

End of Treatment for paediatric Leukaemia and Haematology patients

Introduction

As parents we understand that End of Treatment (EOT) can bring with it a variety of different feelings and emotions, as well as more practical questions. This leaflet is designed to give you information to read and digest at a time that feels right for you.

Practical information

The exact date of your child's EOT can be obtained from your child's Clinical Nurse Specialist (CNS) and/or treating consultant.

In the case of treatment for leukaemia, the EOT can often be calculated many months in advance.

About 8 weeks before your child's expected EOT date, the CNS will arrange a home visit. This will be to discuss the EOT process, ongoing monitoring plans and to answer any questions or concerns you may have. After this meeting you will be provided with the details of your discussion. This will be in writing for you to keep and to refer back to in the future.

Nursery/schooling/education

Whether your child has already returned to school or nursery while having treatment, or if you are looking for them to return to education, your CNS will be able to provide information and support.

If your child has already returned to school, your CNS can arrange to speak with their teacher or key worker to discuss which of the on-treatment adaptations should remain in place and for how long. This will also be put in writing for the school to keep on file should they need to refer to it in the future.

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Department

**Paediatric
Oncology**

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**Patient
Information**

Temperatures

While your child has been having treatment you will have become used to taking their temperature on a regular basis. You will also be used to taking them into the Emily Kent Unit (EKU) when they have had a temperature of 38 degrees or higher.

One of the biggest changes for a parent or carer when their child ends treatment is coming to terms with the fact that they will now be treated the same as other children. This means that you will no longer need to routinely rush them into the EKU.

The exception to this would be if your child has not yet had their port or Hickman line removed.

Your child will continue to have open access to EKU for 6 months after the EOT. Therefore, you are able to contact EKU directly if your child becomes unwell and you are concerned.

For non-urgent routine childhood illnesses, you are encouraged to talk to your GP in the first instance.

Port/Hickman line removal

Your child may have had their port or Hickman line removed before their EOT date. If not, this will be arranged by the CNS as soon as possible. Please be aware that it could be up to 8 weeks after the EOT as an appointment will depend on the availability of surgery slots.

The surgery to remove the port/Hickman line will normally take place at Gloucestershire Royal Hospital. Every effort will be made for your child to attend the EKU on the surgery date. If this is not possible, both parents/carers and the child should be aware that they may be asked to attend the ward day surgery unit before and after the operation.

Bloods

As with the change in temperature protocol, you will also need to get used to the fact that your child will no longer have weekly blood tests, as these are no longer required for the dosing of chemotherapy. This can feel strange, and parents and carers often describe it as being unnerving or as if they have lost the “safety net” of knowing how their child is doing.

Patient Information

This is normal and an understandable reaction to a change in routine and it may take time to get used to and feel comfortable about.

Ringling the bell

You and your child may wish to ring the end of treatment bell. This can either be done at the hospital or you are able to borrow a bell to ring at home or another venue of your choosing.

When and if, you chose to ring the bell, is completely up to each individual family. It is down to what feels right for your child and family. Please feel free to discuss this further with either your CNS, the ECU Family Support Worker or a member of the ECU Play team.

Emotions

Each child and family coming to the EOT may feel several different emotions. This could include relief, apprehension, excitement, nervousness, exhaustion or relapse worries to name just a few.

Some families may wish to have the minimum amount of contact as possible with their medical team, whereas others may still want regular contact for support. Both approaches are normal and you will be supported in whichever feels right for you and your child.

Supporting you

There are many information booklets that you and your child may find informative and helpful for when they reach EOT. Some of these may be provided by your CNS or alternatively can be accessed via the CCLG website (www.cclg.org.uk).

Several other local and national charities produce information leaflets including:

Young Lives Vs Cancer

Website: www.younglivesvscancer.org.uk/life-with-cancer/support-when-ever-you-need-it/your-young-lives-vs-cancer-intro/

**Patient
Information****Grace Kelly Childhood Cancer Trust**

Website: www.gkcct.org

Cancer Research UK

Website: www.cancerresearchuk.org

Blood Cancer UK

Website: <https://bloodcancer.org.uk>

Leukaemia Care

Website: www.leukaemiacare.org.uk/support-and-information/

Southwest Oncology Delivery Network

This is a useful link to the Southwest Oncology Delivery Network which includes post treatment information for parents and carers.

Website: www.SWCTYACancerNetwork.nhs.uk

Emotional support

There is no right or wrong way to feel when your child gets to EOT. Parents often report feeling underwhelmed when the day arrives after so much anticipation or fear for what the future holds. Others may feel a sense of relief and excited anticipation for the future.

You may prefer to address these feelings privately but many people often feel they would find it useful to talk to someone, work through their emotions and perhaps put in place coping strategies for the future.

The Gloucestershire Hospital Paediatric Oncology Service has a designated psychologist for children and families to access support.

You can also access support via the following charities:

Maggie's

Website: www.maggies.org/our-centres/maggies-cheltenham/

Charlies

Website: www.charlies.org.uk

Leukaemia Care

Website: www.leukaemiacare.org.uk

**Patient
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Acknowledgement

This information leaflet has been written by parents, for parents and carers. We have tried to make sure that this information is as up to date as possible but please let us know of any amendments needed.

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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?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation

* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85