

# End of treatment

Information for patients and parents





## What happens when treatment finishes?

When your child completes their treatment they will have a number of tests and investigations. These tests are carried out to check for any signs of disease and side effects of treatment. They will give us a 'baseline' that we can use for monitoring in the future.

Following these investigations you will have an end of treatment meeting with your Consultant and Nurse Specialist, and any other relevant professionals. There may also be a Paediatrician or Nurse invited to attend from your local hospital or by video link.

At this meeting you will be given a summary of your child's treatment and a follow up plan. The plan will tell you how often you need to come for follow up appointments and the tests we will use to monitor disease and the possible short and long term side effects of treatment. We will also decide with you where your follow up should happen.

When your child first finishes treatment they will be seen by a doctor as an outpatient. The frequency of appointments varies dependant on your child's diagnosis. As time goes by the interval between visits lengthens until by the time five years have passed you may only need to be seen once a year. Your child will probably continue to be reviewed by our long term follow up service for many years after all treatment has finished.

If your child lives near one of our Shared Care centres you may go there for some or all of their follow up appointments.

## What happens at follow up visits?

The main purpose of a follow up appointment is to have a general check up with the doctor and to arrange any tests or investigations that are needed. Your child will be weighed and measured at each visit, as it is important to check they are growing normally

Blood counts are checked until they are back to normal. If your child had leukaemia, blood counts are checked only in the first 2 years following treatment completion.

Any X-rays or scans that are needed are done to check that there are no signs of disease coming back. The frequency of scans, including heart scans, X-rays and other investigations, is dependent on the treatment your child has had. The frequency of appointments and tests will reduce over time as the chances of the disease returning become smaller and smaller as time passes.

Some children will have long term problems associated with their diagnosis or treatment. As time passes the check-ups increasingly focus on making sure that any long term side effects of treatment are found and, if necessary, treated.

If you want to talk to someone in between visits to clinic you can contact your Key Worker or Social Worker. They can advise you or arrange for someone else to contact you. Alternatively you can contact the ward or clinic.

## When can my child's line or port come out?

As soon as possible after treatment is finished and any scans or tests are completed we will request for your child's central line to be removed. This usually happens around 3 months after treatment completion. The line will be removed under a general anaesthetic so it will mean coming to hospital as a day case. It may also mean waiting for a place on an operating list. This is because having a line out is always less urgent than having one put in.

## What do I do if my child has a temperature or is unwell?

To begin with, it will be very difficult not to worry every time your child is unwell, even though the most likely cause is a normal childhood illness. For parents whose children have never been seriously ill, it is easy to keep childhood illnesses in perspective; this is much harder if your child has had a serious illness. Every sore throat or headache may be a real source of worry to you.

In the first few weeks after treatment stops, your child may still have low blood counts or still have a central line and will need to come to hospital if they have signs of infection.

Your child's immunity will usually have recovered by six months after treatment. For this reason we ask that you contact the clinic or ward in the first instance for advice. If your child has a normal blood count and no central line we may recommend that you see your GP.

You can also contact the clinic or ward at any other time if you are worried or concerned about your child.

## When can we stop infection prevention measures?

Following treatment completion it is important to continue infection prevention measures until your child's blood counts are recovered.

For the first 3 months we recommend that you continue to follow dietary advice.

If your child takes preventative antibiotics we will tell you when it is safe to stop these. This is usually once the lymphocyte cells are recovering.

For the first 6 months following treatment your child is still at risk if they come into contact with anyone who has chicken pox or measles. If your child has a contact with someone with these illnesses please contact clinic or the ward.



## Will my child need to have more immunisations?

The timing and type of immunisations that your child will need depends on the chemotherapy treatment they had.

### Recommendations for children treated with standard chemotherapy

Children who have received standard chemotherapy will need to have booster injections of all their immunisations six months after treatment completion. Children who did not complete their initial vaccination schedule before they were diagnosed will need to be fully re-immunised from the beginning.

