



# Shared Care and the Family-Held Record

## What is Shared Care?

The term 'shared care' is used to describe the joint delivery of care, not necessarily in the same place or at the same time, by members of the primary care team - such as GPs and Practice Nurses - and of a specialist team - such as a Consultant Oncologist and specialist nursing team.

## Shared Care at a Principle Treatment Centre (PTC)

Great Ormond Street Hospital for Children NHS Trust (GOSH) and University College Hospital London Foundation Trust (UCLH) operate as a unified cancer centre, known as the Principle Treatment Centre (PTC) working as part of the North London Network. The Royal Marsden Hospital with St George's Hospital operates as a PTC for the South.

The PTC works in collaboration with a network of local shared care hospitals called Paediatric Oncology Shared Care Units (POSCUs) so that appropriate elements of treatment and supportive care can be given closer to the patient's home.

As a PTC we will aim to provide:

- Accurate diagnosis relying on sophisticated imaging, blood tests and examination of biopsy samples and bone marrow samples.
- Allocation of an appropriate treatment protocol/plan selected by a children's specialist.
- Provision of information to you and your family and the local hospital (POSCU).
- Administration of complex intravenous chemotherapy drugs.

It is our policy to share care with your local paediatrician and your local hospital (POSCU).

In reality, this means that some or most of your child's care will be carried out locally.

The advantages of shared care include:

- your child is admitted to hospital under a familiar team of doctors and nurses.
- you and your child will not have to travel as far to your local hospital (POSCU) as you may do to the PTC, which can have advantages in the event of acute infection.

Your local hospital can check blood counts, blood cultures and give intravenous antibiotics and blood products, supervise oral chemotherapy and give some intravenous chemotherapy and coordinate the provision of other local services, which you may require.

## What may be different between your POSCU and your PTC

We share care with many hospitals, and every hospital may do procedures differently. This is not to say that they are incorrect. Local practice and policy can differ, and each healthcare team must follow their own policies. While we work closely with POSCUs to let them know about our own procedures, they do not have to follow these precisely.

You may also find that the facilities also differ between your PTC and POSCU. These are some of the common differences;

## Care of your child's central line

The hospitals with which we share care all follow basic principles in the use of central venous access devices (CVADs). There is more information about this in your Family-held record.



It is common to encounter some differences in the care of your child's CVAD. For example:

- **Line flushing technique** For example, some teams use a two-person technique when removing needles from Implantable Ports (de-accessing).
- **The solution used to flush the CVAD after use** Some teams use Sodium Chloride 0.9% and Heparin to flush CVADs. Others use only Sodium Chloride 0.9%. There is evidence that both of these practices are effective.
- **Central venous line dressings** You may find your POSCU use a different type to the ones used at your PTC. This should always be a dry, transparent dressing that sticks to the skin.
- **Time spent cleaning the end of your child's line** This will depend on the type of cleaning wipe used. At GOSH, we use a 2% chlorhexidine gluconate and alcohol based wipe for 30 seconds and then wait until visibly dry.

## Facilities

When attending your child's POSCU they will usually be nursed in an isolation cubicle. This is to protect them from contact with other patients and families on the ward who may have an infection. This means your child may not be able to use play areas on the ward. When your child attends the day care or outpatient unit at the PTC, they will only be isolated if they have an infection can be passed to others. This means they will usually be nursed in a bay with other children who have similar conditions.

## Coming in to hospital

If your child has a high temperature or is unwell they will usually go straight to the inpatient ward at your POSCU. Some POSCUs may ask you to take your child to A & E before they go to the ward. If this is the case for your child's POSCU, a member of the team will let you know before you are discharged.

## What is the Family Held Record?

The Family-Held Record (FHR) is a resource to support you in caring for your child during their treatment.

All families are given a Family-Held Record (FHR) when their child starts treatment. This folder is for you to keep.

Some parents find it useful to take their FHR to each appointment or ward attendance. This is completely optional.

## What is in the Family-Held Record?

- Important contact details for the teams at your child's PTC, POSCU and community nursing team. This information is at the front.
- Information on what action to take if your child becomes unwell at home. This is the pink section.
- A table listing the blood counts affected by treatment, signs and symptoms and lower levels.
- A table for you to document your child's blood results. Some parents have told us they find this section useful to use.
- A section for you to keep notes, if you would like to.
- Common side effects of your child's treatment.
- Information on life at home during treatment. This includes practical advice, sources of support and details of charities.
- A glossary of common medical terms. This is the last page.
- A plastic pocket to store your child's flowsheets. This is at the back of the folder.

If you have any queries about Shared Care or your Family-Held Record, please ask a member of the team at your PTC. The contact details can be found on page 4 of the Family-Held Record.