entitlement, employment, financial grants, access to respite breaks and referral to charities for support with wishes and experiences.



 The secretary provides secretarial support to the service and usually knows where everyone is and where to contact them. If in doubt during the working day, please do not hesitate to contact the secretary.

### Planning a holiday

When going on holiday or planning a break away from home, your child will need to have a 'holiday letter' with the contact details of the nearest hospital to your accommodation. The hospital ward will be made aware that your child will be staying in the area and will be provided with your child's relevant medical details. This is in case your child is unwell during their holiday and you need to access treatment.

The CNS team will need to have 2 weeks' notice before the date of your planned trip and 4 weeks' notice during the school holidays.

You can email the support worker at <a href="mailto:hannah.bressington@nhs.net">hannah.bressington@nhs.net</a> or the Clinical Nurse Specialist at <a href="mailto:qhn-tr.paedonccnsgrh@nhs.net">qhn-tr.paedonccnsgrh@nhs.net</a>

## Requesting medication

If you require any prescribed medicines for your child, please email your request to <a href="mailto:ghn-tr.PaedOncGRH@nhs.net">ghn-tr.PaedOncGRH@nhs.net</a>

You should allow 3 days before the date when the medicines are required.

### **Community visits**

The CNS team will provide some of your child's/young person's (YP) supportive care at home. When arranging a visit to your home, please allow a 60 minute time frame for the appointment.

### Appointments in the EKU

All children will be given an appointment time for planned treatment and procedures. Appointments are arranged to allow enough time for your child to be reviewed by the doctor and for chemotherapy to be given.



When attending the Acute Lymphoblastic Leukaemia (ALL) clinic, please note that the appointment for your child's medical review will be with the consultant and with the nursing staff for treatment.

Sometimes we may have to change appointment times but we will try to accommodate your preferences when possible.

### **EKU open access**

All children having treatment, and up to 6 months after treatment, have open access to the EKU. This mean that you can contact the EKU directly if you have any concerns.

If your child is having treatment and has a temperature or is generally unwell, you do not need to wait for an appointment. Please contact the EKU nurse on 07813 456 570 for advice.

## **Hospital parking**

If your child is receiving treatment as an inpatient or outpatient, you are entitled to a free car parking pass. This is for the Orchard Centre car park and all other visitor car parks at Gloucestershire Royal Hospital. You will need to take a signed form to the Parking Office to get the free parking pass, please ask any member of staff about this.

A blue badge will allow you to park in any designated disabled space on the hospital site.

### **Young Lives vs Cancer**

This is a national charity which supports families of a child who has cancer or leukaemia. Young Lives vs Cancer funds the social worker for the Paediatric Haematology and Oncology Service at Gloucestershire Royal Hospital. The charity provides care grants, information and 'Home from Homes' in Bristol (places for families to stay while their child is in hospital there).

For more information about the charity, please visit: www.younglivesvscancer.org.uk/what-we-do/



#### **Contact information**

#### Dr Thomas Kus Consultant Paediatrician – Service Lead

Tel: 0300 422 8491

Monday to Friday, 9:00am to 5:00pm

Email: T.Kus@nhs.net

#### Dr Augusta Isaac Consultant Paediatrician

Tel: 0300 422 8491

Monday, Tuesday and Friday 9:00am to 5:00pm

Email: <u>Augusta.lsaac@nhs.net</u>

#### Dr Chrissie Parfitt Consultant Paediatrician

Tel: 0300 422 8484

Monday, Tuesday, Wednesday and Thursday, 9:00am to

5:00pm

Email: cparfitt@nhs.net

#### Lou Alexander

### **Lead Paediatric Oncology Clinical Nurse Specialist**

Tel: 0300 422 8572 Mobile: 07880 794 642

Monday to Friday, 8:00am to 4:00pm

Email: l.alexander1@nhs.net

## Kelly Prosser-Tyrrell Paediatric Oncology Clinical Nurse Specialist

Tel: 0300 422 8484 Mobile: 07811 989 050

Tuesday, Thursday, some Wednesdays, Friday 8:00am to

5:00pm

Email: Kelly.Prosser@nhs.net

## Hannah Bressington Family Support Worker

Tel: 0300 422 8572

Monday, Tuesday and Friday, 8:00am to 4:00pm

Mobile: 07980788535

Email: hannah.bressington@nhs.net



## Megan Willsher TYA Specialist Nurse

Tel: 0300 422 3446 Mobile: 07833 441 289

Monday, Tuesday, Wednesday and Friday, 7:30am to 5:30pm

Email: Megan.Willsher@nhs.net

#### **Katie Hanks**

#### **Young Lives vs Cancer Social Worker**

Email: SouthWestTeam@younglivesvscancer.org.uk

#### **Paediatric Oncology Secretary**

Tel: 0300 422 8491

Monday to Friday, 8:00am to 4:00pm

#### **Emily Kent Unit**

Tel: 0300 422 8567 Mobile: 07813 456 570 Available 24 hours a day

#### Children's Centre

Tel: 0300 422 8307 Tel: 0300 422 8308

Available 24 hours a day

#### **Paediatric Co-ordinator**

Tel: 07917072814

Available 24 hours a day

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## Making a choice

## **Shared Decision Making**

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



## **Ask 3 Questions**

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

- 1. What are my options?
- 2. What are the pros and cons of each option for me?
- 3. How do I get support to help me make a decision that is right for me?







AQUA https://aqua.nhs.uk/resources/shared-decision-making-case-studies/