In the first year off treatment we would recommend that your child and all close family contacts are given the seasonal influenza vaccine in the autumn.

### Recommendations for children treated with intensive chemotherapy plus a stem cell or bone marrow transplant

Re-immunisation usually starts from 12 months after transplant. There are some immunisations which children who have had a transplant should not receive and it is best to discuss any immunisation plans with your transplant team. There is a special leaflet giving further details. Children treated with intensive chemotherapy should not receive the Tuberculosis vaccine (TB or BCG vaccine) without this first being discussed with your child's consultant.

We will write to your GP requesting them to give these vaccinations when they are due.

In the first year off treatment we would recommend that your child and all close family contacts are given the seasonal influenza vaccine in the autumn.

## The long term follow up service

The Long Term Follow up Service is provided for children and young people who finished treatment a minimum of five years ago and have had:

- Cancer or any other condition treated by a cancer specialist during childhood or as a young adult.
- A non-cancerous illness which required a bone marrow transplant during childhood or as a young adult.
- The team is made up of doctors, specialist nurses and psychologists.
- Every child or young person will be allocated a Key Worker (a nurse) who they and their GP can contact between hospital visits if necessary.

## What do we do?

- Empower survivors to take control of their lives and live life to the full.
- Provide you and your GP with a copy of the treatment summary and care plan. This has details of the diagnosis, treatments received and any potential late effects that may be experienced.
- Carry out surveillance for potential late effects of disease and its treatment as well as co-ordinate the management of any of these should they arise.
- Offer healthy lifestyle advice e.g. eating healthily, exercising regularly.
- Offer support, information and advice during and between clinic visits.

Our Long Term Follow up Service is based in two areas - Children's Haematology and Oncology Day Unit at Leeds General Infirmary up to and including the age of 17 years and Bexley Wing at St James's University Hospital from the age of 18 years.

## Getting Back to 'Normal'

Throughout treatment it is very likely that you have looked forward to seeing the day when your child's treatment comes to an end and when you can 'get back to normal'. Extended family and friends may be asking you if you are looking forward to celebrating the end of your child's treatment. But the reality for many families is that the end of treatment, (just like the point of diagnosis) brings about a whole host of additional worries and so it is perfectly natural to feel mixed emotions or experience fears and anxieties at this time.

Your child's diagnosis was likely to be the catalyst for a number of changes that have occurred in your family during the course of treatment. These changes may have been both positive and negative. Although it has been challenging your family have found a way over time to adapt and adjust to these changes and it likely that this will be the case again at the end of treatment.

Looking towards the future at the end of treatment the focus may move towards getting back to normal. But what is 'normal'?

There is really no such thing as a 'normal' family life because all individuals and families are different. What is important is that you are able to set and achieve goals that you feel help get your family 'back on track'.

This may include things like:

- My child being back at school full time
- Returning to work
- Enjoying family time together

Increasing exercise and taking part in PE lessons more, as your child's condition allows. There are events such as Junior park runs on Sunday mornings where you can hop, skip, walk or run 2K with other families (parents are encouraged too!) and for age 14+ there is now 5k Your Way on the last Saturday of the month for patients with cancer.

<https://www.parkrun.org.uk/events/juniorevents/#4.69/55.05/-2.95>

<https://5kyourway.org/>

As your child comes to the end of treatment and the frequency of their medical appointments reduce, you may find that you have more time to spend together as a family and to plan ahead. Having time to concentrate on home life for many parents means that they are able to re-establish structure and routine and set and implement consistent rules and boundaries, which promote positive behaviour for children.

It is important to remember that getting back on track takes time and it is not always a smooth road because of the number of changes your family have negotiated during the course of treatment. Many of the services you have worked with during the course of your child's treatment can continue to support you off treatment, and you will find all our contact details at the back of this leaflet - do not hesitate to contact us. However families can also access support services closer to where they live which is often preferable to families as they look to get back on track and spend more time away from hospital at home.

## Support services that may helpful

The following information addresses some of the issues that may still be present for your family after treatment has finished along with some ideas for accessing support.

### Behaviour/Boundaries

Family Support Teams (FST) are based in most local Children's Centres. They support families who have a child under 5 years of age (any child in the family) and can help with rules and boundaries for all of the children.

The FST also offer free parenting courses to help parents develop strategies and confidence in boundary setting.

Approaching your child's school or nursery could also help you with ideas for boundary setting and rules within the home.

Reward charts are particularly useful for younger children and free downloads are available at: [www.rewardcharts4kids.com](http://www.rewardcharts4kids.com)

### Benefits/Housing

One Stop Shops in Leeds help with claims for benefits and housing applications. There are similar centres outside of the Leeds area. Details can be found online.

### Debt

Local Citizen's Advice Bureau can help with debt advice: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) to search your nearest branch

Step Change Debt Charity (formerly Consumer Credit Counselling Service) phone: **0800 138 1111**

## Education

Learning Zone staff support the education of young people during treatment, and work to help plan for the future. Teachers and Specialist Learning Mentors are happy to take education or vocational queries regarding school or college from young people and their families after the end of treatment. The service is open 5 days a week Monday –Friday and the Specialist Learning Mentors work across the school holidays. See Contact List at the end of this booklet.

## Family Time

Spending time together as a family after treatment is really important when families have spent months or years separated. Trips out don't have to be expensive and council websites can tell you what is on in your area. For example Leeds has Leeds Breeze. By putting in your postcode and the age of your children they can tell you what is going on in your area. <https://breezeleeds.org>

Children's Centre's also run holiday programmes and you can pick up a leaflet from the centre. For families who have a child aged 5 and under the service also runs an Outreach Service where the information can be brought to you at your home every 2 weeks by a worker.

## Work

If you are experiencing problems with work as a consequence of having to care for your child due to their on-going health issues then the social work team or the Children's Haematology & Oncology Outreach Team can write a letter to your employer to help evidence your situation.

## Support for siblings

If siblings require support at the end of treatment families can seek advice from the child's school (who can often access Learning Mentors, support groups and counselling). If siblings undertake a caring role for their brother or sister which has a physical or emotional impact on them they can access support from Young Carers agencies such as:

- Willow Young Carers Service, Leeds
- Bradford Young Carers Service
- Hull Young Carers

Parents can refer, as can professionals.

## Candlelighters

The support offered by Candlelighters lasts a lifetime. Whether that be today, tomorrow or anytime in the future. Candlelighters offer a wide range of services including:

- Complimentary therapies
- Talking therapies
- One to one young person support
- Mums, Dads and family groups in your local area
- Grandparents' tea parties
- Family events
- Financial advice
- Sibling groups

And much more...

<https://www.candlelighters.org.uk>

<https://www.facebook.com/CandlelightersTrust>

<https://www.facebook.com/candlelightersthesquare>

## Useful Contacts:

### *Social Work Team*

Paediatric and Adolescent Oncology and Haematology,  
D Floor, Martin Wing. Great George Street, Leeds, LS1 3EX

**Telephone: 0113 535 1489**

### *The Medical Needs Teaching Service*

The Learning Zone, Floor B, Clarendon Wing, Leeds General  
Infirmary, Leeds, LS2 9NS

**Telephone: 0113 392 3711**

### *Children's Haematology & Oncology Outreach Team*

Children's Haematology & Oncology Day Unit, C Floor,  
Clarendon Wing. Great George Street, Leeds, LS1 3EX

**Telephone: 0113 392 2323**

### *Children's Oncology Day Unit*

Children's Haematology & Oncology Day Unit, C Floor,  
Clarendon Wing. Great George Street, Leeds, LS1 3EX

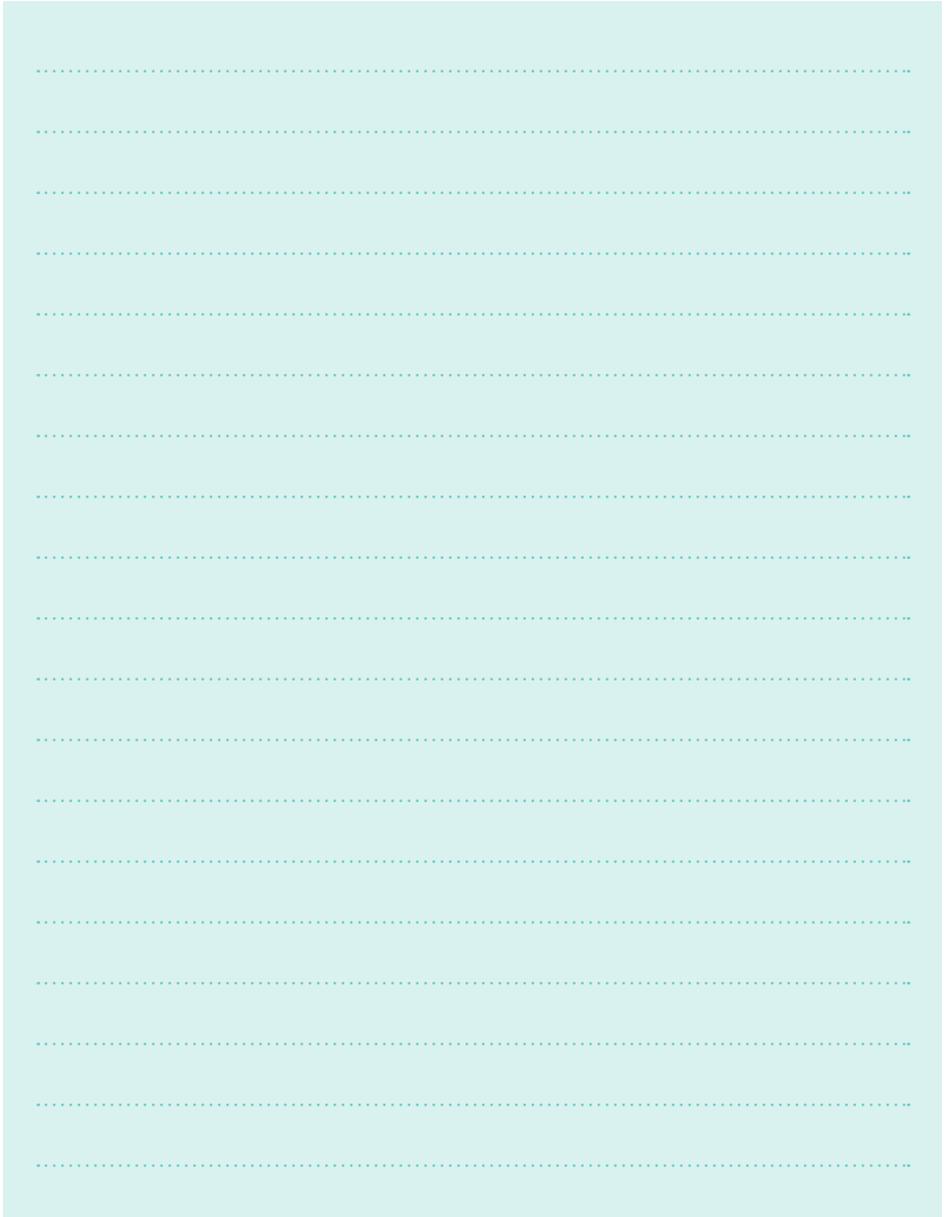
**Telephone: 0113 392 7179**

### *Candlelighters*

8 Woodhouse Square, Leeds, LS3 1AD

**Telephone: 0113 887 8333**

# Notes:

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## What did you think of your care?

Scan the QR code or visit [bit.ly/nhsleedsfft](https://bit.ly/nhsleedsfft)

*Your views matter*



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